AN INVESTIGATION INTO THE FUNCTIONAL AND PSYCHOSOCIAL IMPACT OF LIVING ORGAN DONATION

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General Abstract

Objective: In April 2006, the Scottish Liver Transplant Unit (SLTU) became the first NHS transplant unit in the UK to offer the option of Living Donor Liver Transplantation (LDLT). This represented a unique opportunity to evaluate the functional and psychosocial impact of LDLT upon healthy donors and their recipients. Subsequent aims were to investigate the challenge of introducing LDLT in Scotland and to establish the perceived deterrents and attractions of the procedure. An additional aim was to evaluate the impact of Living Donor Kidney Transplantation (LDKT) upon donors and recipients.

Design: A series of cross sectional and longitudinal studies were designed for the purpose of this thesis (3 quantitative, 2 qualitative, and 1 mixed methods).

Method: Self report questionnaires were used in each of the quantitative studies, with the addition of neuropsychological computerized tests in two studies. Semi-structured interviews were employed in the qualitative studies.

Main Findings: •Prior to its introduction general support for the option of LDLT was found, although it was highlighted that the risk involved was not well understood by the general public. •Since becoming available LDLT has <u>not</u> been a readily acceptable treatment option from the perspective of patients due to the perceived risk for the donor, but it may be considered as a "last option". Family members were motivated to save their loved one's life but the personal implications of donating resulted in reconsideration of LDLT. • Staff at the SLTU perceived a lack of family commitment in relation to LDLT, which is explained as a cultural factor contributing to the slow uptake of LDLT. In Scotland, a donation from a younger to an older generation is not easily accepted. This, in addition to patients' optimism that a deceased donation will arrive, and the poor health of potential donors, is thought to have affected the uptake of LDLT. As has the unit's conservative approach to the promotion of LDLT. This approach is the result of a perceived reduction in the need for LDLT and a preference to avoid the risk to a healthy donor and conduct transplants with deceased donations. • In over 3 years, only one couple completed LDLT. The recipient showed functional and psychosocial improvement from pre to post procedure, whilst the donor showed slight deterioration in aspects of quality of life 6 weeks post donation, which did not always completely return to a baseline level by 6 months. The donor made sacrifices to provide her husband with a fresh start to life and unmet expectations were found to effect quality of life. •Willingness to become a liver donor is not thought to be influenced by the frame of the information provided. •Like the LDLT donor, LDKT donors experience some functional and psychosocial deterioration at 6 weeks post donation, but donors largely recover by 6 months post donation. However, the anticipated benefit to recipients was not evident and may not be quantifiable until after 6 months post operation.

Conclusion: This thesis has added to current knowledge on living organ donation and specifically represents the first psychological evaluation of a UK LDLT programme. The slow uptake of LDLT was unexpected and has resulted in informative, novel research.

Publications Arising From This Thesis

- McGregor, L.M., Hayes, P.C., and O'Carroll, RE. (2008). Living liver donation: Attitudes of the general public and general practitioners in Scotland. Psychology and Health, 23(5), 603-616.

- McGregor, L.M., Swanson, V., Hayes, P.C., Forsythe, J.R. and O'Carroll, RE. (2009). Considering adult living donor liver transplantation: a qualitative study of patients and their potential donors. Psychology and Health. First published on: 07 May 2009 (iFirst).

- McGregor, L.M., Ferguson, E., and O'Carroll, RE. (To be submitted). Living donor organ transplantation: the effect of message frame on an altruistic behaviour.

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- McGregor, L.M., Dickson, A., Swanson, V., Forsythe, J.R. and O'Carroll, R.E. (In preparation). The first living donor liver transplant in Scotland: a qualitative study of the recipient's experience.

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Abbreviations

ANOVA	Analysis of Variance
CANTAB	Cambridge Neuropsychological Test Automated Battery
DAT	Donor Advocate Team
DMS	Delayed Matched to Sample
RIE	The Royal Infirmary of Edinburgh (also known as Edinburgh Royal Infirmary)
FLP	Functional Limitations Profile
GSES	Generalised Self Efficacy Scale
HADS	Hospital Anxiety and Depression Scale
HBM	Health Belief Model
IPQ-R	Illness Perceptions Questionnaire - Revised
LDKT	Living donor kidney transplantation
LDLT	Living donor liver transplantation
LOTR	Life Orientation Test Revised
MOT	Motor Screening
PCS	Primary Sclerosing Cholangitis
RBMT	Rivermead Behavioural Memory Test
RLOC	Recovery Locus of Control
RTI	Reaction Time
RVP	Rapid Visual Information Processing
SF36	Short Form 36
SLTU	Scottish Liver Transplant Unit
SRM	Self Regulation Model
TPB	Theory of Planned Behaviour
VAS	Visual analogue scales
WHOQOL-BREF	World Health Organisation Quality of Life Scale – Brief version

Chapter 1 General Introduction

1.1 *Overview*

This chapter introduces the reader to the rationale for investigating living organ donation, specifically Living Donor Liver Transplantation (LDLT), and highlights the challenges and consequent opportunities that have evolved to shape the overall structure of the thesis.

1.2 *What is Living Donor Liver Transplantation (LDLT)?*

Living Donor Liver Transplantation (LDLT) is a surgical procedure whereby a healthy individual donates part of their liver to a patient whose own liver is failing to function. A new liver is needed by the patient in order to survive. The procedure is possible due to the ability of the liver to regenerate after resection, both within the donor and the recipient (Marcos, Fisher, Ham, Shiffman, Sanyal, Luketic et al, 2000). LDLT was pioneered in Japan in the late 1980s and has since become available in select transplant units in Europe, North America and Asia (Northup & Berg, 2005). The procedure was originally developed for use with children dying from liver disease but success of the procedure encouraged its adaptation for adults on the liver transplant waiting list. For an adult recipient the right lobe of the donor's liver is required which constitutes approximately 60% of the donor's entire liver mass. Anatomically, this results in a more complex procedure compared to when the recipient is a child and the smaller left lobe (40%) of the donor's liver is required (Renz & Roberts, 2000). Consequently, the risk of complications for the healthy adult donor to an adult recipient has been documented to be as high as 67%, with estimates increasing to 100% in a more recent systematic review (Beavers, Sandler, & Shrestha, 2002; Middleton, Duffield, Lynch, Padbury, House, Stanton et al, 2006). In addition, the risk of death for the healthy donor is currently estimated to range between 0.23 and 0.5% (Middleton et al, 2006). In light of the risk involved for the donor, the introduction of adult-to-adult LDLT is thought to be set within a context of ethical and moral dilemmas and has placed LDLT at the centre of much controversy (Middleton et al, 2006; Neuberger, Farber, Corrado, & O'Dell, 2003).

1.3 Research Problem

Liver transplantation has traditionally been performed using a liver from someone who has died, a procedure that typically leads to successful outcomes for patients (Bathgate, Garden, Forsythe, Madhaven, Finlayson, Simpson et al.**,** 1999; O'Carroll, Couston, Cossar, Masterton, & Hayes, 2003). However, a scarcity in the number of livers donated following death limits the potential of this procedure (Barber, Falvey, Hamilton, Collett, & Rudge, 2006; British Medical Association, 2007). An increase in the number of people who have donated livers after death in the UK may have increased over the past 10 years but so has the number of people in need of a liver transplant. Consequently, supply remains insufficient to meet demand (NHS Blood and Transplant, 2009). At a UK level, between April 2008 and March 2009, 8% of patients on the liver transplant waiting list died before they could receive a transplant (NHS Blood and Transplant, 2009).

In order to increase the supply of donated livers and other organs many medical, surgical and political advances have been made. The use of split livers and the acceptance of marginal livers are examples of methods by which the supply of livers from deceased donors are now being maximised (see Appendix 1 for explanation of terms).

From a political perspective, whilst the proposal of a system of presumed consent (see Appendix 1) continues to be debated, the Human Tissue Act 2004, and the equivalent Human Tissue (Scotland) Act 2006, proposed guideline changes aimed at increasing the donor pool. One such change is an amendment to regulations which serve to reinforce the validity of an individual's wish to donate following their death. Within the Act, a declared wish to donate organs (e.g. joining the NHS organ donor register) should be regarded as authorisation for organ removal following death, and this should supersede any objections offered by the surviving family (Scottish Executive, 2006). It is thought that one of the main reasons for the shortage of donated organs is family refusal to consent to the removal of their deceased relative's organs. This explanation was confirmed in an audit conducted in the UK in 2006, where family refusal rate was calculated to be 41% (Barber et al, 2006). The Human Tissue Act 2004 / Human Tissue (Scotland) Act 2006, which came into force in September 2006, hoped to rectify this by giving precedence to the deceased individual's known wishes. However, there would appear to be difficulty in the implementation of this change as good practice would suggest that the family is still consulted and their refusal may still be accepted (Simpkin, Robertson, Barber, & Young, 2009). In a recent report by UK Transplant it was indicated that family refusal continued to occur in many cases, with the rate of refusal remaining at about 40% between 2008 and 2009 (Barber et al, 2006; NHS Blood and Transplant, 2009).

Living donation is yet another way to increase the supply of organs for transplant and decrease the number of deaths on the waiting list. However, the necessary harm inflicted on a healthy donor is a major concern and detracts from the procedure's potential. The donor does not need an operation therefore surgeons must perform a procedure that can only cause harm to a healthy person. This is contradictory to their professional code of conduct which dictates that as doctors they must ‘first do no harm’ (Florman & Miller, 2006).

Justification for the procedure comes from the benefit to the recipient. With living organ donation the procedure can be planned for a time when the recipient is in relatively good health. In addition, the organ can be checked prior to transplant and the cold ischemic time (time between organ removal and organ insertion) is reduced as the donor and recipient are operated on at the same time (Belghiti & Durand, 2000; Jones, Payne, & Matas, 1993). Such factors are thought to enhance the quality of the donated organ and the success of the procedure, but the main benefit from living donation is with regard to its timing. With living donation the patient can receive a transplant before they deteriorate and die, indicating a “survival benefit” with LDLT (Brown, 2008). However, despite the benefits, the risk to the donor invokes apprehension. This is particularly true with LDLT where the long term physical and psychological impact upon both donors, and recipients, has not yet been fully established (Neuberger & Price, 2003).

LDLT between adults was only performed for the first time in the USA in 1997, and although an increase in its use was found in select transplant centres worldwide, a comprehensive evaluation of the risk to the donor and the impact on a donor’s quality of life had not been conducted (Trotter, Talamantes, McClure, Wachs, Bak, Trouillot et al, 2001). This incomplete knowledge has implications for informed consent and therefore the welfare of donors. This matter was publicly highlighted with the death of Mr Mike Hurewitz in 2002: Hurewitz died three days after donating part of his liver to his brother. As a result, the transplant unit at Mount

Sinai hospital in New York suspended its living donation programme for 2 years to allow an evaluation of the unit’s procedures and medical care (Josefson, 2002). In reaction to the death, the Transplant Council of New York City formed a committee to review issues in relations to LDLT and recommendations to further safeguard the donor in future LDLT programmes were subsequently offered (Committee on Quality Improvement in Living Liver Donation, 2002). The Adult-to-Adult Living Donor Liver Transplantation (A2ALL) Cohort Study was also established at this time in an attempt to collate LDLT data across nine transplant centres in the USA and provide more precise estimations of the benefits for recipients and the risk to potential donors (Ghobrial, Freise, Trotter, Tong, Ojo, Fair et al, 2008).

As LDLT is a relatively new surgical procedure, only conducted in select transplant units, research in this area remains limited, particularly in terms of the psychological implications for donors. The research that has been conducted generally indicates that LDLT does not adversely effect the overall quality of life of donors, but there have been some inconsistent findings with feelings of distress, continuing abdominal pain and body image changes following LDLT documented (Hsu, Hwang, Lee, & Chen, 2006; Kim-Schluger, Florman, Schiano, O'Rourke, Gagliardi, Drooker et al, 2002; Pascher, Sauer, Walter, Lopez-Haeninnen, Theruvath, Spinelli et al, 2002; Trotter et al, 2001). The results of the research to date are limited in general interpretation due to vast methodological differences including the timing of assessments, uncertainty over whether donors were donating to a child or to an adult, and the minimal use of standardised psychological measures.

Patients with liver disease are often reported to show impairment in cognitive functioning (O'Carroll, Hayes, Ebmeier, Dougall, Murray, Best et al, 1991). Whilst the exact nature of the cause of this deterioration is uncertain, the liver’s reduced working capacity is invariably involved. As a general explanation, one of the liver’s main functions is to remove toxins from the body but a diseased liver cannot efficiently perform this necessary function therefore toxins are reabsorbed back into the blood stream. Such biochemical imbalance within the blood is then thought to travel to the brain, allowing toxins to enter brain tissue which subsequently results in cognitive impairment, known as hepatic encephalopathy (HE) (Collie, 2005; O'Carroll, 2008). HE can range from subtle attention and concentration problems to a coma and therefore its presence, irrespective of level, has the potential to adversely effect a patient’s quality of life (Wein, Koch, Popp, Oehler, & Schauder, 2004). Following LDLT, the donor is left with only 40% of their liver, yet the author is unaware of any research that specifically addresses the possibility of a decline in cognitive functioning similar to that observed in patients with liver dysfunction. The donor’s liver function has been found to normalise within weeks following the operation but the liver itself can take several months to re-grow (Middleton et al, 2006; Neuberger & Price, 2003). The effects of this period of reduced liver mass on a donor’s cognitive functioning is unknown, yet has the potential to significantly impact the donor’s quality of life and, therefore, requires investigation (O'Carroll, 2008).

In April 2006, LDLT was introduced for the first time in the UK on the NHS. The Scottish Liver Transplant Unit (SLTU) at The Royal Infirmary of Edinburgh (RIE) developed an LDLT programme to provide patients on the Scottish liver transplant waiting list an alternative to waiting for a deceased donation. It was the view of the author and colleagues that a comprehensive psychological and cognitive assessment of the impact of LDLT on both donors and recipients was warranted from the programme’s launch.

1.4 Purpose of the research

The introduction of LDLT at the SLTU provided an opportunity to conduct novel research, adding to limited worldwide knowledge of the area, and producing the first results from the UK. The focus of the research was to evaluate changes to physical functioning, quality of life, cognitive abilities, mood and relationships from pre to post transplant/donation. In addition, it was hoped to obtain insight into the acceptance of this new procedure by studying the decision making process, the nature of concerns, anxieties and expectations, and predictors of recovery. Having a relative on the liver transplant waiting list is assumed to be a difficult and emotional time for families, particularly in the knowledge of a deceased organ donor shortage. Therefore, the availability of LDLT, whilst being an opportunity to help, also has the potential to create implicit pressure to donate, or to accept a donation, against the individual’s personal wishes. It is important to be aware of such pressure and to recognise its potential to disrupt family dynamics and effect emotional and psychological wellbeing. Obtaining information about the experience of LDLT from the moment it is introduced as an option would allow appropriate advice to be given, and supports to be put in place, to safeguard the donors and recipients of LDLT.

The SLTU had estimated completion of 54 living donor assessments within the first three years of its availability: 10 in the first year, 20 in the second and 24 in the third. The hospital’s experience with living kidney transplantation meant 50% of the donors assessed were expected to proceed with the procedure, resulting in an estimated 27 LDLT procedures over 3 years (Scottish Liver Transplant Unit**,** 2004). In anticipation of a slow recruitment rate, the aim of the thesis was expanded to include the donors and recipients of living kidney donation. Living Donor Kidney Transplantation (LDKT) (see Section 1.5) is an established procedure at the RIE with 20 performed between 2008 and 2009 alone, constituting 19% of all completed kidney transplants that year (NHS Blood and Transplant, 2009). However, longitudinal research on the psychological aspects of the donation process and outcome are limited within the unit and beyond (Lumsdaine, Wray, Power, Jamieson, Akyol, Bradley et al, 2005). An opportunity to assess the success of LDKT at the renal transplant unit and to add to current knowledge on the impact of living kidney donation in general was seized. An additional aim was then to compare the results of living liver donors and recipients to the donors and recipients of a more established, less risky procedure that is LDKT, as a way of obtaining more insight into the experience of each.

A previous comparison of LDKT and LDLT donors, post donation, suggested many similarities in the experience but also highlighted significant differences in perceptions of risk and aspects of recovery (Rudow, Charlton, Sanchez, Chang, Serur, & Brown, 2005). Rudow et al (2005) found that kidney donors experienced significantly higher unexpected problems post donation whilst the liver donors were more likely to think that their own health was negatively affected by the donation. In addition, the perceived risk of death, altered appearance, bleeding and infection was higher amongst liver donors. The current thesis aimed to advance upon such findings, permitting a more detailed comparison of donors in terms of psychosocial and functional changes.

Recruitment problems with regards to LDLT donors and recipients dictated a change in the original aim of the thesis. Instead of concentrating on the actual experience of LDLT, the opportunity arose to focus the research on the challenge of introducing LDLT in Scotland, and to gain an understanding of the procedure's attractions and deterrents.

1.5 What is Living Donor Kidney Transplantation (LDKT)?

Living Donor Kidney Transplantation is a surgical procedure by which a healthy individual can donate one of their two healthy kidneys to a patient whose own kidneys are failing. The first LDKT procedure was conducted between identical twins in 1954 by Dr Joseph Murray in the USA (Murray, 1982). The second LDKT procedure was not conducted until 1960, again with identical twins, but this time in the UK, by Sir Michael Woodruff at the Royal Infirmary of Edinburgh (RIE) (Woodruff, Robson, Ross, & Nolan, 1961). With advances in immunosuppressant (anti-rejection) medication, the donor no longer has to be the twin of the recipient. It is now possible for non-blood related relatives, friends and strangers to become donors, increasing patients' accessibility to LDKT.

Similar to LDLT, the main benefit of LDKT for the recipient lies predominantly in its timing whereby time spent on the transplant waiting list can be significantly reduced. However, dialysis treatment means the urgency with which a new kidney is required is less than when a new liver is required. Dialysis involves the patient being connected to a machine designed to simulate the function of a kidney a few days a week, and can be accessed until a kidney suitable for transplant becomes available. An equivalent treatment is not available for patients with liver disease. However, dialysis is not considered a permanent treatment as it only performs about

5% of the function of a normal, healthy kidney (Stein & Wild, 2002). A kidney transplant is therefore preferable as it provides a recipient with a well functioning healthy kidney, and subsequently offers additional benefits: kidney transplant has been shown to increase survival rates, improve quality of life, and be more cost effective than dialysis (Gordon, 2001).The disadvantage to LDKT is the necessary risk to the healthy donor but compared to the risk for a liver donor (1 in 200 chance of death) the mortality risk for a kidney donor is relatively low, currently thought to be 1 in 3000 (Matas, Bartlett, Leichtman, & Delmonico, 2003).

1.6 Summary of aims

- To assess the functional and psychosocial impact of LDLT upon donors and recipients.

- To assess the functional and psychosocial impact of LDKT upon donors and recipients and to compare results with LDLT donors and recipients.

- To investigate the challenge of introducing LDLT in Scotland and to establish the perceived deterrents and attractions of the procedure.

1.7 Rationale for methodology

Both quantitative and qualitative research methodologies were employed in this thesis to provide a comprehensive analysis of an under-researched area. Quantitative data collection allows differences between groups and over time to be measured and their significance addressed. Qualitative data collection, in comparison, allows a more in-depth investigation of thoughts, feelings and opinions, which can aid the interpretation of quantitative results.

To achieve the aim of establishing the functional and psychosocial impact of LDLT, and LDKT, on donors and recipients, a number of quantitative measures were employed. Variables measured included physical limitations, daily functional disability, illness perceptions, locus of control, relationships, quality of life, optimism, self efficacy, distress/mood and cognitive functioning, including memory, concentration, attention and psychomotor speed. Measures were administered on three separate occasions, from pre to post donation in order to assess changes in results over the course of the LDLT/LDKT experience, and were selected for use based on their previous contributions to research and ease of administration. A full description of each measure is provided in the Methodology section (Chapter 2).

For Chapter 3 (Attitudes towards LDLT) and Chapter 7 (The effect of message frame), quantitative questionnaires were considered the most appropriate methodology as direct comparisons between groups were warranted. The questionnaires were specifically devised by the author and colleagues, with influence from previous research, and are described in the relevant chapters.

In a new area of research, qualitative interviews are a valuable method of data collection as the restrictions of any predetermined ideas of the researcher are minimised. Issues not specifically measured by the quantitative measures can arise and enlighten our understanding of a new phenomenon. Specifically, longitudinal qualitative data is not a common design feature of research with an illness population and yet has the potential to give additional insight into a patient’s experience. The relationship that is built between the patient and the interviewer can encourage disclosure of issues and views previously withheld at the first interview and an opportunity to assess the process of change in thoughts, feelings and opinions can be gained (Murray, Kendall, Carduff, Worth, Harris, Lloyd et al, 2009). A qualitative methodology was therefore incorporated into the case study with Scotland’s first LDLT donor and recipient (Chapter 6).

In an area where previous published research is non-existent, qualitative data collection can provide detailed baseline information upon which theory can be developed and, therefore, was also chosen as an appropriate methodology for use within the exploratory studies described in Chapters 4 (Considering LDLT) and 5 (Views of medical staff).

1.8 Qualitative analysis

The interview data collected in chapters 4, 5 and 6 were analysed using thematic analysis. This analytic process requires the identification and interpretation of patterns found within the given data set, i.e. interview transcriptions. There are many ways in which to analyse qualitative data but it has been argued that thematic analysis is the foundation upon which other theoretical methods of analysis such as grounded theory and Interpretative Phenomenological Analysis have developed (Braun & Clarke, 2006). Thematic analysis as a technique on its own, offers a flexible approach to data analysis that is free from a specific theoretical framework and therefore was considered appropriate for use in these exploratory chapters.

General guidelines for the completion of thematic analysis, as proposed by Braun and Clarke, were followed in each relevant chapter. The 6 step guide ranges from reading and re-reading the transcripts in order to become familiar with the data, to producing the final report with appropriate, supporting quotes from the text to provide transparency of theme formation. Intermediate steps require the generation of codes, which involves the noting of interesting aspects of the data. The codes are then reviewed for similar and contrasting relationships and connections, combining to form possible themes which are then reviewed in relation to the entire data set. Once the themes have been established they are then defined and appointed a title, ready for interpretation in the final report (Braun & Clarke, 2006).

1.9 Main theoretical framework

Leventhal's self-regulation model (SRM) provided the main theoretical framework upon which the original study with LDLT donors and recipients was devised (see Appendix 2 for an illustration of the model). The SRM generally stipulates that when an individual's health is threatened, they are motivated to return to a 'normal' state of health. How this is achieved is dependent upon the individual's perception of the threat, which includes both cognitive and emotional aspects (Leventhal, Nerenz, & Steele, 1984). Previous research has shown that an individual's perception of their illness or condition can influence their physical and psychological recovery (Covic, Seica, Gusbeth-Tatomir, Gavrilovici, & Goldsmith, 2004; Moss-Morris & Chalder, 2003). Therefore, understanding how LDLT and LDKT donors and recipients perceive and manage their condition was an important research objective.

In addition, research was informed by the Theory of Planned Behaviour (TPB) and Health Belief Model (HBM) (Ajzen, 1988; Rosenstock, 1966). Both models suggest that our attitudes and beliefs can predict the health related behaviours we perform and therefore it was the author's aim to extract from donors and recipients their attitudes and beliefs regarding LDLT and to assess how these impacted their decision to pursue living donation or not. The exploratory nature of this thesis did not test one specific theoretical model but rather sought to encourage open consideration of potential influencing factors.

1.10 Structure of the thesis

This thesis describes six studies relating to the topic of living organ donation:

Chapter 2 provides an overview of the quantitative measures used in Chapters 6 and 8. Each measure is described with regards to its development and participant instructions.

Chapter 3 describes the preliminary study of this thesis, developed to ascertain background information to future studies. The agreement to conduct LDLT at the SLTU was a significant development within the UK's NHS. The procedure was known to have stimulated mixed views within the medical and surgical environment therefore it was felt important to establish public and professional attitudes towards the introduction of LDLT, prior to its inception in Scotland. A quantitative survey design was employed with general practitioners and members of the general public.

Chapters 4 and 5 are qualitative studies conducted in response to the lack of uptake of LDLT in Scotland. Chapter 4 describes the reasons why LDLT had not been conducted within the first 8 months of its availability in Scotland from the perspective of possible recipients and donors. Chapter 5, in contrast, describes the views of the medical staff (surgeons, consultant physicians and transplant coordinators) employed at the SLTU.

Chapter 6 is a longitudinal study which describes the experience of Scotland's first and only LDLT couple from pre to 6 weeks, then 6 months post operation. Quantitative and qualitative aspects were incorporated into the study to provide a comprehensive understanding of the effect LDLT has on the functional and psychosocial wellbeing of both the donor and recipient.

Chapter 7 is an experimental study that looks at willingness to become a living organ donor and tests the influencing potential of message frame. Willingness to donate a liver and a kidney are both considered to allow a comparison of the results for high risk and low risk procedures.

Chapter 8 is a longitudinal, quantitative study that was designed to investigate the functional and psychosocial wellbeing of LDKT donors and recipients through the transplant experience, from pre to 6 weeks, then 6 months post operation.

Chapter 9 is a general discussion of the studies conducted in this thesis. Limitations, conclusions and implications for theory and clinical practice are offered as are suggestions for future research.

Chapter 2 Methodology

2.1 Overview

The main aim of this thesis was to assess the functional and psychosocial impact of Living Donor Liver Transplantation (LDLT) and Living Donor Kidney Transplantation (LDKT) upon donors and recipients. This chapter describes the quantitative measures selected to achieve this aim and provides justification for the inclusion of each, along with a brief description of what measure completion involves. Participants were asked to complete measures on three separate occasions: pre operation, 6 weeks post operation, and 6 months post operation. An ordered list of the intended measures for completion at each time point, by donors and recipients, is presented in Table 2-1. The corresponding results are described in chapters 6 and 8 for LDLT and LDKT respectively. Reliability data (cronbach α) will be presented within the results section of each relevant chapter.

2.2 Short Form 36 (SF36) (Ware, 2000)

The Short-Form 36 (see Appendix 3) is one of the most common measures of health related quality of life and has been employed in a vast array of research areas, including patients with end stage renal disease (Cleary & Drennan, 2005; Wight, Edwards, Brazier, Walters, Payne, & Brown, 1998), kidney transplant patients (Griva, Ziegelmann, Thompson, Jayasena, Davenport, Harrison et al, 2002) and kidney donors (Tellioglu, Berber, Yatkin, Yigit, Ozgezer, Gulle et al, 2008). In addition, it is the most frequently used measure in studies investigating the quality of life of liver transplant patients (Tome, Wells, Said, & Lucey, 2008). The scale's reliability and validity has been supported throughout such research.

Table 2-1: Summary of tests administered at each time period

Time 1	Time 2	Time 3
Pre-transplant/donation operation	6 weeks post transplant/donation operation	6 months post transplant/donation operation
Recipient	Recipient	Recipient
SF36 FLP IPQ-R RLOC VAS WHOQOL-BREF LOT-R GSE HADS CANTAB RBMT	SF36 FLP IPQ-R VAS WHOQOL-BREF HADS CANTAB RBMT	SF36 FLP IPQ-R VAS WHOQOL-BREF HADS CANTAB RBMT
Donor	Donor	Donor
SF36 FLP RLOC VAS WHOQOL-BREF LOT-R GSE HADS CANTAB RBMT	SF36 FLP IPQ-R VAS WHOQOL-BREF HADS CANTAB RBMT	SF36 FLP IPQ-R VAS WHOQOL-BREF HADS CANTAB RBMT

The SF36 contains 36 items divided into 8 separate health domains: Physical functioning, Role-physical, Bodily pain, General health, Vitality, Social functioning, Role emotional and, Mental Health. These 8 domains can be divided further into 2 measures: a Physical Health component and a Mental Health component. Of the Physical Health component, the Physical functioning domain correlates most highly and is considered the best measure of physical health (Ware, 2000).

When devising this thesis it was felt important to obtain a global measure of quality of life on the understanding that living donation may affect the quality of donors' and recipients' lives beyond a health perspective. Consequently the WHOQOL-BREF (described below) was employed as the predominant measure of quality of life. However, an additional measure specific to physical limitations was included to allow functionality to be assessed prior to and following the operation. WHOQOL-BREF measures satisfaction with physical abilities but the SF36 measures what the participant can physically do, an important distinction. Given the frequent use of the SF36 and the need to keep the response burden of participants to a minimum, only the Physical functioning domain of the SF36 was included in the questionnaire battery.

The Physical functioning domain is made up of 10 questions each requiring a response from 3 options: *Yes limited a lot, Yes limited a little,* and *No not limited at all*. The options are scored 1 to 3 respectively and are summed to produce a raw score between 10 and 30, with higher scores indicating better physical functioning. In order to allow the raw scores to be compared to norms from the general population, the scores are transformed onto a scale of 0 (worst physical functioning) to 100 (best physical functioning).

2.3 Functional Limitations Profile (FLP) (Patrick & Peach, 1989)

The Functional Limitations Profile (FLP) is the British version of the Sickness Impact Profile (SIP) (Bergner, Bobitt, Pollard, Martin, & Gilson, 1976). The SIP, and now the FLP, are widely used measures of disability and corresponding health status. Developed in the United States, the SIP contains 136 items referring to aspects of daily living, divided into 12 categories: *Ambulation, Body care and Movement, Mobility, Household Management, Recreation and Pastime, Social interaction, Emotion, Alertness, Sleep and Rest, Eating, Communication,* and *Work.*

The items within each category are assigned weights which correspond to the severity of that item in relation to all the other items in that category. In order to adapt the measure for use with the British population the phrasing of some items was changed accordingly, and the weightings of each item were modified to reflect British perceptions of item severity. This modified version was renamed The Functional Limitations Profile (FLP) (Charlton, Patrick, & Peach**,** 1983; Jenkinson, Stradling, & Petersen, 1997; Patrick & Peach, 1989). The FLP has since been found to be a reliable and valid measure, which is sensitive to change (Charlton et al, 1983; Hutchinson & Hutchinson**,** 1995; Jenkinson et al, 1997; O'Neill, Normand, Cupples, & McKnight**,** 1996). The FLP is included in this thesis to measure the extent of disability associated with donating or receiving a living organ donation and how this can affect even simple tasks of daily living.

The FLP, like the SIP, contains 12 categories of activities that are thought to be essential to daily living, encompassing both physical and psychosocial dimensions. The categories, *Ambulation, Body care and Movement*, *Mobility* and *Household Management* include items relating to a physical dimension, and *Recreation and Pastime, Social interaction, Emotion, Alertness,* and *Sleep and Rest* include items relating to a psychosocial dimension. Additional categories, *Eating, Communication*, and *Work* are also included in the full FLP (Charlton et al, 1983). However, to reduce response burden only 2 categories from the physical dimension (*Ambulation* and *Mobility*) and 2 categories from the psychosocial dimension (*Recreation and Pastime,* and *Alertness*) were included in this thesis (see Appendix 4). These categories were chosen as the corresponding items included actions thought to be most relevant to both recipients and healthy donors. As cognitive functioning post operation was a particular research interest, the opportunity to assess the impact of subtle difficulties with concentration, attention and memory on daily functioning was also addressed with the inclusion of *Alertness.*

Within each category, the participant is presented with a number of items. The participant is instructed to read each item and only select it if they believe that a) the item reflects their situation that day, and b) they consider it to be due to the state of their health. Each item has been assigned a specific value, corresponding to its weighting in that particular category. For each statement the participant selects, the value of each are added, divided by the maximum total value score possible for that category, and then multiplied by 100, to produce an overall category score. The *Ambulation* category contains 12 items pertaining to walking and use of stairs e.g. I walk shorter distances or often stop for a rest, and the *Mobility* category contains 10 items concerning how a person gets about inside and outside of their house e.g. I do not go into town. In addition to a separate *Ambulation* and *Mobility* category score, these two categories can be combined to produce a physical dimension score. The values of each item selected within both the *Ambulation* and *Mobility* categories are added, and then divided by the summation of the total value scores for the said categories. This figure is then multiplied by 100 for the final physical dimension score. Higher scores indicate greater limitation in functioning.

Similar calculations allow a psychosocial dimension score to be computed from the *Recreation and Pastime* category which contains 8 items relating to a person’s usual activities e.g. I spend shorter periods of time on my hobbies and recreation, and the *Alertness* category containing 10 items concerning general alertness e.g. I am confused and start to do more than one thing at a time.

In addition to four separate category scores and two dimension scores, an overall FLP score is also calculated using a format similar to that used to compute dimension scores. However, only the two dimension scores are included in the analysis described in Chapters 6 and 8.

2.4 The Revised Illness Perception Questionnaire (IPQ-R) (Moss-Morris, Weinman, Petrie, Horne, Cameron, & Buick, 2002)

How a patient perceives their illness is thought to have an effect upon illness-related behaviours such as coping strategies, and other psychological outcomes such as health related quality of life (Covic et al, 2004; Moss-Morris et al, 2002). Therefore, illness perceptions were considered an important factor to be measured in this thesis. The revised version of the Illness Perception Questionnaire (IPQ-R) was selected for this purpose (Moss-Morris et al, 2002) (see Appendix 5).

The original Illness Perceptions Questionnaire (IPQ) (Weinman, Petrie, Moss-Morris, & Horne, 1996) was developed as a quantitative measure for the assessment of Leventhal's Self Regulatory model (SRM) (also known as the Common Sense Model) (Leventhal et al, 1984). The SRM describes the way in which an individual perceives their illness as being made up of 5 components: identity, consequences, timeline, control/cure and cause. The IPQ was designed to measure each component. Through extensive research employing the IPQ, ways in which the measure could be improved were highlighted encouraging the development of the revised version in 2002 (Moss-Morris et al, 2002).

The IPQ-R, like the original IPQ is made up of three sections: symptoms of the illness, illness perceptions, and possible causes of the illness. As the nature of symptoms and causes were not essential to the aim of this thesis, only the section on illness perceptions was incorporated into this thesis. This section consists of 38 statements to which participants are asked to respond on a 5-point likert-type scale (*Strongly disagree, Disagree, Neither agree nor disagree, Agree* and *Strongly agree*). The questions are divided into 7 components:

Timeline acute/chronic: enquires about a person's belief on how long the illness will last (6 items, e.g. "My illness will last a short time"). Higher scores indicate stronger beliefs that the illness is a chronic illness.

Timeline cyclical: enquires about fluctuation of symptoms and changes within the illness (4 items, e.g. "My illness is very unpredictable"). This is an additional component incorporated into the revised version of the IPQ. Higher scores indicate stronger beliefs about the inconsistent nature of the illness.

Consequences: asks about perceptions regarding the impact of the illness on lifestyle and well-being (6 items, e.g. "My illness is a very serious condition"). Higher scores indicate a stronger perception of negative consequences.

Personal control: asks about beliefs regarding personal ability to control the illness (6 items, "The course of my illness depends on me"). Higher scores indicate a more positive perception of control.

Treatment control: enquires about perceptions regarding the usefulness of the prescribed treatment to cure or manage the illness (5 items, e.g. "My treatment can control my illness"). Higher scores indicate a more positive perception on the usefulness of treatment. Both Treatment control and Personal control are treated as one single component in the original IPQ but subsequent factor analysis proposed their separation in the revised version.

Illness coherence: enquires about the degree to which the illness makes sense to the individual and has meaning to them (5 items, e.g. "My illness doesn't make any sense to me”). This component is an addition to the revised version of the IPQ. Higher scores indicate stronger personal understanding of the illness.

Emotional representations: asks about the individual’s emotional responses to having the illness (6 items, e.g. “My illness makes me feel angry”). The inclusion of this component is an important development within the IPQ-R as it is an essential element of the SRM which was overlooked in the development of the original IPQ (Hagger & Orbell, 2005; Moss-Morris & Chalder, 2003). Higher scores indicate a more negative emotional response to the illness.

The IPQ-R has shown good results within tests of reliability and validity (Hagger & Orbell, 2005; Moss-Morris et al, 2002). Although the IPQ-R is a generic measure of illness perception, it can be easily modified for the specific condition under investigation and therefore has been used in research involving various illnesses, such as end stage renal disease (Timmers, Thong, Dekker, Boeschoten, Heijmans, Rijken et al, 2008) and chronic fatigue syndrome (Moss-Morris & Chalder, 2003b). This thesis is thought to include one of the first studies to use the IPQ-R with patients awaiting a liver transplant. The authors advise that the term “my illness” can be substituted with the appropriate illness under investigation (Moss-Morris et al, 2002). In this thesis, after much deliberation, and advice from the authors of the IPQ-R, it was decided to substitute “my illness” with “my kidney (or liver) disease” and “my kidney (or liver) condition since the transplant”, for recipients at pre and post transplant respectively. For donors, the IPQ-R was only completed post transplant and it was agreed to substitute “my illness” with “my condition following the donor operation”.

2.5 Recovery Locus of Control (RLOC) (Partridge & Johnston, 1989)

Perceived control is recognised as an important factor in determining the decisions individuals make and has become an integral part of models of health behaviour e.g. Health Belief Model (HBM) and the Theory of Planned Behaviour (TPB). Perceived control specifically in relation to recovery following a medical procedure or treatment is an area requiring further investigation. Previous studies with stroke patients have found that individuals who have a strong internal recovery locus of control, that is, have a strong belief that their own efforts will effect their progress, were more likely to have a faster recovery and show greater independence 3 years after the stroke than those who believed their own efforts were less important than the efforts of other people and chance (i.e. an external locus of control) (Johnston, Pollard, Morrison, & MacWalter, 2004; Partridge & Johnston, 1989). The Recovery Locus of Control Scale (RLOC) (see Appendix 6) has been shown to have good internal consistency in addition to good predictive and content validity (Partridge & Johnston, 1989). The RLOC was devised to measure the degree to which patients perceive the control over their recovery to be internal or external. This measure is employed in this thesis to assess if perceptions of control over future recovery, measured prior to living donation/transplantation, can predict physical and psychosocial well-being post living donation.

The RLOC contains 9 statements which participants are asked to read and note their agreement with on a 5 point likert-type scale (*Strongly agree, Agree, Uncertain, Disagree* and *Strongly disagree*). Of the 9 statements, 5 reflect internal beliefs (items 1, 3, 5, 7 and 9) e.g. *How I manage in the future depends on me, not on what other people can do for me,* and 4 reflect external beliefs (items 2, 4, 6 and 8) e.g. *Its often best just to wait and see what happens*. The overall score reflects the degree of internal control, therefore the external items are reversed scored (i.e. *Strongly agree* = 1). The scores of each response are summated and range between 9 and 45 with higher scores indicating a stronger internal locus of control.

2.6 Visual Analogue Scales for relationships and social issues (VAS) (Lumsdaine et al, 2005)

Visual Analogue Scales (VAS) are a simple method of obtaining a general indication of an individual's view on a specific topic. VAS were employed in this thesis to assess issues related to the psychosocial aspects of living donation that are not, to the best of the authors knowledge, measured in a standardized questionnaire. Previous studies with donors of living liver and kidney donation have highlighted adverse financial consequences following living organ donation, concerns for own future health, improved relationships and a willingness to donate again (Beavers, Sandler, Fair, Johnson, & Shrestha, 2001; Chen, Hsu, Hwang, & Lee, 2006; Karliova, Malagó, Valentin-Gamazo, Reimer, Treichel, Franke et al, 2002; Schover, Streem, Boparai, Duriak, & Novick, 1997; Trotter et al, 2001). Using visual analogue scales within this thesis to address these topics will allow participants the opportunity to consider the extent to which they are experiencing these issues, and will allow a more detailed picture of any changes following the transplant.

The questions relate to any improvements and/or adverse effects that living donation has had on the relationship between donor and recipient, and between donor/recipients and other friends and family. In addition, the recipients are asked about their concern for the welfare of the donor, and donors are asked about concerns for the operation; concern for the remaining kidney (or part of liver); any financial loss as a result of donating; any discomfort from the scar, and if they would donate again (see Appendix 7).

Recipients are presented with 5 questions to be answered on a visual analogue scale at each of the three time periods. Donors are presented with 6 and 8 questions at pre and post transplant assessments respectively.

Participants are asked to read each question and mark a cross on the corresponding line where they feel their views lie. Each line is 10cm in length and both ends are labeled with an extreme view, i.e. the 0cm point is labeled '*Not at all',* and the 10cm point is labeled '*An extreme amount'*. No other information is given on the line. All questions on the VAS, over each of the three time periods, follows this format apart from question 8 presented to donors post transplant (*If it were possible, would you donate part of your liver/a kidney again?).* In relation to this question the 0cm and 10cm points are labeled *Definitely No* and *Definitely Yes* respectively. The questions and VAS format included in this study have been employed in a previous longitudinal study with living kidney donors and recipients (Lumsdaine et al, 2005).

Scoring of the VAS simply involves measuring the distance between the cross and the end of the line indicating no change/concern/problems (i.e. 0cm). The figure is converted to a percentage to compensate for any line length inaccuracies noted following printing of some questionnaires.

2.7 World Health Organisation Quality of Life – Brief version (WHOQOL-BREF) (The WHOQOL Group, 1998)

In response to increasing awareness of the importance of an individual's subjective quality of life in medical outcome studies, in addition to survival and morbidity rates, the World Health Organisation initiated the development of a cross culturally valid measure of quality of life. A 100 item questionnaire was developed known as the WHOQOL-100 (Hawthorne, Herrman, & Murphy, 2006b).

Following the successful application of the WHOQOL-100, an abbreviated version was developed that would be more appropriate for use in longitudinal studies, in studies where completion time was limited, or where participants were unwell (Hawthorne et al, 2006b; Skevington, Lofty, & O'Connell, 2004).The WHOQOL-BREF saw a reduction in the number of questionnaire items from 100 to 26.

Twenty-four of the WHOQOL-BREF’s items can be divided into four domains considered important to quality of life: Physical health (7 items), Psychological (6 items), Social relations (3 items) and Environment (8 items). An additional general question pertaining to quality of life (How would you rate your quality of life?) and one to general health (How satisfied are you with your health?) are also included, completing the 26 items (The WHOQOL Group, 1998) (see Appendix 8).

For each item, participants are asked to respond on a 5-point likert-type scale. The dimensions of the scale were designed to either reflect intensity (How much the person had experienced things?), capacity (How completely the person was able to do things?), frequency (How often the person felt or experienced things?), or evaluation (How good or satisfied the person felt about things?) (Skevington et al, 2004). When completing the WHOQOL-BREF, participants are asked to consider how they have felt over the past 2 weeks specifically, rendering the measure suitable for re-administration at a minimum of 2 week intervals. Within each domain higher scores indicate better quality of life.

Since its inception, the WHOQOL-BREF has been employed in various research areas and its psychometric properties of reliability and validity have been repeatedly confirmed as adequate (O'Carroll, Smith, Couston, Cossar, & Hayes, 2000; Skevington et al, 2004; The WHOQOL Group, 1998). The WHOQOL-BREF has been shown to have good test/retest reliability when a sample of patients are not subject to a medical intervention, yet is sensitive to change with patients following liver transplantation (although the social relations domain is less sensitive than the others) (O'Carroll et al, 2000).

2.8 Life Orientation Test – Revised (LOTR) (Scheier, Carver, & Bridges, 1994)

Following a health/treatment intervention it is noted that some patients fare better in their physical and psychological well-being than others. Explanations for this outcome have considered the influence of certain personality variables. A commonly investigated feature is optimism, specifically dispositional optimism.

Dispositional optimism is a relatively stable aspect of an individual’s personality that refers to the expectancy that, when confronting important life events, good as opposed to bad things will generally happen (Scheier, Magovern, Abbott, Matthews, Owens, Lefebvre et al, 1989; Wrosch & Scheier, 2003).

Previous research has shown that patients displaying high levels of dispositional optimism were less frequently readmitted to hospital and had faster recovery following coronary artery bypass surgery (Scheier, Matthews, Owens, & Schulz, 1999); showed better quality of life at one year post treatment for head and neck cancer (Allison, Guichard, & Gilain, 2000); post surgery for breast cancer (Schou, Ekeberg, & Ruland, 2005), and better mental health post liver, lung and bone marrow transplant (Goetzmann, Klaghofer, Wagner-Huber, Halter, Boehler, Muellhaupt et al, 2007). The benefits of possessing high levels of optimism are thought to be mediated by coping style in that optimistic people are more likely to use problem focused coping strategies which leads them to make plans for their future and set goals for recovery. This in turn is thought to lead to better physical and psychological outcomes following treatment. Pessimists on the other hand are more likely to use denial as a coping mechanism and are consequently not likely to seek out social and medical support and advice, leading to poorer outcomes (Scheier et al, 1994; Scheier et al, 1989; Wrosch & Scheier, 2003).

Previous research has also indicated that people who have signed the organ donor register have higher levels of dispositional optimism than those who have not registered (Rodrigue, Cornell, Jackson, Kanasky, Marhefka, & Reed, 2004). We were keen to assess levels of optimism amongst potential living donors in this study, and to assess the influence of optimism measured prior to the operation upon post donation outcomes with donors and recipients.

The most common measure of dispositional optimism is the Life Orientation Test (LOT) and the revised version of the Life Orientation Test (LOT-R) (Herzberg, Glaesmer, & Hoyer, 2006). Following criticism of the LOT, in 1994 a revised version was developed which reduced the length of the test and simplified the format and accompanying instructions. The LOT-R correlates highly with the original LOT and has shown be a valid and reliable measure (Scheier et al, 1994). The LOT-R is employed within this research study (see Appendix 9).

The LOT-R consists of 10 items (e.g. *In uncertain times, I usually expect the best*) to which the participant is asked to respond on a 5 point likert-type scale (*Strongly disagree, Disagree, Neither agree nor disagree, Agree* and *Strongly agree*). The responses are scored 0-4 respectively. Of the 10 items, 4 are filler questions and are not included in the final score (items 2, 5, 6 and 8). Items 3, 7 and 9 are reverse scored (i.e. *Strongly disagree* to *Strongly agree* are scored 4-0 respectively).

Therefore, scores can range from 0 to 24 with higher scores indicating higher optimism.

2.9 Generalised Self Efficacy Scale (GSES) (Schwarzer & Jerusalem, 1995)

Self efficacy is a concept that was first described by Albert Bandura in relation to his social cognition theory (Bandura, 1977). Self efficacy describes an individual’s belief that they personally are capable of dealing with stressful or challenging life situations (Schwarzer, Bläßer, Kwiatek, & Schröder, 1997). Self efficacy has been regarded as domain specific in that levels of self efficacy can differ depending on the situation being considered. However, it has also been suggested that self efficacy can be a generalised concept referring to an overall level of confidence in a person’s own abilities to deal with a wide range of situations. It is this general view of self efficacy that is measured in this study (Schwarzer et al, 1997).

The Generalised Self Efficacy Scale (GSES) (see Appendix 10) was first produced in German but has since been translated into numerous other languages (Schwarzer & Jerusalem, 1995). Since its inception, tests of validity and reliability have confirmed its appropriateness as a measure of the single construct that is general self efficacy (Barlow, Williams, & Wright**,** 1996; Leganger, Kraft, & Røysamb, 2000; Schwarzer et al, 1997). The GSES has been associated with psychological well-being in patients with arthritis (Barlow et al, 1996) and is a significant predictor of health status and quality of life in cystic fibrosis patients (Wahl, Rustoen, Hanestad, Gjengedal, & Moum, 2005). The GSES is included in this thesis to assess if self efficacy measured prior to living donation was predictive of recovery post donation/transplant.

The GSES is made up of 10 statements relating to how a person may deal with a novel or difficult situation e.g. *I can always manage to solve difficult problems if I try hard enough.* Participants are asked to consider how much each statement applies to them and to make the appropriate response on a 4-point likert-type scale: *Not at all true, Hardly true, Moderately true, Exactly true.* Each response is scored 1-4 respectively with no reverse scoring required. Summated scores range from 10 to 40 with higher scores indicating greater general self efficacy.

2.10 Hospital Anxiety and Depression Scale (HADS) (Zigmond and Snaith, 1983)

High levels of depression and anxiety have been found in patients awaiting liver and kidney transplantation when compared to healthy controls and transplanted patients, and pre transplant anxiety, in particular, has previously been found to influence quality of life post liver transplant (Martin, Tweed, & Metcalfe, 2004; O'Carroll et al, 2003). Longitudinal studies generally support the benefits of transplant in reducing anxiety and depression, but the procedure can also result in an increase in such distress for a percentage of recipients (Christensen, Ehlers, Raichle, Bertolatus, & Lawton, 2000; Goetzmann, Ruegg, Stamm, Ambühl, Boehler, Halter et al, 2008; Virzí, Signorelli, Veroux, Giammarresi, Maugeri, Nicoletti et al, 2007). Following living kidney donation, Martin et al (2004) found recipients had depression and anxiety scores higher than patients who had received a deceased donation, and comparable to patients on dialysis, whilst Erim and colleagues found improved affect scores in living liver donors following donation (Erim, Beckmann, Kroencke, Valentin-Gamazo, Malago, Broering et al, 2007). With such results in mind we considered it important to include a measure of anxiety and depression in this thesis to allow changes to be explored from pre to post living donation.

The Hospital Anxiety and Depression Scale (HADS) (see Appendix 11) was employed as a measure of depression and anxiety within this thesis. The HADS is a commonly used measure and owes its popularity to its robust and simple format. It has been used previously in transplantation research (Erim et al, 2007; Goetzmann et al, 2008; Martin & Thompson, 2002; Martin et al, 2004; O'Carroll et al, 2003).

The HADS was first developed in 1983 by Zigmond and Snaith. The original purpose of this measure was to identify individuals with possible depression and anxiety disorders within medical patients (Zigmond & Snaith, 1983). It was hoped that the measure would serve to highlight to doctors patients with emotional disorders that went beyond emotional reactions to their physical diagnosis and symptoms (Johnston, Pollard, & Hennessey, 2000; Snaith, 2003).

The measure is made up of 7 non-somatic statements pertaining to depression and 7 to anxiety, presented in an alternate format. Each statement has four response options available which vary in degree of emotional distress and are scored 0-3, with 3 assigned to the response option depicting the highest distress, e.g. *“Not at all”* (score 0), *“From time to time, occasionally”* (score 1), *“A lot of the time”* (score 2), and *“Most of the time”* (score 3). The participant is asked to consider each statement with regards to how they have felt over the past week and respond accordingly. Total scores for the depression and anxiety domains each range from 0-21 with higher scores depicting higher levels of depression and anxiety respectively. Despite some argument over the most appropriate cut off score to distinguish individuals with and without a possible depression or anxiety disorder, a recent literature review supported the authors’ original instruction to have a cut off score of 8 (Bjelland, Dahl, Haug, & Neckelmann, 2002). Scores of 8 and above can be divided further into three groups allowing clinicians an indication of the disorder's severity: mild (score 8-10), moderate (score 11-15) or severe (score 16-21) (Zigmond & Snaith, 1983).

Although the scoring of the measure can highlight possible disorders to a clinician, the language used within the measure itself does not show a transparent link to a mental health problem. This, in addition to its simple layout and quick and easy completion renders it an acceptable measure for use within a patient population (Johnston et al, 2000; Snaith, 2003; Wilkinson & Barczak, 1988).

Since its inception, research has been conducted to test the reliability and validity of the measure. The first review of the literature was published in 1997, and it was concluded that the HADS was a "reliable and valid instrument for assessing anxiety and depression in medical patients" (Herrmann, 1997). This finding was supported in a more recent review, which included research involving the HADS in both medical and non-medical populations (Bjelland et al, 2002). The internal reliability and test/retest reliability has additionally been confirmed in a sample of patients with end stage renal disease (Martin & Thompson, 2002).

2.11 Cambridge Neuropsychological Test Automated Battery (CANTAB) (Sahakian & Owen, 1992)

Previous research has shown the existence of cognitive deficits within patients suffering from renal disease (Gelb, Shapiro, Hill, & Thronton, 2008) and liver disease (O'Carroll et al, 1991). A biological explanation for the existence of cognitive impairments within these patient groups remains complex however, it is generally thought to be the result of toxins, normally expelled from the body via a healthy working liver or kidneys, accumulating within the blood stream (Collie, 2005; Pliskin, Kiolbasa, Hart, & Umans, 2001). Studies have shown that transplanted patients generally perform at a level similar to the healthy population, suggesting that cognitive deficits may be reversible (Griva, Hansraj, Thompson, Jayasena, Davenport, Harrison et al, 2004; Kramer, Madl, Stockenhuber, Yeganehfar, Eisenhuber, Derfler et al, 1996; Schulz, Kröncke, Kraft, Wein, & Rogiers, 2004).

Despite evidence for cognitive improvements, other studies have suggested that impairments do not completely return to a normal level, with transplanted patients performing below the level of healthy controls (Gelb et al, 2008; O'Carroll, Turner, Flatley, McGregor, & Hayes, 2008). As cognitive impairment can have a detrimental effect on adherence to medication and advice, and other psychosocial factors e.g. employment, it is an area that urgently requires further investigation (Griva, Thompson, Jayasena, Davenport, Harrison, & Newman, 2006). The majority of previous studies have been cross-sectional in design but longitudinal studies with assessments conducted pre and post kidney or liver transplant would allow more insight into the nature of impairments and improvements in neuropsychological functioning. For this reason a brief neuropsychological test battery was employed within the current research at each of the three time points.

Studies reported to date that have assessed cognitive functioning in liver and kidney patients have mostly employed traditional neuropsychological tests such as the Trail Making Test (TMT) and the Mini-Mental State Examination (MMSE). It has been suggested that such tests may not be sensitive enough to highlight subtle cognitive deficits and that computerised tests may be more likely to detect any changes, as found in a study involving patients following coronary surgery (Silbert, Maruff, Evered, Scott, Kalpokas, Martin et al., 2000). Therefore a computerised battery of neuropsychological tests, collectively known as the Cambridge Neuropsychological Test Automated Battery (CANTAB), was selected for use within this study. CANTAB has been used extensively with psychiatric populations and patients with known neurodegenerative diseases such as Alzheimer's disease (Fray, Robbins, & Sahakian, 1996). Its validity and reliability has been established in such studies (Levaux, Potvin, Sepehry, Sablier, Mendrek, & Stip, 2007).

CANTAB was originally developed in 1986, by Barbara Sahakian, Trevor Robbins and colleagues, at the University of Cambridge. There are a total of 19 tests included in the battery and each has been designed to assess either memory, attention or executive function (Levaux et al, 2007). The strengths of CANTAB lie within its ease of use (including touch screen responses), administration and storage of data, and being able to record participant accuracy and speed in milliseconds (Fray et al, 1996; Levaux et al, 2007).The availability of parallel versions of tests also lends itself particularly well to longitudinal studies.

In order to keep the participation requirements to a minimum only four of the CANTAB tests were administered: *Motor screening (MOT)*; *Reaction time (RTI)*; *Rapid Visual Information Processing (RVP),* and *Delayed matching to sample (DMS).* These tests specifically test memory and attention, and include measures of psychomotor speed, cognitive abilities specifically found to be impaired pre kidney transplant and improved upon post kidney transplant (Griva et al, 2004; Griva et al, 2006; Lacerda, Guimaro, Prade, Ferraz-Neto, Karam, & Andreoli, 2008). Liver transplant candidates have shown impairment in these cognitive abilities which improve when a transplant is received although not always to a level comparable with norms (O'Carroll et al, 2003; O'Carroll et al, 2008; Schulz et al, 2004).

Within each test, a practice session is incorporated and scripted instructions are read to the participant. The computer generated results consist of an array of output variables and the most relevant two were selected from each of the tests for analysis in this thesis:

MOT: This is a screening test to highlight participant difficulties in understanding simple instructions, and visual and movement problems. It is therefore recommended to be given at the start of every CANTAB testing session but is not included within the analysis. It allows the participant to become accustomed to the computer and touch screen format and follows an initial demonstration from the test administrator. The test itself takes 3 minutes to administer.

RTI: This is a test of reaction and movement time when both a predictable and unpredictable visual stimuli is presented. Reaction and movement times assess cognitive and motor function respectively. In the first section the participant is asked to release a button and touch a specific area of the screen following presentation of a yellow spot. In the second section, the yellow spot can appear in any one of 5 specified areas and the participant must touch the screen wherever the yellow spot appeared. This test takes approximately 5 minutes to administer. A parallel version of this test is performed at each of the three times points (pre-transplant, 6 weeks post transplant, and 6 months post transplant) to reduce the possibility of practice effects. The speed with which the button is released (Reaction time), and the speed with which the correct location is selected (Movement time), when 5 choices are present, are the selected output variables for analysis. The distinction between reaction and movement time is thought to differentiate any deterioration in motor function from deterioration in cognitive function.

RVP: This is a test of sustained visual attention and information processing. This test involves the presentation of numbers 2 to 9 appearing in a random order, one at a time in a box in the centre of the computer screen. The digits change at a speed of 100 digits per minute. The participant is instructed to press a button whenever they see any of the three specified target sequences of three numbers (357, 246 and 468). This test takes approximately 7 minutes to administer. There are no parallel versions available and so the same test is run at the three different time points. The number of times the sequence is correctly responded to (Total hits) and the time taken to correctly respond (Mean latency) are the selected output variables for analysis.

DMS: This is a test of visual memory, involving immediate and delayed perceptual matching. The participant is presented with a pattern constructed of 4 parts, each a different colour. Below this pattern are four more patterns from which the participant is asked to select the one that is identical to the pattern presented in the top half of the screen, by touching the corresponding pattern. Of the four choice patterns one is identical to the original, one has the same shape as the original, one has the same colour order as the original and one is a novel distractor (both shape and colour order is different to the original). The choice patterns are either displayed simultaneously, with the original pattern shown in the top half of the screen, or the original pattern is first removed before the choice patterns are displayed. Choice patterns are either displayed after a delay of 0, 4 or 12 seconds. This test takes approximately 10 minutes to administer and a parallel version is presented at each of the three time points. The total number of patterns correctly remembered after the longest delay of 12 seconds (Correct delays at 12000ms), and the speed of response when the correct pattern is identified (Mean latency) are the selected output variables for analysis.

The tests are completed in the order listed above. The *RVP* is considered a more demanding test compared to the *RTI* and *DMS* and therefore it was decided to place this in the middle. It was felt that to introduce this test first would discourage continued participation and to complete the test last would possibly leave participants feeling disheartened by the neuropsychological testing section.

2.12 Rivermead Behavioural Memory Test (RBMT) (Wilson, Cockburn, Baddeley, & Hiorns, 1989)

As indicated in the previous section describing the CANTAB, studies have indicated that pre transplant patients often present with impairments of memory that can improve post transplant (Gitlin, Lewis, & Hinkley, 1986; Griva et al, 2004; O'Carroll et al, 2003; Pliskin et al, 2001). The CANTAB includes a test of visual memory (*DMS*) but verbal memory was also deemed an important aspect to investigate since performance in this area has previously been found to be superior with kidney transplant patients compared to those on dialysis (Griva et al, 2004). Subtests from the Rivermead Behavioural Memory Test (RBMT) were therefore employed in conjunction with the CANTAB.

The RBMT is a well validated battery of tests designed to emulate everyday memory tasks suitable for repeat testing in order to monitor changes in memory over time. The RBMT consists of 12 subtests of memory but to keep participation time to a minimum, only the 2 subtests designed to specifically measure verbal memory were employed in this study: *Story Immediate* and *Story Delayed*.
Story immediate: Participants are asked to listen carefully to a short story read out

by the administrator and then to repeat back as much as they can remember (see Appendix 12 for example of story used). The story contains 21 items for the participant to remember. A score of 1 point is given for each item remembered correctly and a half point for items partially remembered. Raw scores are therefore out of 21 with a higher score indicating better short-term working memory.
Story delayed: After a filled delay participants are asked if they remember the story that was read to them earlier and are instructed to recall as much as they can at that point. The delay was approximately 1 hour. Again 1 point is given for each item remembered correctly and a half point for items partially remembered. If the participant cannot remember the story, the interviewer can give a prompt of, "*The story began with (first 2/3 words of story)*". If a prompt is necessary, 1 point is deducted from the participant's total score. Again raw scores are out of 21 and higher scores indicate better short term memory function.

There are 4 parallel versions of the story available within the Story immediate and Story delayed subtests, making it suitable for a longitudinal study whereby participants are re-tested at a later date.

Chapter 3 Living liver donation: Attitudes of the general public and general practitioners in Scotland

3.1 Abstract

Objective: In April 2006, the Scottish Liver Transplant Unit in Edinburgh became the first NHS transplant unit in the UK to offer adult-to-adult Living Donor Liver Transplantation (LDLT). This procedure allows a healthy individual to donate part of their liver to someone with end-stage liver disease. With donations from the deceased in short supply, this procedure has the capacity to save lives. The aim of this study was to explore the attitudes of the general public and general practitioners (GPs) towards LDLT, before its implementation.

Design: A total of 1041 members of the Scottish general public and 155 GPs working in Scotland participated in this study. Frequency counts and chi square tests were employed to evaluate results.

Method: Participation involved completion of a short questionnaire devised for this study.

Results: Frequency counts showed that only 34% of the general public wish to donate their organs following death compared to 85% of GPs. With regards to an acceptable risk of death before volunteering to donate, 25% of GPs would accept a 1 in 20 risk of death, whereas 50% of the general public either could not make a decision or selected “No risk”.

Conclusion: The majority of participants supported the option of LDLT; however the question of how well people understand the concept of risk was highlighted in this study.

3.2 Introduction

Liver disease can take many forms, from the autoimmune disorder primary billiary cirrhosis, to alcohol induced liver cirrhosis. Regardless of cause, progression of the disease will inevitably lead to a number of patients requiring a liver transplant. However, the shortage of livers donated following death means that not every person in need of a liver transplant will receive one (see Chapter 1:General Introduction for more information). Many patients who make it on to the liver transplant waiting list either have to be removed from the list or die before a suitable liver becomes available. In Scotland alone, between April 2006 and December 2006, 13 patients died whilst on the elective liver transplant waiting list and 35 patients were added (unpublished data taken from the Scottish Liver Transplant Unit's database). The situation fails to show any signs of improvement as the incidence of liver cirrhosis continues to increase in Britain. In Scotland, the rate of death from cirrhosis of the liver is one of the highest rates in Western Europe (Leon & McCambridge, 2006).

In an attempt to increase the donor pool, reduce the amount of time a patient needs to wait for a transplant, and therefore minimise the number of deaths on the liver transplant waiting list, an alternative to transplantations using livers from deceased donors has been developed. This new surgical procedure is known as Living Donor Liver Transplantation (LDLT) (see Chapter 1 for description). Despite the risks involved for the healthy donor, the immediate benefits of LDLT means the procedure has gained widespread acceptance as a life-saving treatment for adults with severe liver disease (Shrestha, 2003).

The UK's first NHS LDLT programme commenced at the Scottish Liver Transplant Unit (SLTU) in April 2006. Prior to the LDLT programme starting in Scotland it was considered important to ascertain the views of the Scottish population regarding the introduction of LDLT and the implications for potential donors and recipients. Attitude surveys on LDLT have previously been conducted, but have focused either on the general public or medical professionals separately (Cotler, Cotler, Gambera, Benedetti, Jensen, & Testa, 2003; Cotler, McNutt, Patil, Banaad-Omiotek, Morrissey, Abrams et al, 2001; Neuberger et al, 2003). These previous studies have each found support for the option of LDLT whilst highlighting the moral and ethical issues to be considered.

Within this study, we assessed both the Scottish general public and General Practitioners (GPs) employed within Scotland using the same attitudinal measure. This was to allow direct comparisons between the two groups. GPs were selected as a comparison group due to their role as medical professionals not directly involved in liver transplantation, but to whom future patients, the general public, may turn to for health related advice.

3.3 Hypotheses

- GPs will have more awareness of LDLT than the general public.
- GPs will show stronger support than the general public for the introduction of LDLT in Scotland.

3.4 Methodology

The aim of this study was to investigate attitudes towards Living Donor Liver Transplantation and was a between-group design. Two groups were selected for participation in this project: a representative sample of the general public and GPs in Scotland. A short questionnaire, suitable for both groups, was developed specifically for this study. Ethical approval was granted by the Lothian NHS Ethical Review Committee (letter dated, November 3rd 2005).

3.4.1 Participants

3.4.1.1 GPs

Each of the 15 Scottish NHS Health Boards were contacted in order to obtain the names and addresses of GPs employed in that area. We were advised by the regional co-coordinator from the Scottish Practices and Professionals Involved in Research (SPPIRe) organisation that in order to recruit a minimum of 100 GP participants, it would be necessary to invite approximately 300 to participate. For each health board, 7.6% of the GPs listed were randomly selected to receive an invitation to participate in the study. A random number generator was used to select the GPs from each health board who would be asked to participate. A total of 301 GPs were sent an invitation pack. This pack consisted of a cover letter (see Appendix 13), a copy of the questionnaire and a stamped addressed envelope. The cover letter explained the purpose of the study, why they had been invited, what participation would involve, and that consent to use their data in the analysis was automatically accepted with return of the questionnaire. Participants were instructed to return the completed questionnaire in the stamped addressed envelope provided. A total of 155 (51.5%) GPs completed and returned the questionnaire (male = 53.5%, female = 46.5%). Age was categorized into 6 groups from 16 to 65 years and above with 32.3% and 40% of GPs falling in the 35-44 and 45-54 years categories respectively. Due to the training requirements of GPs, no participants fell into the 16-24 age range. Data collection was conducted between November and December 2005.

3.4.1.2 General Public

An external independent research company was employed to collect attitudinal data from the general public. Market Research UK (MRUK) conducts a monthly survey with a representative sample of the Scottish adult population, interviewing participants in their own homes. MRUK divide the Scottish map into 52 constituency-based sampling points. The size of each sampling point is representative of the geographic population spread. Participants are randomly selected within each sampling point although quotas are established for age, gender and socio-economic status. Interviews are limited to one per household. The questionnaire developed for this study was added to MRUK's monthly omnibus survey. Data collection was from 11th -17th November 2005. MRUK researchers informed each participant that the answers they gave were to be treated confidentially. Prompt cards were employed to allow participants to read the possible answers to the questions read out by the MRUK researcher. A total of 1041 members of the general public were interviewed (male = 49.6%, female = 50.4%). Due to the quota requirements of MRUK, between 13.1% and 19.1% of the general public were found in each of the 6 age categories ranging from 16 to 65 years or more.

3.4.2 Questionnaire

A list of questions were devised and sent for review by three medical professionals within the Scottish Liver Transplant Unit. The questions were largely influenced by previous attitudes surveys (Cotler et al, 2003; Cotler et al, 2001; Neuberger et al, 2003) and touched upon issues such as the circumstances under which someone would and would not donate, and the practical, moral and ethical aspects of coordinating a living donation programme. The decision was made to only include questions relevant to the proposed LDLT programme in Scotland. For example, as the programme will only allow adults to donate to close adult relatives, questions pertaining to donation to children and strangers were omitted. The final list of questions covered the following topics: previous knowledge of LDLT; willingness to donate following death; justification for LDLT; financial reimbursement for donor; responsibility for donor payment; acceptable levels of risk; possible donor complications, and support for LDLT to be offered throughout the UK. A total of 15 questions, each requiring a simple tick-box response, were included in the final questionnaire.

3.5 Results

Frequency counts were generated for the responses to each question. Differences between the two groups were analysed using chi-squared tests. Whilst the two groups did not significantly differ on gender, the distribution of age ranges did significantly differ (χ^2 (5, n =1196) = 99.73, $p<0.01$).

For questions 4a to 4e, 7 and 8, the response variables *strongly disagree* and *disagree*, and *neither agree nor disagree* and *don't know* were collapsed to ensure adequate cell sizes for chi-squared analysis. The response variables *strongly agree* and *agree* were kept separate as the cell sizes were acceptable for analysis. For question 9 *strongly oppose* and *tend to oppose* were combined as were *neither support nor oppose* and *don't know*. The variables *strongly support* and *support* remained separate.

Question 1: Had you ever heard of LDLT before now?

A significant difference was found between the distribution of responses for GPs and the general public (χ^2 (2, n =1196) = 41.60, $p<0.01$). A higher proportion of

GPs (76.8%), compared to the general public (49.3%), had heard of LDLT before completing the questionnaire (see Table 3-1).

Question 2: Do you wish to donate your organs when you die?

A significant difference was found between the two groups with regard to the distribution of responses (χ^2 (2, n = 1196) = 152.02, p<0.01). A higher proportion of GPs (85.2%) stated that they wished to donate their organs when they died compared with the general public (33.6%). In contrast, a higher proportion of the general public either selected "no" or "don't know" when compared to GPs (see Table 3-1).

Table 3-1: Previous knowledge of LDLT and willingness to donate following death

			Response %		
Question	Group	N	Yes	No	Don't know / No response
Q1: Had you ever heard of LDLT[a] before now?	GPs[b]	155	76.8	23.2	-
	General public	1041	49.3	49.0	1.7
Q2: Do you wish to donate your organs when you die?	GPs	155	85.2	13.5	1.3
	General public	1041	33.6	37.5	28.9
Q3: Are you currently on the donor register or carry a donor card?	GPs	155	66.5	32.3	1.3
	General public	1041	19.5	79.3	1.2

[a]LDLT = Living Donor Liver Transplantation [b]GPs = general practitioners

Question 3: Are you currently on the donor register or carry a donor card?

A significant difference between the distribution of responses for GPs and the general public was found (χ^2 (2, n =1196) = 157.10, p<0.01). A higher proportion of

GPs (66.5%) said “yes” compared with the general public (19.5%), and a higher proportion of the general public (79.3%) said “no” compared to GPs (32.3%) (see Table 3-1). Of the general public who wished to donate their organs following their death, 55.4% were either on the donor register or carried a donor card. Of the GPs who wished to donate their organs after death, 78% were either on the donor register or carry a donor card.

Question 4a: To what extent do you agree that NHS transplant units have a duty to their patients to offer adult Living Donor Liver Transplantation?

There was a significant between-group difference in response to this question (χ^2 (3, n =1196) = 29.61, p<0.01). Although the majority of participants within each group agreed with the statement, the proportion of GPs who strongly agreed with this statement (14.2%) was lower than the proportion of the general public who indicated strong agreement (28.0%). GPs were more likely than the general public to neither agree nor disagree with this statement (see Table 3-2).

Question 4b: To what extent do you agree that it is important for Scotland to be competitive in the health/medical field by offering new surgical procedures?

A significant between-group difference was found with regards to this question (χ^2 (3, n =1196) = 33.52, p<0.01). Again the majority of participants within each group agreed with the statement (48.4% and 47.1% for the general public and GPs respectively). However, a larger proportion of GPs selected either “disagree” or “neither agree nor disagree” compared with the general public. In addition, a higher proportion of the general public strongly agreed with the statement compared with GPs (see Table 3-2).

Question 4c: To what extent do you agree that the increasing number of deaths on the liver transplant waiting list justifies the risk LDLT poses for an individual donor?

A significant between-group difference was found with the responses to this question (χ^2 (3, n =1196) = 44.04, $p<0.01$). Within both groups the majority of participants agreed with the statement. However, a higher proportion of the general public (23.2%), compared with GPs (9.7%), strongly agreed with the statement. In contrast, a higher proportion of GPs (16.1%) disagreed with the statement compared with the general public (5.2%) (see Table 3-2).

Question 4d: To what extent do you agree that the surgeon and medical team would not perform the operation unless they were confident of a positive outcome for both the donor and recipient?

There is no statistically significant relationship between the groups and their response to this question (χ^2 (3, n =1196) = 7.57, $p = 0.06$). The distribution of responses did not significantly differ between GPs and the general public. Within each group, the majority of participants agreed with this statement (see Table 3-2).

Question 4e: To what extent do you agree that the donor should be paid travel expenses and any loss of earnings obtained during the transplant experience?

A significant difference exists between the two groups with regard to their distribution of responses (χ^2 (3, n =1196) = 18.13, $p<0.01$). The majority of participants within each group responded “agree”. However, a larger proportion of GPs (11.6%) disagreed that the donor should be paid travel expenses and any loss of earnings compared with the general public (4.5%) (see Table 3-2).

Question 5: Who do you think should pay this money (travel expenses and loss of earnings) to the donors?

There is no statistically significant between-group difference (χ^2 (4, n =776) = 8.57, p= 0.07). The distributions of responses for the two groups do not significantly differ. Within each group a large majority of participants believe that the Government should pay travel expenses and any loss of earnings to the donor (see Table 3-3).

Table 3-2: Justification for LDLT and financial reimbursement for donor

			Response %			
Question	Group	N	Strongly Agree	Agree	Neither agree nor disagree	Disagree
Q4a: NHS[a] transplant units have a duty to their patients to offer adult LDLT[b].	GPs[c]	155	14.2	40.0	36.8	9.0
	General public	1041	28.0	44.2	24.7	3.2
Q4b: It is important for Scotland to be competitive in the health/medical field by offering new surgical procedures.	GPs	155	25.8	47.1	20.6	6.5
	General public	1041	35.9	48.4	14.8	0.9
Q4c: The increasing number of deaths on the liver transplant waiting list justifies the risk that LDLT poses for an individual donor.	GPs	155	9.7	51.6	22.6	16.1
	General public	1041	23.2	40.0	31.6	5.2
Q4d: The transplant surgeon and medical team would not perform the operation unless they were confident of a positive outcome for both the donor and recipient.	GPs	155	36.1	45.8	14.2	3.9
	General public	1041	30.5	41.7	23.9	3.9
Q4e: The donor should be paid travel expenses and any loss of earnings during the transplant experience.	GPs	155	23.2	43.9	21.3	11.6
	General public	1041	26.0	38.5	30.9	4.5

[a] NHS = National Health Service; [b] LDLT = Living Donor Liver Transplantation; [c] GPs = General practitioners

Table 3-3: Responsibility for donor payment

Question	Group	N	Response %				
			Recipient or their family	The hospital	The Government	Charities	Don't know / No response
Q5: Who do you think should pay travel expenses and loss of earnings to the donor?	GPs[a]	155	5.8	1.9	81.7	5.8	4.8
	General Public	1041	4.8	4.3	75.1	3.1	12.6

Table 3-4: Acceptable levels of risk

Questions	Group	N	Response %							
			1 in 20	1 in 50	1 in 100	1 in 500	1 in 1000	1 in 2000	No risk	Don't know/ No response
Q6a: Acceptable level of risk of death for someone donating to a loved one.	GPs[a]	155	8.4	5.2	21.3	18.7	17.4	23.9	1.3	3.9
	General public	1041	7.4	6.5	9.1	7.0	8.8	12.8	18.1	30.3
Q6b: Acceptable level of risk of death for YOU before you would donate to a loved one.	GPs	155	25.2	15.5	20.0	9.0	12.3	14.2	-	3.9
	General public	1041	11.6	9.8	8.5	4.9	6.1	8.8	18.5	31.7
Q6c: Acceptable level of risk of death for a LOVED ONE if they were donating part of their liver to you.	GPs	155	2.6	3.9	23.2	13.5	16.1	24.5	13.5	2.6
	General public	1041	3.2	5.8	6.0	5.4	8.8	12.5	29.9	28.5

[a] GPs = General practitioners

Question 6a: What level of risk of death, if any, do you feel is acceptable for someone donating to a loved one?

A significant between-group difference was found with regards to an acceptable level of risk for someone donating to a loved one (χ^2 (7, n =1196) = 121.43, $p<0.01$). A higher proportion of the general public, compared with GPs, either could not respond to this question or stated that only no risk was acceptable (see Table 3-4).

Question 6b: What level of risk of death, if any, do you feel is acceptable before you would donate to a loved one?

A significant between-group difference was found (χ^2 (7, n =1196) = 122.19, $p<0.01$). A higher proportion of the general public, compared to GPs, either could not decide upon an acceptable level of risk or chose no risk (see Table 3-4).

Question 6c: What level of risk, if any, do you feel is acceptable for a loved one if they were donating part of their liver to you?

A significant between-group difference was found (χ^2 (7, n =1196) = 134.40, $p<0.01$). Again, a higher proportion of the general public, compared to GPs, either could not select an acceptable level of risk or believed no risk was acceptable (see Table 3-4). For both groups, participants were prepared to accept a higher degree of donor risk when they were donating compared to when a loved one was donating to them e.g. 25.2% of GPs would accept a 1 in 20 risk of death if they were donating but this fell to 2.6% if a loved one was donating to them.

Question 7: To what extent do you agree that these possible problems (e.g. abdominal pain, leaking scars, difficulty sleeping) will affect a person's decision to donate?

A significant difference between the distribution of responses for the general public and GPs was found (χ^2 (3, n =1196) = 37.67, p<0.01). Within each group the majority of participants agreed that such possible problems would affect a person's decision. However, a higher proportion of GPs agreed or strongly agreed compared with the general public (see Table 3-5).

Question 8: To what extent do you agree that possible social and financial difficulties will affect a person's decision to donate?

A significant between-group difference was found (χ^2 (3, n =1196) = 32.71, p<0.01). Within each group the majority of participants agreed that a person's decision to donate would be affected. However, a higher proportion of GPs agreed compared with the general public (see Table 3-5).

Question 9: To what extent do you support or oppose the introduction of LDLT throughout the UK?

A significant difference between the distribution of responses for GPs and the general public was found (χ^2 (3, n =1196) = 11.63, p<0.01). Within both groups the majority of participants tend to support the introduction of LDLT throughout the UK. However, a higher proportion of GPs support LDLT compared to the general public, whilst a higher proportion of the general public are unsure compared to GPs (see Table 3-6).

Table 3-5: Possible donor complications

			Response %			
Question	Group	N	Strongly Agree	Agree	Neither agree nor disagree	Disagree
Q7: To what extent do you agree that possible medical problems (e.g. abdominal pain, leaking scars, and difficulty sleeping) will affect a person’s decision to donate?	GPs[a]	155	10.3	61.9	9.0	18.7
	General public	1041	20.2	44.4	24.7	10.8
Q8: To what extent do you agree that possible social and financial difficulties (e.g. future employment, mortgage applications, and health insurance premiums) will affect a person’s decision to donate?	GPs	155	11.6	67.1	8.4	12.9
	General public	1041	21.4	47.3	22.6	8.7

Table 3-6: Support for LDLT to be offered throughout the UK

			Response %			
Question	Group	N	Strongly Support	Support	Neither support nor oppose	Oppose
Q9: To what extent would you support or oppose the introduction of LDLT[b] in NHS[c] transplant units throughout the UK[d]?	GPs[a]	155	21.9	62.6	12.3	3.2
	General public	1041	21.6	52.2	24.0	2.2

[a] GPs = General practitioners, [b] LDLT = Living Donor Liver Transplantation; [c] NHS = National Health Service; [d] UK = United Kingdom;

3.6 Discussion

As hypothesized, GPs were more aware of the option of Living Donor Liver Transplantation (LDLT) but GPs did not consistently hold stronger positive views, perhaps suggesting some reservations to the introduction of LDLT within the medical community.

GPs and the general public gave particularly different responses with regard to the wish to donate organs following death. Only one third of the general public stated that they wished to donate their organs when they died compared with 85% of GPs. Of the general public who said they wished to donate, only 55.4% were on the donor register or carried a donor card. This is in comparison to 78% of GPs. It can therefore be suggested that GPs are more supportive than the general public towards the process of deceased organ donation and transplantation.

At the time of writing this study, a recent report indicated that only 29% of the Scottish population were on the organ donor register (Scottish Transplant Coordinators, 2007). The donor register is a valuable source of evidence of a person’s views regarding organ donation, particularly useful if there is any doubt within the family as to what their recently deceased relative would have wanted. Confirmation of a person’s wishes has become more important since the implementation of the Human Tissue (Scotland) Act 2006 (Scottish Executive, 2006) (see Chapter 1: General Introduction). Prior to this, the annual report for the Scottish Transplant Coordinators 2006/2007 indicated that 27.5% of families approached regarding consent for the removal of their relative’s organs refused (Scottish Transplant Coordinators, 2007).

It is important to note that within this study approximately one third of the general public stated that they **did not** wish to donate their organs following their death, leaving another third who were undecided. Transplantation using a liver from someone who had died is the preferred method of transplantation compared to LDLT due to such transplants not subjecting a healthy person to the significant risks associated with major abdominal surgery (confirmed in Chapter 5: Views of medical staff). LDLT is therefore only an alternative to donations from the deceased and not a replacement. Establishing ways in which this undecided group within the general public can be helped to make an informed decision and how best to encourage those in favour of organ donation to take active steps to join the organ donor register remain crucial research challenges.

In relation to these challenges, an attempt to increase the number of people offering to donate following their death has been suggested in the form of a system of presumed consent (see Appendix 1). Presumed consent would result in all members of the general public donating following their death unless they officially indicated, in life, a preference to refrain from this action. This topic has been at the centre of much debate for many years, yet a recent survey by the British Medical Association revealed that 74% of participants in Scotland support the introduction of a system of presumed consent (British Medical Association**,** 2007).

GPs and the general public accept the idea of LDLT in general and believe it should be offered to patients, but on a more personal level there appears to be less support for the procedure. The first hurdle with promoting any living organ donation is accepting that causing harm to one individual is defensible when the objective is to improve or save the life of another (Conesa, Ríos, Ramírez, Sanchez, Sanchez, Rodríguez et al, 2006). Within this current study, the majority of participants agreed that the number of deaths on the liver transplant waiting list justified the risk to the donor, a finding similar to that of Cotler et al (2003). However, approximately one third of the general public and a quarter of GPs were unsure of their opinion regarding this central issue. This suggests caution towards the acceptance of living donation.

This study also demonstrated trust in the medical professionals to only conduct an operation when they were confident of a positive outcome. However, when asked to put themselves in the position of a donor or recipient and consider the risk of death to the donor, support for LDLT was reduced. The risk of death for a living liver donor is thought to be approximately 1 in 200, and yet approximately 30% of the general public could not select an acceptable level of risk and 20% chose no risk. This finding highlights concerns that the general public may not fully understand the concept of risk, a conclusion also found in a previous attitude survey (Neuberger et al, 2003).

Previous studies have shown that understanding numerical information is difficult for the majority of people in the general population. However, when numerical data is described as a frequency (i.e. 1 in 200) as opposed to a percentage (i.e. 0.05%), the information is considered more understandable (Berry, 2004). For this reason, within this study, the possible levels of risk were described as frequencies. However, it has also been suggested that frequencies generate more frightening images, which may have contributed to our results regarding acceptable levels of risk (Slovic, Monahan, & MacGregor**,** 2000).

Research has shown that when making decisions about risk, heuristics are often used to help reduce the complexity of the situation (Berry, 2004). It has previously been suggested that experts commonly refer to the available published statistics when judging risk whereas lay people often rely on more emotional factors, such as the severity of the possible outcomes (Slovic, 1987). This difference in judgement could explain the results in this present study whereby GPs appeared more accepting of risk in this medical situation than the general public. The risk questions in this study asked for participants to consider the possible death of themselves or a loved one and to do so in terms of a new operation where the long term risks and benefits are unknown. Such an emotive, negative context in which to make a decision may have resulted in the general public being more cautious, leading them to either not respond to the questions of risk or select the "no risk" option.

This leads to the subject of message framing where the way information is worded can affect a person's interpretation of a situation. Framing a situation in a positive context has been found to affect decision-making and understanding (Berry, 2004). Had the levels of risk in this study been described as chance of survival as opposed to risk of death (i.e. 199 in 200 chance of survival compared to 1 in 200 risk of death) the results may have shown greater support for LDLT (this is investigated further in Chapter 7: impact of message frame). It is important to note that in a clinical setting, the potential donor and recipient would have the risks and benefits of LDLT fully explained to them before proceeding with the operation. In Scotland a donor advocate team (DAT) is in place to ensure that the donor fully understands the risks involved.

The results highlight the altruistic nature of living donation. A higher degree of risk is clearly acceptable for a participant when they are donating to a loved one compared to when a loved one is donating to them. This finding is similar to that of a previous study whereby patients on a transplant waiting list were found to be more willing to donate than to receive a living donation (Martínez-Alarcón, Ríos, Conesa, Alcaraz, González, Montoya et al, 2005). Such findings highlight possible implicit pressures that may be involved in the decision to become a living liver donor. Before a potential donor can be accepted for LDLT, the DAT has to be satisfied that the individual is free from coercion, but given the circumstances surrounding LDLT it may be impossible for implicit pressure to be completely absent. It is a challenge for the donor advocate team working with the donor to establish the pressures that may be involved in the decision making process and ensure the donor is happy to donate.

It is clear that the majority of participants support the introduction of LDLT throughout the UK, with only a small percentage opposing the new procedure, a response pattern similar to a previous study (Neuberger et al, 2003). Participants are aware of the need for an alternative method of transplantation for those on the transplant waiting list, but with consideration of the current risk involved and the uncertainty of long-term outcomes, it would appear that this support is, understandably, guarded. However, it must be noted that at the time of data collection less than half of the general public and only three quarters of GPs had heard of LDLT. It is possible that acquiring further knowledge and experience with the procedure, and having more accessible information about the risks and benefits, will affect the attitudes of the general public and GPs. Consequently, it is the intention of the author to repeat this study again when the LDLT programme in

Scotland has been running for 2 years. This will allow the assessment of any changes in attitude over time.

A limitation of this study can be found with regards to the age ranges of the participants. The distribution of age ranges significantly differed between the two groups due to the quota requirements of MRUK and the training and retirement restrictions of GPs but this was not investigated further. Future research could assess the influence of age upon attitudes.

In summary, the majority of participants within both groups showed support for the introduction of Living Donor Liver Transplantation. However, there was a significant difference in the distribution of responses to the majority of questions, between the two groups. Of particular interest was the general public's response to the questions regarding acceptable levels of risk. Half of the general public either could not answer the questions or selected *no risk*, a finding which supports previously voiced concerns that many members of the general public have difficulty understanding the concept of risk.

Chapter 4 Considering Living Donor Liver Transplantation: a qualitative study of patients and their potential donors

4.1 Abstract

Objective: In April 2006, the Scottish Liver Transplant Unit became the first NHS transplant unit in the UK to offer adult Living Donor Liver Transplantation (LDLT). However, within the first 21 months of its availability, no patients on the transplant waiting list had completed this treatment. This study was designed to obtain the views of patients and their families, in their role as potential donors, with regards to the option of LDLT.

Design: This study was of a qualitative interview design. A total of 21 patients and 20 potential donors participated and their responses were analysed using thematic analysis.

Method: A semi-structured, telephone interview was conducted with each participant.

Results: The main reason why patients did not pursue LDLT was their perception of risk to their donor and their anticipated feelings of guilt if the donor was harmed. However, many patients would possibly consider LDLT as a “last option”. For donors, considering becoming a donor was an automatic response, driven by their need to help their loved one survive. However, consideration of the effects of donating upon their own immediate family often superseded their wish to donate.

Conclusion: Potential donors need to be allowed time to consider the implications of LDLT upon their own lives, yet it is essential that patients understand that LDLT cannot be a last option, and realistic consideration of their options should be encouraged.

4.2 Introduction

Traditionally, liver transplants are performed using a liver donated by someone who has died. However, a major problem with this procedure is the insufficient number of livers being donated following death to allow much needed transplants to be conducted (Barber et al, 2006; British Medical Association, 2007). Patients subsequently have no choice but to wait on the transplant list until a suitable liver is found. In order to reduce the amount of time a patient must wait for a liver, and therefore increase the chance of performing a liver transplant when the patient is in a relatively good state of health, Living Donor Liver Transplantation (LDLT) has been introduced (see Chapter 1: General Introduction).

LDLT allows a healthy family member to donate part of their liver to a relative on the transplant waiting list. In a recent systematic review of the LDLT literature it was reported that the mortality rate for adult donors ranged from 0.23 to 0.5 % (Middleton et al, 2006). Morbidity rates ranged from 0-100% (with a median rate of 16.1%) and included biliary leaks, wound infections and pneumonia (Middleton et al, 2006).

Additional advances in transplant procedures, such as the acceptance of livers for transplant from non-heart beating donors (see Appendix 1), and the ability to split a deceased donated liver to benefit two patients, have been introduced and found to be effective in increasing the much needed supply of livers (Neuberger & Gimson, 2007). However, in addition, medical advances have allowed the criteria for liver transplant eligibility to be widened, subsequently increasing the demand for livers (Neuberger & James, 1999). In Scotland alone, by early 2006, approximately one patient per month was dying whilst they waited for a deceased liver transplant (McGregor, Hayes, & O'Carroll, 2008).

Due to the shortage of donated livers in Scotland, and in the knowledge that LDLT is gaining widespread acceptance in the USA, Asia, Canada and some parts of Europe as an effective treatment for patients with end stage liver disease, the Scottish Liver Transplant Unit (SLTU) submitted a funding bid to allow them to provide the first LDLT programme in the UK. This was granted and in April 2006, the programme commenced. It was anticipated that the unit would perform approximately 10 donor assessments in the first year of the programme, with 50% proceeding to LDLT. However, by December 2006, the unit had not yet formally assessed any potential donors for LDLT despite informing all eligible patients on the transplant waiting list that this was now a possible option. At this stage, with the support of the SLTU, a qualitative research project was developed to specifically gain a better understanding of why patients on the Scottish liver transplant waiting list, who were eligible for LDLT, were not pursuing living donation.

Understanding human behaviour in relation to health and illness is at the core of health psychology research. Living liver donation is a relatively new area of research and as such little is known about the decision making processes behind the specific behaviour of a) accepting or not accepting a living liver donation from a healthy family member and b) donating or not donating part of your liver to a loved one on the transplant waiting list.

Decision making theories have developed over the years shifting from a scientific description of rational thought processes to the inclusion of other more unpredictable factors e.g. personal experience, emotions and, social and environmental contexts (Gordon, 2001). Psychologists have incorporated such advanced decision making theories into models of health behaviour e.g. the Theory of Planned Behaviour (TPB) (Ajzen, 1988) and the Health Belief Model (HBM) (Rosenstock, 1966).

The TPB is one of the most widely used theoretical models in health behaviour. The TPB explains behaviour as being guided by the individual's attitude towards the specific behaviour (i.e. beliefs about the outcome of the behaviour itself), subjective norms (i.e. beliefs about how other people will view the behaviour) and perceived control over performing the behaviour (i.e. beliefs about the possession of required skills, information or opportunities) (Armitage & Conner, 2001). With the HBM, the focus is on the costs and benefits, which the individual perceives to be inherent in the specified health behaviour. Consideration is given to their susceptibility to, and the severity of, the said health problem, the benefits of performing the advised behaviour and the barriers stopping them, and any internal or external cues to take action (Ogden, 2003).

As already described LDLT can reduce the time the patient spends on the liver transplant waiting list and consequently can save the patient's life. It was therefore considered to be important from a clinical and a psychological perspective to establish why the decision to pursue the option of LDLT had not yet been made.

4.3 Method

All patients considered by the medical team to be a potential candidate for LDLT receive an information booklet about living donation from the SLTU. Patients awaiting re-transplantation, patients with acute liver failure, and patients with other medical or surgical contraindications are not considered suitable for LDLT. A list of all patients who had received this information booklet since the LDLT programme commenced at the SLTU was obtained and each sent a letter of invitation to participate in this study (see Appendix 14). Consequently, participants were either currently on the transplant waiting list or had received a deceased donation.

Each patient who participated was asked to provide information about a family member, who was aware of the LDLT programme at the transplant unit, and could be invited to participate. Thirteen patients provided the name of one family member, 4 gave 2 names and 4 patients chose not to provide any family information. Family members were interviewed due to their position as potential donors and will be referred to as ‘donors’ throughout the remainder of this chapter.

All interviews were conducted between April and October 2007. At this stage it was agreed that data saturation had been met. Ethical approval for this study was granted by the Lothian Research Ethics Committee (letter dated, 11th January 2007).

4.3.1 Participants

4.3.1.1 Patients

A total of 32 patients were invited to participate in this study and 21 (65.63%) were interviewed (7 did not wish to take part, 2 died prior to participation, and the author was advised by the medical team that 2 were too ill to be contacted again). The interview transcripts of 20 patients were analysed (1 interview was lost due to recording problems) and included 6 females and 14 males, with an average age of 51.15 years (SD = 10.48; range = 30-68). For those on the transplant waiting list at the time of interview (N=13), the duration of time on the list was an average of 205.69 days (SD = 113.99, range = 54 – 393). For those who had received a deceased donation at the time of interview (N=7), the average time previously spent on the list was 127 days (SD = 47.01, range = 44 – 202). The liver disease that had resulted in the need for a liver transplant varied and were often multiple, including

Primary Sclerosing Cholangitis (N=6), Primary Biliary Cirrhosis (N=5), Hepatitis C (N=5), Alcoholic Liver Disease (N=3), Non-Alcoholic Fatty Liver Disease (N=2) and Autoimmune Chronic Active Hepatitis (N=1). For 5 participants liver cancer, Human Immunodeficiency Virus, haemochromatosis or haemophilia were also listed as having contributed to the need for transplant.

4.3.1.2 Donors

A total of 21 family members were invited to participate and 20 (95.24%) accepted. This 'donor' group included 13 females and 7 males, with an average age of 43.22 years (SD = 10.48, range = 21-60). The nature of the relationship with the patient varied but mainly included daughters (N=5), wives (N=3), brothers (N=2), sisters (N=2), and sons (N=2). The remaining 6 participants were a father, mother, husband, niece, partner and brother-in-law.

4.3.2 Data collection

We developed two interview schedules, one for donors and one for patients (see Appendices 15 and 16). The topics covered in both interview schedules are listed in Box 4-1.

Box 4-1: Interview topics

Brief summary of situation
Views on information pack distributed by transplant unit
First reactions to learning LDLT was a possible option
Perceived risks and benefits of LDLT for patient and donor
Issues considered during decision making
Satisfaction with staff involved with LDLT programme
Views on the set up of the LDLT programme at transplant unit
Other comments

The interview was not structured around one particular theoretical model but rather explored general areas derived from the literature and through discussions between the author and colleagues. It was important to provide a structured way for the researcher to elicit feedback about the new LDLT programme established specifically within the SLTU, which in turn, would encourage participants to describe their own personal thoughts and beliefs regarding LDLT.

The researcher (and author) was an employee of the University of Stirling and therefore independent from the transplant team. It was made clear that participation would be confidential and would therefore not affect any treatment they, or their relative on the waiting list, were currently receiving. The researcher had not previously met any of the participants. Each patient was given the option of being interviewed either in their own home, at the Royal Infirmary of Edinburgh, or by telephone. The SLTU is a national centre, serving liver patients from all over Scotland. As a family member, donors were not restricted to Scotland and potentially could come from anywhere in the UK and beyond. It was therefore considered vital to be as flexible as possible with respect to the mode of data collection to allow all patients and their donors, especially those who do not live in the Edinburgh area and those too unwell to travel, to take part. All participants selected a telephone interview. A consent form was sent to the participants once the date and time for the interview was arranged (see Appendix 17). Participants were instructed to sign and return the consent forms in the stamped addressed envelope provided with the consent letter. Each interview lasted approximately 30mins. All interviews were carried out by the same researcher, digitally recorded and transcribed verbatim. Transcripts were anonymised.

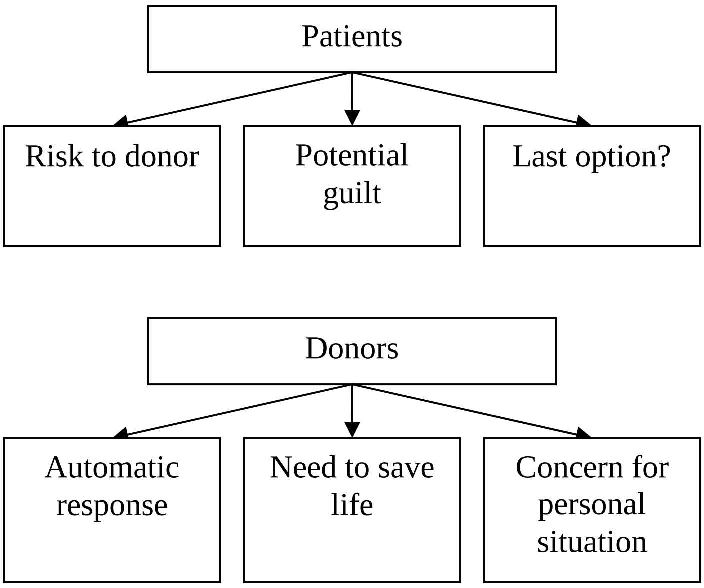
4.3.3 Data analysis

Thematic analysis was used to analyse the interview transcripts. Thematic analysis allowed the researcher to identify, analyse and report themes within the interview transcripts (Braun & Clarke, 2006) (see Chapter 1: General Introduction, section 1.8). Potential themes were discussed and the main themes verified with a senior colleague. For the purpose of this chapter the themes that emerged in relation to the decision to pursue living liver donation or not are reported. Themes in relation to the practical aspects of the living donation programme i.e. attitudes towards staff and information packs are not included.

4.4 Results

Three key themes emerged from the transcripts of patients: Risk to donor, Potential guilt, and Last option? Analysis of the transcripts of donors revealed three key themes: Automatic response, Need to save life and Concern for personal situation.

Figure 4-1: Patient and donor themes



4.4.1 Patient Themes

4.4.1.1 Risk to donor

The main reason why patients were not actively pursuing LDLT was their perception of risk to their potential donor (see Box 4-2).

Box 4-2: Risk to Donor
(*Tx = transplanted, WL = on waiting list)

I didn’t actually want to entertain it. I wouldn’t even go down, even dream of putting any of my family through that sort of thing, like.
[Patient 4, WL]

Em, I wouldnae put anybody at risk to be honest. It’s just my personal point of view. I wouldnae ask anybody to do that for me. Eh, because there is a risk to it…
[Patient 6, Tx]

It’s not something I’m, I’m even going to consider to be honest with you because I don’t feel I can put somebody else at risk.
[Patient 7, WL]

…it was just the side of it that I just felt, I don’t want like, someone close to me putting their self in danger.
[Patient 10, WL]

If it was, say, giving a pint of blood I would have said ‘Lovely’, no trouble at all. I mean it was nothing against where the, the donor liver was coming from. It was the principle of endangering somebody else’s life.
[Patient 13, Tx]

How do you ask somebody to put their life on the line for you? It’s quite difficult.
[Patient 16, WL]

There were different levels of risk mentioned within the transcripts. The most dominant being reference to risk of death, or physical harm, to the donor. However, reference was also made to perceived risk to the donors’ quality of life, encompassing possible family strains, employment, financial and general health problems. For many patients the level of risk reported by the professionals did not appear to matter. The possibility of any risk prevented them from pursuing living donation. Patients did not want their healthy family members to suffer in any way because of them. The patients knew only too well the effects of liver disease and did not wish to put a loved one in that position. It was in relation to this perceived risk that many patients believed it was something they simply could not ask of a family member. The majority of patients agreed that living liver donation was, in principle, a good thing and many were encouraged to know that another option was now available, but they themselves could not make the decision to proceed. They felt they could not ask a family member to contemplate donating given the associated risk involved. Patients did not want to explicitly ask a family member to donate, they did not want to be in a position whereby they would be putting their loved ones lives at risk and they did not want to be the cause of their loved ones' pain, discomfort, disability or even death.

4.4.1.2 Potential Guilt

This feeling of responsibility for their donor's suffering is linked to another common theme found within the patient transcripts, potential guilt (see Box 4-3). Patients' anticipated feelings of guilt, if anything adverse should have happened to the donor as a result of the donation operation, appeared to be too much to consider. It was not just the risk to the donor that prevented patients from pursuing LDLT, but in addition the guilt that would potentially follow the operation. Again, like perceived risk, different levels of guilt can be identified. Guilt is anticipated if 'anything happened' and also more explicitly if the donor 'didn't survive'. However, when listening to the conversations of the patients, the interviewer interpreted the reference to 'anything happening' as including death of the donor. It appeared that for many the thought of the donor's death was too frightening to even articulate. Many patients could not bring themselves to speak freely about the possible death of the donor as it was too distressing for them to think about.

Box 4-3: Potential Guilt
(* Tx = transplanted, WL = on waiting list)

Plus if anything had happened and I'd been okay and they'd been poorly I just would never have forgive, I wouldn't have been able to live with myself.
[Patient 19, Tx]

No, it's just purely that I don't think I could live with myself if it, you know, if I actually, something happened to the other, you know, the person who was donating the liver or part of their liver.
[Patient 7, WL]

Oh gosh, you know what? I could never of, ever of had it on my conscience. That if anything would have happened to her, I would have, oh, I wouldn't, I couldn't of lived with myself, honestly.
[Patient 1,Tx]

I wouldnae like to think that I would like to come out ok and then something would happen to her. I mean you couldnae live with yourself if that happened.
[Patient 12, WL]

I'd hate to think that I survived and the relative that gave me the part didnae survive, if you know what I mean.
[Patient 11, Tx]

Many patients understood that a liver transplant was their only option for recovery however, a living donation would consequently involve their loved one being harmed and feeling ill for a period of time. To benefit in the face of someone else's adversity is difficult for many transplant patients to consider. With deceased donations, someone has had to die and another family has had to lose a loved one before the patient can receive a life saving transplant. However, with deceased transplantation, feelings of personal responsibility towards the donor can be reduced as the donor and their death were unconnected to the patient. With living donation the patient feels responsible for the donor's situation and is witness to any adversity experienced by the donor. Many patients described how they could not live with themselves if anything happened to the donor whilst their condition improved, with some patients commenting that they *"would've probably rather have died"*, rather than put their loved ones at risk (see Box 4-3).

4.4.1.3 Last Option?

Despite the risk and anticipated feelings of guilt, many patients are acutely aware of their perilous situation and their need for a liver transplant, therefore the option of LDLT is not completely disregarded. Some patients see LDLT as a possible ‘last option’ (see Box 4-4).

Box 4-4: Last option?
(*Tx = transplanted, WL = on waiting list)

Em, so I basically, put it (referring to the information pack about LDLT) at the bottom of the pile and said something like, I’ll look at, you know, in a few months, if you know, nothing happens or, you know, my condition changes or anything, I’ll, I’ll bring it out.
[Patient 19, Tx]

I thought well, it’s not, although there is a dangerous side to it but if, if somebody was wanting to, if things got so bad there, it was the only way I was going to survive or whatever.
[Patient 4, WL]

No, if I was, if I did get that bad and that it was an absolute necessity ….then we would maybe consider it.
[Patient 5, WL]

Unless I, unless somebody said to me you’ve only got three months to live, it’s, it’s not something I, I want to, it’s not the route I want to go down, you know…… If all else fails then we’ll do that.
[Patient 9, WL]

And it was always something that we thought, well if we get to a bad stage we’ll maybe think about it.
[Patient 10, WL]

It could be interpreted that whilst the patient feels relatively well, the risk to the donor appears high, and the procedure of LDLT itself is not, at that point in time, essential. However, if the patient was to deteriorate significantly, they may be prepared to re-consider the option of LDLT. Patients would prefer to wait for a deceased donation rather than put a loved one at risk, but as they become more and more unwell the probability of a deceased donation arriving in time seems less likely. Patients anticipate that there may come a point when LDLT is the only option left, and only then will it be considered. LDLT was not something patients wished to commit themselves to at such an ‘early stage’ of their illness. Perhaps as a way of coping with the emotional aspects of LDLT, the time to give it real consideration is ‘put off’, to a time when the situation is considered much more desperate. At this point the options are extremely limited, and therefore patients may feel they can be relieved of some of the responsibility of making a decision. If the donor is still happy to donate at the stage where the patient is so ill that they are close to death, then the responsibility for the decision to proceed with LDLT may appear to shift more to the donor.

For patients currently on the transplant waiting list, the idea that LDLT was a possible last option was more evident. However, it was also touched upon by those who had received a deceased donation prior to their interview.

4.4.2 Donor Themes

4.4.2.1 Automatic response

For many donors, to consider becoming a living liver donor is automatic upon hearing that the option of LDLT may be available for their loved one (see Box 4-5). In the initial stages very little thought appears to be given to the risks of the procedure, indeed little is actually known about what LDLT entails. For many donors, LDLT offers them the opportunity to actively help their loved one on the transplant waiting list. The option consequently cannot be ignored. It would appear that many donors feel a duty to at least try and help, irrespective of the risk. Many family members feel obliged to do whatever is possible to help. Instead of *“having to wait for, well basically somebody to die”*, donors can actively do something to change the situation. The decision to offer to donate therefore appears quite a simple one: their loved one needs only part of a healthy liver, something donors feel they may be able to provide. For a large number of donors, the fact that LDLT is now available is encouraging. Regardless of whether or not they are suitable to donate, donors appear happy that an alternative to deceased transplantation is available. Living donation *"opens up another avenue"* for patients on the liver transplant waiting list. Learning about LDLT results in an almost automatic response to consider themselves as a donor and investigate this possible option.

Box 4-5: Automatic response
(*Tx = patient transplanted, WL = patient on waiting list)

…but I mean you don't think about these things it's just a case of, you know, if you can do something then obviously you're going to.
[Donor 7, Tx]

It's surprising what you would do when your back's against the wall and it's a member of your family, it is.
[Donor 10, Tx]

Aye, he brought me into the world so I had to basically give him a chance, eh?
[Donor 3, Tx]

Knowing these risks, for a member of family you would do anything, you would.
[Donor 4, Tx]

Eh, it was fairly, fairly high risk though, but I was quite willing to do that for my brother. Em, I'm not sure that I be… I don't think I would probably do it for a stranger.
[Donor 17, WL]

4.4.2.2 Need to save life

Related to the 'automatic response' to offer to donate is the drive to save their loved ones life (see Box 4-6). Whilst the patients' main focus is on the risk to the donor, the donor's main focus is finding a way to save the patient's life. Many donors admit they are 'scared' of what the procedure will involve for them but the possibility of improving their loved ones situation is a more significant issue.

Box 4-6: Need to save life
(*Tx = patient transplanted, WL = patient on waiting list)

Well it's going to save his life, I says that's exactly what I would do
[Donor 10, Tx]

…well obviously we would have done anything to save his life.
[Donor 20, Tx]

Em, although it does tell you that it's more dangerous for the donor em, but then I thought well if there's a chance it saves him then, all be it, I'd go ahead and do it.
[Donor 9, Tx]

Therefore I told her I would have been willing to donate without looking into any of the pros and cons, simply because it would have saved her life…
[Donor 4, Tx]

So at the weekend I was just watching him going downhill and downhill….that's when I stepped in. I thought, 'I can't sit here and watch him die', I can't.
[Donor 13, WL]

I just think that's a horrible situation to be in anyway. Plus the fact that I would hate her to get to the point that she's so unwell that she can't have em, a transplant, and something was to happen to her and I hadn't at least tried, you know, do something for her.
[Donor 15, WL]

Helping the patient will help the donor too as they will no longer have the stress of watching their loved one suffer and deteriorate in front of their eyes. The donor is aware that both they and the patient will benefit if the transplant is successful. For many donors, any possible adverse outcome for themselves is often not fully considered in the initial stages of the donor's decision-making process. The most relevant thought appears to be whether or not this new procedure could save the patient's life. When the effects of the operation on the donor are considered, reassurance is sought through the belief that the medical team would not perform the procedure unless they were confident of a successful outcome for both the donor and the patient. Again this may be interpreted as the moving of some of the responsibility for the decision to donate or not onto the authority of the medical team, indeed many donors spoke of trust in the medical team and their capabilities.

4.4.2.3 Concern for personal situation

Despite the reflexive response to investigate the option of LDLT further, with the intention of doing something to try and save their loved one, other considerations could not be ignored. For many donors their own personal circumstances have a big part to play on their decision to donate or not (see Box 4-7).

Box 4-7: Concern for personal situation
(*Tx = patient transplanted, WL = patient on waiting list)

Em, I have considered it but eh, I have em, it’s kinda been, it kinda weighs out because I’ve got a son and I don’t know the complications.
[Donor 5, WL]

Em, I would, I would have to say probably in my case because of my kids. That would be the only thing that sort of put me off.
[Donor 6, WL]

So what we had is a situation where we have elderly parents, who are frail, a young family who are relying on us, me as the only breadwinner eh, in the, in the house…
[Donor 8, WL]

…as I say, if it’s people with kids, you know, if stuff does happen then it’s, you know, it’s no very fair on the kids…
[Donor 9, Tx]

I mean I’ve got a young family and that as well and, ken it was, it was something I wasn’t too sure about.
[Donor 11, Tx]

My one concern is my daughter, who is 14, and that if anything was to happen to me, she is well provided for.
[Donor 15, WL]

For some, circumstances, such as having a young family, prevent the LDLT process starting whereas for others significant re-organisation of their own lives would be required. Most donors want to do something to help but when they consider the effects donating could have on their own children and extended families, living donation does not become such an attractive or feasible option. Practical aspects of donating come into play, such as child care, financial implications and work commitments. For many, such practicalities appear insignificant in the face of the immediate problem of their loved one’s health, but nevertheless some donors are aware that these things would have to be investigated and that the decision to donate is not just theirs to make. When we consider the donors interviewed who spoke of LDLT in retrospect, i.e. patient had since received a deceased donation, there would appear to be slightly more emphasis on the patient’s refusal as a reason for not pursuing LDLT. For donors whose loved ones were still on the transplant waiting list, their personal situation was more often mentioned. Personal circumstances were also a concern in the former group of donors but looking back, there was a belief that these could be overcome and that the patient themselves was the main hurdle. For donors with patients currently on the waiting list, their personal situation was all the more relevant and perhaps therefore they were seen to give it more consideration.

Personal situations also have a part to play in deciding which family member could be considered as a possible donor. The decision as to who would be the most suitable is often based on age, dependants and other significant events e.g. relative has just got married, with older members of the family being seen as more likely candidates. There would appear to be a common belief that patients should not take from someone from a younger generation. Someone the same age or older is considered more acceptable. Many patients also referred to the age and other ‘personal circumstances’ of the donors when demonstrating their objection to living donation. Donors are aware that patients are not keen for them to donate and this, in addition to consideration of their own family/work commitments and responsibilities, may persuade donors to agree that LDLT is a ‘last option’.

4.5 Discussion

The implementation of a Living Donor Liver Transplant (LDLT) programme at the Scottish Liver Transplant Unit in Edinburgh was a significant development for the UK’s NHS. However, for the first 21 months of its availability, this new procedure was not carried out. This has predominantly been due to the patients’ perception of risk for their healthy, potential donor and their consequent refusal to proceed with LDLT assessment. Patients feel they ‘couldn’t live with themselves’ if anything adverse happened to the donor as a result of the operation. In direct contrast, the altruistic nature of living donation is supported in the finding that many potential donors are willing to donate and do not appear to fully consider the risk involved, as they are too focused on helping their loved one survive. Both donors and patients wish to protect the other.

In some instances, donors’ enthusiasm for pursuing LDLT is tempered when they consider their own personal circumstances in relation to family and work commitments and responsibilities. For potential donors who wish to enquire about LDLT, their progress is often terminated due to medical factors, such as blood incompatibility, the availability of a deceased donation for the patient, or quite simply, the patient refusing to accept their offer. For patients, their determination to refuse LDLT is only likely to be reduced when they consider a time when their imminent survival requires living donation.

As LDLT was only introduced into the UK NHS in April 2006, this study is the first of its kind. Other countries such as the USA, Spain, Germany and South Korea have either investigated retrospectively the attitudes of people who have donated part of their liver (Karliova et al, 2002; Lee, Jeong, Ha, No, Hong, Kwon et al, 2005) or have only considered the views of patients on the transplant waiting list (Martínez-

Alarcón et al, 2005). The methodology in previous studies has also mainly been quantitative in nature. This study is unique in that it investigates why living donation has not yet been pursued, from the perspective of both potential recipients and donors. The qualitative design of the study allows explanations to be heard in the participants' own words, allowing a deeper understanding of the LDLT decision making process to be attained.

Despite the strengths of the study, weaknesses must be acknowledged. Firstly, with respect to the analysis of the interview transcripts, the coding was completed by the researcher who carried out each of the interviews. Although the formation of the themes was agreed with the co-authors it is acknowledged that an additional independent coder may have enhanced the reliability of the results.

Another possible limitation is that each participant opted for a telephone interview, which, with qualitative research, has its inherent difficulties. The main problems come from the lack of non-verbal cues, in that the interviewer cannot tell if a participant has finished their line of thought before moving on to another topic, and participants and interviewers often talk over one another, making transcribing difficult. In anticipation of these difficulties, we were keen to have face-to-face contact with participants but as this was a national study, we offered to be as flexible as possible so as to maximise recruitment, particularly of very ill participants who lived a considerable distance from the hospital. It was the decision of the participant to have a telephone interview. Telephone interviews allowed patients and donors to take part in the comfort of their own homes without taking too much time out of their day. LDLT appeared to be a difficult topic for some participants to talk about, with the interview provoking thoughts they perhaps had not put into words before, and many appeared to initially worry that taking part in this research project would be seen as registration to go ahead with the procedure. For many there was nervousness around speaking about LDLT and the telephone interview enabled them to keep a distance whilst at the same time allowing them to speak freely. Previous research has shown that telephone interviews can be used successfully in qualitative research with no significant differences emerging when telephone and face-to-face transcripts are compared (Sturges & Hanrahan, 2004). For patients who rejected the invitation to participate comments as to why this was support the assumptions outlined above. They were adamant their decision was made to not proceed with LDLT as they did not want to involve their families. They did not wish to discuss the option further. It should also be noted that the donors interviewed were nominated by the patient and were all considered close family members. It would also be of interest to interview more distant relatives on their views of living liver donation (Gordon, 2001).

A study by Martínez-Alarcón and colleagues found a similar attitude with patients on the transplant waiting list in a Spanish hospital (Martínez-Alarcón et al, 2005). Patients were generally not keen to pursue living donation by a family member despite having had family members offer to donate to them. Only 32% of patients on the liver transplant waiting list would accept a living donation from a family member. However, unlike our present study, why patients felt this reluctance was not questioned.

From the donors' perspective, the findings of this study are similar to those of Lee and colleagues (Lee et al, 2005) where donors who had previously donated part of their liver to a loved one were asked questions regarding their decision to donate. In response to the question surrounding the main reasons for donating, over 90% stated that it was to save the life of their family member. It was concluded that donors were determined to donate however, they were naturally apprehensive about possible complications and the effect donating would have on their own lives. This is a finding echoed in this current study and also in a study with potential living liver donors in Germany (Papachristou, Walter, Dietrich, Danzer, Klupp, Klapp et al, 2004). Papachristou et al (2004) describes one of the few qualitative studies conducted with potential living liver donors. Participants were potential donors who had already made the decision to come forward to receive formal donor assessment. The interview conducted was part of their formal assessment. It was found that the main motivation for becoming a donor was their wish to keep their loved one alive (Papachristou et al, 2004).

Karliova and colleagues found that living liver donors considered the decision to donate an easy one, which did not require much thought once the option was put to them (Karliova et al, 2002). Our study adds to these findings and has the additional benefit of including the views of potential donors who, for one reason or another, may not proceed with donation. It would appear that not only potential donors in Scotland but also perhaps donors in general feel the offer to donate is a ‘reflexive’ response to hearing that LDLT is available for a loved one on the liver transplant waiting list. It may be viewed as an instinctive reaction to at least consider helping a loved one in need. Despite concern for the risks and the effects on other members of the family, LDLT can proceed, driven by the purpose of saving a loved one’s life.

These results are similar to studies involving patients with end stage kidney disease and potential living kidney donors. For example, Lennerling and colleagues (2004) found that one of the main motivations of participants who were being formally assessed to become a living kidney donor was a wish to help. The donors were not as concerned about their own situation as they were about the patients' (Lennerling, Forsberg, Meyer, & Nyberg, 2004).

In addition, Gordon (2001) conducted an interview study with patients with end stage renal disease and found that many patients did not want to accept a living kidney donation due to risk to the donor, however if the patient believed they were close to death, the offer of a living donation would be accepted. Similar to our study, patients perhaps saw living donation as a 'last option'.

The results of this study have important implications for the clinicians and medical professionals involved in the living liver donation programme. It is important to be aware that potential donors often make the initial decision to donate without thoroughly considering the implications and therefore the transplant team need to ensure that donors are aware of all the risks and benefits before they commit to proceeding with the procedure. Their determination to save a loved one's life may be conflicting with other family and work responsibilities, potentially causing additional stress to an already stressful situation and help should be given to work through these concerns.

Likewise, it is important to be aware that patients have an extremely difficult decision to make as, in their determination to not be the cause of a family member putting their life at risk, they may be denying themselves a chance to survive. Many patients indicated that they may consider LDLT as a last option however, it is important for the patient to understand that LDLT will cease to be a feasible option if their condition deteriorates to the point of only having days to live. LDLT cannot be a last option. The programme at the SLTU currently estimates that the living donation process will take approximately three months, allowing both donors and patients time to have the required assessments and make certain their decision to go ahead with LDLT. Consequently, LDLT will not be performed in a tight time frame. It is crucial that the patient and the donor fully understand that both need to be in good health to give the procedure the highest chance of success. If a patient is close to death, it is unlikely that they would survive major surgery and therefore the risk to the donor is not justified.

The LDLT programme at the SLTU includes a Donor Advocate Team (DAT) whose purpose is to specifically look after the donors' well-being. The DAT was established to ensure that donors proceeding with LDLT are given a full medical and psychosocial assessment prior to donation. It is the role of the DAT to confirm that donors fully understand all the risks and benefits involved in the procedure. Following this research, it was fed back to the SLTU and DAT that it is important to emphasise, to both patients and donors, that LDLT cannot be seen as a 'last option'.

The results of this study give an initial picture of the complex nature of the decision making process involved in LDLT, by highlighting competing considerations for both the patients and the donors. Whilst many donors immediately consider becoming a donor, driven by the need to save their loved one's life, their decision to donate is affected by consideration of their own personal situation with regards family and work responsibilities. On the other hand, patients do not wish to accept a living donation from a family member due to the risk involved, and the subsequent feelings of guilt if anything adverse happen to the donor as a result of the living donation operation. However, patients' decision to not pursue LDLT would be affected if it was believed that they were close to death and consequently LDLT was their last and only option. If we consider the results in respect to the TPB, the influence of perceived control is particularly highlighted as crucial to the decision to pursue LDLT or not. Donors regard the option of LDLT as a means by which they can take some control over the patients' fate and physically do something to help save their loved one's life. In contrast, patients view LDLT as presenting too high a risk for the donor and take control of the situation by not allowing the LDLT assessment to proceed. However, as their condition deteriorates whilst waiting for a deceased donation, their perceived sense of control over the situation diminishes and LDLT becomes a more viable option. Social norms may also play an important part as seen from donors believing that offering to donate was their duty as a family member.

The results of this study may also be partly explained within the framework of the HBM, as both donors and patients consider the costs of the procedure against the perceived benefits. Donors see the benefit of potentially saving their loved one's life but this is weighed against the possible detriment to their own family and work commitments. In contrast, patients focus more on the donor's susceptibility or risk of death or harm, with anticipated guilt acting as a possible barrier to their acceptance of LDLT. As their personal susceptibility to death increases, their views may change in that LDLT becomes an option to be considered. Deterioration in the patient's condition could also be seen as a 'cue for action' from both the donors' and patients' perspectives.

Future research could perhaps employ a quantitative application of the theoretical models of behaviour to the area of living liver donation. This would allow a more quantitative evaluation of the decision making process of donors and patients, perhaps identifying different influencing factors for those donor/patient pairs who agree to pursue living donation compared to those who do not.

Since completion of this study, surgeons at the Scottish Liver Transplant Unit have performed the first living donor liver transplant operation in Scotland. In January 2008, in recognition of the lack of donated livers following death, a wife donated part of her liver to her sick husband, saving his life (Rose, 2008). We anticipated that publicity regarding the first successful LDLT procedure would trigger further procedures. However, the initial publicity this event produced was sadly eclipsed by news of Prince Harry’s deployment to Afghanistan, but nevertheless the success of Scotland’s first living donor liver transplantation may act to reduce the perception of risk to the donor, encouraging more patients on the transplant waiting list to consider LDLT as a possible option for them.

Chapter 5 Living donor liver transplantation: a qualitative study with medical staff at the Scottish Liver Transplant Unit

5.1 Abstract

Objectives: The first Living Donor Liver Transplantation (LDLT) was performed in Scotland in January 2008 at the Scottish Liver Transplant Unit (SLTU), 21 months after it became an available option for patients. One year later it remained the only LDLT procedure conducted in Scotland. This study therefore aimed to elicit the views of health professionals involved in the area of liver transplantation, within the SLTU, as to why LDLT had not yet received greater uptake from patients.

Design: A qualitative study was devised for this aim. A total of 5 transplant surgeons, 7 consultant physicians and 5 transplant coordinators participated and their responses were analysed using thematic analysis.

Method: A semi-structured interview was conducted with each participant.

Results: A reduced need for LDLT was perceived, due to a decline in patient deaths whilst on the cadaveric transplant waiting list, and it was generally agreed that to receive a deceased donation was preferential due to the elimination of donor risk. Both views were thought to influence the unit's adoption of a conservative approach to LDLT promotion, which contributed to the low uptake of the procedure. Patients were also thought to contribute with their belief that a living donation was personally unnecessary, and unacceptable from a younger donor. The poor health of the Scottish population also markedly reduced the availability of suitable donors.

Conclusion: Cultural aspects of the unit and of the Scottish population have contributed to the slow uptake of LDLT. The growth of LDLT in Scotland remains

limited whilst the unit are reluctant to promote the option, patients consider it unnecessary, and potential donors are excluded due to poor health.

5.2 Introduction

In January 2008, the first Living Donor Liver Transplant (LDLT) procedure to be carried out in Scotland was successfully performed at the Scottish Liver Transplant Unit (SLTU). By January 2009, this remained the only LDLT procedure to have been conducted at the SLTU, despite the LDLT programme having been introduced 33 months earlier, in April 2006.

Within transplant units where living liver donations are conducted, the views of donors and recipients on their experience have been sought and areas for improvement to the service have been highlighted (Walter, Papachristou, Danzer, Klapp, & Frommer, 2004). As yet, this is not possible within the SLTU due to the fact that only one LDLT procedure has been conducted. However, it is important to investigate why the uptake of this procedure has been so low as it may have implications for future health and transplant services in Scotland.

Having investigated the views of patients eligible for LDLT and their families, with regards to LDLT (Chapter 4: Considering LDLT), the continuing low uptake of LDLT in Scotland prompted the author to investigate the possible reasons for this from the perspective of medical staff involved in the area of liver transplantation. It was hoped that the results would perhaps inform other transplant units in the UK and beyond, who are contemplating the introduction of LDLT.

Studies investigating the views of medical or healthcare professionals with regards to living liver donation are predominantly of a quantitative nature, involving surveys to determine views on living liver donation in general. Cotler and colleagues (2003) conducted a survey study to elicit the views of surgeons on issues related to LDLT. Questions and subsequent responses served to highlight the moral and ethical difficulties faced by surgeons offering the procedure e.g. potentially causing the death of a healthy donor. However, the potential impact this may have had on the progress of the living donation programme within their own hospital setting was not broached (Cotler et al, 2003). Other studies have similarly investigated the attitudes of general practitioners and hospital personnel towards living liver donation in general but such studies were conducted either prior to or at the onset of a LDLT programme (McGregor et al, 2008; Ríos, Ramírez, Rodríguez, Martínez, Rodríguez, Galindo et al, 2007). The author is unaware of any study which has investigated the views of medical or healthcare professionals regarding the outcome of an established living liver donation programme specifically.

Health care providers are in a unique position to assess the service provision of the NHS and their views have been sought to highlight areas for change and improvement in many fields such as services for eating disorders and depression (Murray, Banerjee, Byng, Tylee, Bhugra, & MacDonald, 2006; Reid, Williams, & Burr, 2009). Essentially health care providers wear two hats, serving as an individual with personal and family obligations and commitments, as well as a professional with medical knowledge and experience. In their role as a medical professional they have access to the organizational structure and government underpinnings of the NHS as well as the personal histories of patients. Therefore, whilst their experience of receiving treatment may be limited compared to that of patients and their families, through their provision of a service, they have additional insight which has the potential to influence the course of treatment.

Like the decision making behaviour of patients and their potential donors (see chapter 4: Considering LDLT), the behaviour of the SLTU team could also be considered within the theoretical framework of the Theory of Planned Behaviour (TPB) (Ajzen, 1988) and/or the Health Belief Model (HBM) (Rosenstock, 1966). How we think influences what we do and therefore in order to understand the behaviour, in this case the offering and conducting of LDLT, we must first understand the thoughts, attitudes and perceptions of those performing the behaviour. The potential influence of the components of the TPB and HBM were explored through open ended interview questions.

Qualitative interview studies offer the opportunity for issues to arise that may be deemed important to the interviewee but were not anticipated by the interviewer due to limited previous research and experience in the area. This is particularly the case in the area of living liver donation which remains a relatively new procedure with limited research surrounding its uptake. Consequently, a semi-structured interview study was deemed appropriate to the aim of this study which was to establish the reasons why living liver donation has not been readily accepted in Scotland.

5.3 Method

The decision was made to employ a qualitative interview study due to the novel and unusual subject matter of the study. A list of all transplant surgeons (N=7), consultant physicians (N=8) and transplant coordinators (N=5) who were currently involved in the area of liver transplantation at the Scottish Liver Transplant Unit was obtained. Each person was sent a letter of invitation (see Appendix 18) which included a description of the study, what participation would involve, and ways in which to register their interest or obtain more information on the study. After 13 days, the medical professionals who had not yet indicated their response were sent a reminder email. Ethical approval for this study was granted by Lothian Local Research Ethics Committee (approval letter dated 4 March 2009).

5.3.1 Participants

A total of 5 transplant surgeons, 7 consultant physicians and 5 transplant coordinators participated in this study (85% response rate) and the interview transcripts of all 17 participants were analysed using thematic analysis (Braun & Clarke, 2006). The remaining 3 invited medical professionals (2 surgeons and 1 consultant physician) failed to respond to the invitation. The 17 participants included 11 males (5 transplant surgeons and 6 consultant physicians) and 6 females (5 transplant coordinators and 1 consultant physician) with an average age of 43.9 years (SD = 4.94, range = 37-52). Each read and signed a consent form prior to commencing the interview (see Appendix 19).

5.3.2 Interview schedule

An interview schedule was devised for this study with the purpose of eliciting the views of the medical professionals about living liver donation (see Appendix 20). The aim was to find out, from their perspective, why only one LDLT procedure had been performed at the SLTU within the first 3 years of the programme's availability. Questions were not constructed around one particular theory, but rather were based on the results of previous research (see Chapter 4: Considering LDLT) and informal discussions with staff at the SLTU. The main areas to be covered are listed in Box 5-1.

Given the busy schedules of the participants, the interviews were fairly structured in order for the author/interviewer to keep participation time to a minimum; however questions were open-ended to allow free expression of views.

Box 5-1: Interview topics

- Reactions to the introduction of the LDLT programme at the SLTU
- Initial expectations of the programme.
- Why only one LDLT had been performed since its inception in 2006.
- Perceived concerns for patients and their family members, in their role as potential donors.
- The future of LDLT in Scotland and the UK.
- Views on the LDLT programme developed at the SLTU.
- Consideration of personally becoming a living liver donor or recipient.
- Any other comments.

Each participant was interviewed at the Royal Infirmary of Edinburgh either within the Clinical Research Facility or another appropriate room within the liver unit (e.g. the participant's office). Interviews lasted an average of 38 minutes and were conducted by the author. The interviews were conducted between 20th April 2009 and 8th June 2009 and were each digitally recorded and transcribed verbatim. Transcripts were anonymised.

5.4 Data Analysis

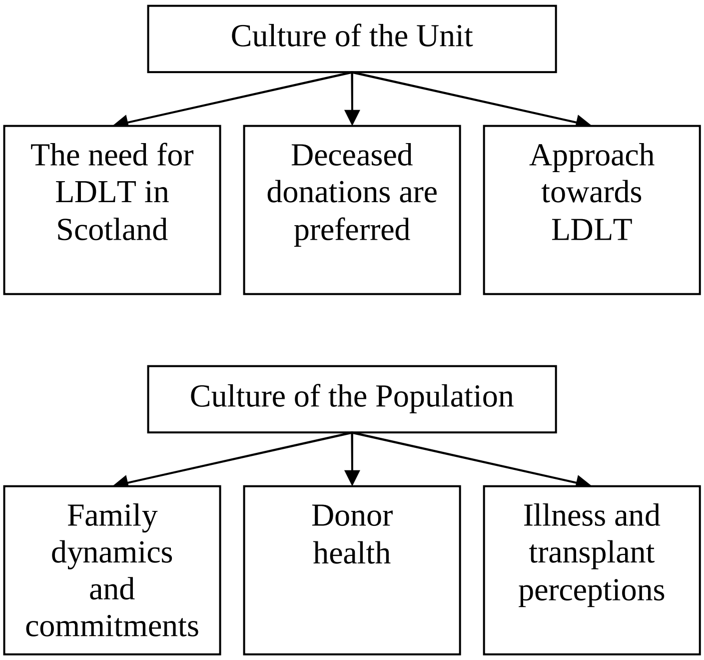
Thematic analysis was used to analyse the interview transcripts, specifically following Braun and Clarke's 6 phases of data analysis (Braun & Clarke, 2006) (see Chapter 1 section 1.8). An inductive, semantic approach to thematic analysis was employed, whereby the themes elicited are derived directly from the data. The themes were identified by the author and then verified with a senior colleague with regards to their content and connections.

5.5 Results

It is clear that medical staff at the Scottish Liver Transplant Unit recognise that the reason for the slow uptake of LDLT in Scotland is multifaceted. There is no one single reason, but rather multiple possible reasons why more than one LDLT procedure has not been carried out and these can be divided into two broad themes: 1) the culture of the unit and 2) the culture of the Scottish population. On the one hand, the unit itself has had a part to play in the course that the introduction of living donation in Scotland has taken, but at the same time the Scottish population, from where patients and any potential donors come from, has also been a crucial influence. Within these two overarching themes, there is a common thread which is the risk to the donor. Whilst the risk to the patients' relative who is donating is the *"glib answer"* [Consultant 101] in response to why LDLT has not taken off in Scotland, the influence of the risk involved in living liver donation goes much deeper and is embedded within the culture of both the unit and the Scottish population.

When considering the culture of the unit, the need for LDLT within Scotland, the preferred option of deceased donations and the unit's approach towards the issue of LDLT are thought to have contributed to its slow uptake. In addition, influencing factors within the culture of the population includes family dynamics and commitment, the health of potential donors, and illness and transplant perceptions (see Figure 5-1).

Figure 5-1: Themes and sub-themes



5.5.1 Culture of the unit

5.5.1.1 The need for LDLT in Scotland

It transpired that one of the main reasons why more LDLT procedures had not been conducted at the SLTU was the reduced level of perceived need for LDLT (see Box 5-2). The introduction of LDLT within the SLTU was considered to be a direct result of the unacceptable waiting list mortality within the unit at that time:

"…at that stage we were having 25% of out patients dying on the waiting list and we had to do something about it"

[Coordinator 104]

In reaction to the increasing number of deaths on the transplant waiting list, the proposal to offer LDLT as an alternative treatment method for patients in need of a liver transplant was instigated. The demand for livers from deceased donors was far outweighing the supply and it was felt that radical action had to be taken. The unit consequently advanced their repertoire of abilities and, in addition to offering LDLT, became more willing to accept livers from deceased donors that previously would have been rejected due to potential problems in quality (i.e. marginal livers), and learned new ways to optimize the livers that were donated (e.g. split livers). Such advances are thought to have reduced the waiting list in spite of the living donation program:

"…in the last couple of years we've increased the number of marginal grafts we've used, we've increased the number of non heart beating grafts we use, we've used split grafts more often so we are really cutting our waiting list down dramatically…"

[Surgeon 109]

All of the above mentioned measures involve the use of deceased donations which have become more accessible over recent years due to the formation of the Northern Liver Alliance and the apparent efforts of the Organ Donor Taskforce (Organ Donation Taskforce, 2008) (see Appendix 1). The Northern Liver Alliance has changed the organization of liver transplant units in the UK, specifically the distribution of donated and retrieved organs. Scotland now has greater access to livers donated from deceased donors which has allowed their sickest patients to be transplanted, and consequently *"offset the death rate"* [Coordinator 104]. The Organ Donor Taskforce is a government group established for the purpose of investigating and implementing ways in which the number of people who donate their organs following death in the UK can be increased. With an increase in deceased donations, more patients on the transplant waiting list will receive a transplant, reducing the time a patient waits on the list and the number of deaths whilst on the waiting list: *"If people aren't going to wait on the list then they aren't going to die on the list…"* [Coordinator 106]. As a consequence it is thought that the need for living organ donation has and will continue to reduce:

> *"…donors in Scotland has gone up to 14 (per) million (of population) from about 9 (per) million (per population) in a year, so I think there's not going to be a need for (LDLT)".*
>
> [Coordinator 106]

The number of people in Scotland who donated following their death has increased over the past year. With national initiatives to increase deceased organ donation, and the acceptance of marginal grafts and split livers, etc, the unit have *"plugged the gap"* by means other than living donation, and so it is thought that the need for LDLT *"is maybe not going to be there now"* [Coordinator 106].

Participants are aware that *"things are only driven because they're needed"* [Coordinator 104] and in respect to organ transplantation this need is determined by the number of deaths on the transplant waiting list: *"Deaths on the waiting list I think are the crux of it"* [Consultant 100]. If the number of deaths on the transplant waiting list goes up so will the need for an additional means of transplant to compensate for the lack of suitable deceased donations. At this point living donation, with its benefit of reducing waiting times, will be a more viable option. If however, the number of deaths on the transplant waiting list is low, then living donation, with its inherent risk to a healthy donor, is considered less justifiable.

It was also highlighted that Scotland's size was counterproductive to a more extensive LDLT programme: *"...our waiting list is far too small. Scotland's far too small for a programme like this."* [Coordinator 106]. Participants often compared the situation at the SLTU to that of liver transplant units in other countries, where the need for living donation was presumed greater due to the higher number of patients waiting for a transplant. Although participants were surmising the circumstances of other countries, it was believed that the fewer restrictions on the type of patients eligible for transplant, and the larger geographical spread of many countries, contributed to the size of the liver transplant waiting lists, time spent on the waiting list, and consequently the number of deaths on the list. It was suggested that the UK *"has a very kind of regulated em, approach to transplantation"* which limits the number of potential transplant candidates. In places such as Toronto, certain groups of patients e.g. *"patients with big cancers who we know that the risks of reoccurrence are higher"* [Consultant 108] are transplanted whereas in Scotland, and the UK, they would not be considered eligible for transplant. With regards to geographical spread, again it was presumed that larger countries were limited in the number of deceased organs they could retrieve for their unit as the distance between cities could not accommodate a sharing scheme like the Northern Liver Alliance, therefore *"they've probably relied on live donation because there isn't the availability of cadaveric organs"* [Surgeon 109]. In Scotland, the geographical and population size means initiatives to optimise deceased donations can be arranged, and the need for living donation is not so urgent.

More patients are being transplanted with deceased donations and fewer patients are dying on the list therefore the need for LDLT is not perceived to be as great as it was when the programme was first introduced. However, it is important to note that LDLT is not a completely redundant procedure within the unit and many believe that it should continue to be offered to their patients. Patients do still die on the waiting list and with liver disease thought to be on the increase in Scotland particularly, it is envisioned that the demand for liver transplants will increase enhancing the need for LDLT in the future.

Box 5-2: Need for LDLT in Scotland

…and one would actually hope that eh, with the moves forward in organ donation that actually the need for considering eh, living related donation may disappear all, altogether.
[Consultant 101]

…I think on the back of em, non-heart beating donations and split livers, more and more people are getting transplanted, so I don't think we need it.
[Coordinator 102]

We've moved from a position where we had 40 patients on the transplant waiting list to 14 on the waiting list em, and therefore, the risks and benefits may, are likely to have changed, so I am less certain that it's needed.
[Surgeon 107]

So if cadaveric organ donation improves then the need for living donation will become even less.
[Consultant 108]

So I suspect it's a need generated by the fact, there is not enough cadaveric donations.
[Consultant 115]

…there's less of an imperative to go ahead with a risky surgical procedure if there's a higher chance that the person will be transplanted and will survive through the normal sort of em, cadaveric liver transplantation.
[Surgeon 110]

…our waiting list has gone down rather than up, and we've had less deaths on the waiting list, so it's very hard to justify it.
[Consultant 111]

You know it's hard to say, we're in a transition state just now, because as I say we're seeing an increase in the organ donors. Certainly last year, and that is the projection isn't it, to increase them over the next five years, so maybe we wouldn't ever need to have a live donation programme…
[Coordinator 112]

I suspect if the initiatives that we have taken to increase the deceased organ donor availability, and nationally the organ donor task force aspirations of increasing donation by more than fifty percent over the next few years, if all these things do happen then the need for it will become even less so hopefully we won't have to do it.
[Surgeon 114]

5.5.1.2 Deceased donations are preferred

Perhaps related to the need of LDLT is the finding that the unit would prefer to transplant patients with a deceased donation as opposed to a living donation as *"that way you don't have to operate on healthy people"* [Coordinator 102] (see Box 5-3). Surgeons and doctors are taught as students to 'first do no harm', and are ethically bound to only provide medical care with the intention of benefiting their patient. However, LDLT involves deliberately causing harm to a healthy individual for no direct physical benefit to that person, which consequently *"goes against the grain"* [Surgeon 109] of traditional medicine. Removing part of a healthy liver from a donor is consequently a difficult concept to accept: *"…mentally it's quite a tough thing to deal with really."* [Consultant 105].

Living liver donations are thought to have outcomes comparable to deceased donations but the latter are generally preferred, *"because it puts less risk on the em, donor, obviously"* [Coordinator 104]. The risk to the donor is what mainly differentiates deceased and living donor transplants and the only way to avoid this risk is to transplant patients with deceased donations:

> *"I think in terms of avoiding all this trouble I think the cadaveric donation would be far better. It is a standard procedure. If you had the luxury to use a full liver in a timely manner and have lots of donors around, then it would avoid all this."*
>
> [Consultant 115]

The team at the SLTU have extensive experience in performing liver transplants using a deceased donation and have very limited experience in conducting LDLT, having performed only one in three years. Whilst confidence in the abilities of the surgeons has grown since the programme's inception, due to training and experience with split liver transplants, the potential for harm to an otherwise healthy donor remains and therefore deceased donations are the preferred transplant method.

From the participants’ perspective, when considering a situation where they would be in a position to accept or offer a living donation, mixed opinions were described. Whilst the benefits of donating or receiving a timely donation were considered first, the risk to the donor, and the impact of the decision on other family members, invoked caution:

“Well I don’t know, again it depends on who it was and what the circumstances are, again you have to look at what your situation is (….) I’d have to look at it from the point of view that I have two young children and a wife and if I wait for it, what blood group I am, how sick I am, that sort of thing, and if my brother came up and said, because my brother has no children and he’s fit and well, and said look I want to donate to you then I would probably say yes. I don’t, if my father or mother said, I’d probably say no I don’t think either or them are fit enough, my sister’s got children, it’s a very individual decision actually and you have to weigh up all the factors”..

[Surgeon 109]

Participants appreciate that the decision to receive or donate a living donation is not easy and is dependent upon a number of circumstantial factors. Until faced with the option of living donation as a reality, opinions as to what one might do in that situation cannot be made explicit. However, what is clear is that having an ample supply of deceased donations would remove the need for such difficult deliberation, and therefore it is agreed that *“improving donation rates is the best way forward”* [Consultant 115].

Whilst being able to offer the option of LDLT may enhance the reputation of the providing unit, because *“it’s seen as a sign of surgical manhood”* [Surgeon 107], putting a healthy person at risk is not something that should be taken lightly. The team at the SLTU, whilst happy and proud to offer LDLT, would prefer to conduct transplants using deceased donations so as to eradicate the need to put a donor at risk.

Box 5-3: Deceased donations are preferred

If I could change anything I would prefer not to do any (*LDLTs*) at all, and get everyone transplanted with a deceased donor liver.
[Surgeon 114]

…a good cadaveric graft is probably the best graft to give….Because it's associated with much less morbidity em, and it doesn't put anybody else at risk.
[Consultant 101]

I think a deceased is probably better because somebody else's life is not getting put at risk…I think it is better, but it's whether it comes in time is the difference. With a living donor you can set your operation and have this healthy part of the liver, so it's the timing. If you were guaranteed to get a cadaveric liver then you would go for that.
[Coordinator 106]

So, you know, if you have a good, well even a marginal liver transplant I think that's better than having, than putting both the donor and the recipient through complex surgery to achieve the end point, I think if you can achieve it with cadaveric transplantation then that's better.
[Surgeon 109]

Participant: For patients I would say a deceased donor. For myself, from a deceased donor as well.
Interviewer: And why do you say deceased?
Participant: I think it's all to do with eh, risk to, to donors.
[Consultant 105]

Well deceased's the better one if there's one available.
[Consultant 108]

I actually probably think a heart beating cadaveric donation is better. I don't think that in a perfect world people should have to donate bits of their... I mean completely healthy people shouldn't have to donate bits of their organs to save other people.
[Surgeon 110]

..living donation is never going to be a first choice if there's an ample supply of cadaveric organs. [Consultant 113]

I'd be delighted if em, we have, if we'd managed in other ways to reduce deaths on the waiting list, living donation is the least attractive way I think…. I think cadaveric livers are eh, em, my comfort zone.
[Consultant 100]

5.5.1.3 Approach towards LDLT

Connected to the perceived need for LDLT, and the preference towards conducting transplants using deceased donations, is the unit's approach towards the promotion of LDLT. It is generally agreed that the unit has adopted a cautious, 'soft sell' approach towards LDLT (see Box 5-4). The option of LDLT is not forced but rather is mentioned as a possibility that the patient may wish to consider. It is suggested that this approach may have contributed to the slow uptake of LDLT: *"I suppose if we were more aggressive we would have increased our numbers"* [Coordinator 104].

One of the main ethical considerations for any unit starting a LDLT programme is the issue of potential coercion. It is agreed that measures should be taken to ensure that the donor is willing to donate for the right reasons, and is not being forced into donating against their wishes. The participants agreed that talking people into opting for living donation is *"not the name of the game"* and to avoid such coercion it is important to *"present it in a balanced way and leave it up to them to make the decision"* [Surgeon 109].

The unit as a whole is thought to operate within a *"damage limitation society"* and is consequently *"risk averse"* [Surgeon 110]. Therefore to avoid risk and protect both their patients and their reputation, a 'stand back' approach was described whereby information about LDLT is made available but is not pursued further until the potential recipient or donor approaches the unit directly:

> *"…you have to put the ball in their court I think, which is what we do, and then they take it from there"*
>
> [Coordinator 112]

The unit does not want to have the responsibility of the decision making. Whilst the staff within the unit can play their part in reducing the risks, through donor testing and surgeon and nurse training, the risk to the donor remains significant and therefore the choice must be with the donor and patient themselves.

It is proposed that other transplant units may conduct more LDLT procedures due to their use of a more aggressive approach from involved staff. LDLT is considered to be a more positive endeavour in other countries and therefore is actively advocated to patients as opposed to simply mentioned as a possible option. There is a suggestion that within the SLTU the negative aspects of LDLT are given more emphasis than the positives, which is in keeping with the 'risk averse' attitude of the unit, but in turn may be deterring patients and potential donors from pursuing LDLT:

"I wonder whether em, we are putting people off by presenting the negatives perhaps too strongly or too em, too prominently compared to potential positives…"

[Consultant 113]

To emphasise the negatives potentially serves to protect the unit and its staff from blame if a patient chooses to go ahead with living donation and complications for the donor arise. When a patient is told they have been put on the transplant waiting list it would be reasonable to assume that they, and their families, are in a highly emotional and vulnerable state, and the suggestion of an alternative treatment may be immediately appealing. The unit feels they must therefore take the time to emphasise the reality of living donation, which includes their lack of experience with LDLT and a real risk to the donor. However, by emphasizing the negative aspects of the procedure, the unit may inadvertently be 'putting off' potential donors and recipients.

Box 5-4: Approach towards LDLT

I think the medical profession in the States is probably a bit more bullish if you like or go ahead if you want to be positive about it about presenting the positives, we maybe had that sort of British or Scottish reticence and caution
[Consultant 108]

…then we give them the information about live donation, and then obviously we then have to stand back till they come back to us,
[Coordinator 103]

but if someone comes to the clinic and I see them I'll tell them what the options are of being transplanted, what the options are of dying on the waiting list, and then based on that the decision is them, its up to them really.
[Surgeon 116]

I think we, in the beginning, our attitude, that we'd been told from em, the States and everybody else with experience was, if people want to do it, they'll come forward, that we've got to be PC, we can't be chasing people em, you know, we've got to sit back and let them come to you, and we tried that and nobody came, so I think as time went on we got more aggressive.
[Coordinator 106]

And I think if we were emotionally being defensive and not wanting to do the transplants, bending over backwards to be fair and express both the negatives and the positives, I think that can carry through, people can pick up on those vibes.
[Consultant 113]

And we deliberately didn't want to put pressure on people so people didn't feel pressure on them, so if they didn't really feel that they wanted to do anything and, you know, that lead on from there.
[Consultant 105]

…and I don't think that I would personally be comfortable with pushing patients into… I don't know if we would have got more donors, but I wouldn't be comfortable with that.
[Coordinator 104]

In, within the UK this was the first unit and we didn't want to appear as bullying people, I suppose, in a sense, into something that was pretty risky.
[Consultant 111]

I don't know whether [other) teams will approach the subject differently and be more proactive or be more positive in their em, if you like em, giving information to potential families, that encourages people to consider it seriously and perhaps not only as a last resort, but sometimes as a choice, which I think em, we haven't really done.
[Consultant 113]

Previous research has indicated that how information is presented/framed to an individual influences their subsequent cognitions and behaviours (Kahneman & Tversky, 1979). In other countries, the positive frame thought to be subscribed to the proposal of LDLT is in contrast to the negative frame approach adopted at the SLTU and this may explain the difference in uptake rates for LDLT. The effect of message frame within the context of living organ donation is investigated further in Chapter 7 (The effect of message frame).

As mentioned a deceased donation is the preferred method of transplant and it is possible that this may transmit to patients who have found themselves in a highly emotional and desperate situation and are perhaps looking for advice and guidance on what to do. The idea of ‘giving out vibes’ which unintentionally encourage patients and their families away from the option of LDLT is an important observation:

> *“…I suspect that our slight subliminal kind of nervousness about it probably transmitted to the patients and the relatives so that rather than presenting it to them saying this is an absolutely great thing to do we were desperate not to be seen to be coercing so we almost went to the opposite extreme and said no, we do have this but boy it’s a really risky business and you’ve got to be very careful about it”.*
>
> [Consultant 108]

If the unit makes a point of not promoting LDLT and only highlights the risks involved, whilst deceased donation is discussed as the norm, then this may be implicitly interpreted as advice against LDLT and the option may not be pursued.

The approach adopted by the unit is in keeping with their ‘risk averse’ attitude and this suits the culture within which both the staff and patients exist: *“I think that reflects what the unit is and that reflects what society is and I’m happy and comfortable with that”* [Surgeon 116]. Previous research has suggested that patients have trust in the medical staff at the SLTU (see Chapter 4: Considering LDLT) and therefore it could be interpreted that to actively and forcefully promote LDLT, at a time when the need for living donation is less, with less people dying on the waiting list and more deceased organs becoming available, would be to betray patients' trust. Patients expect the unit to look after their best interests and, as expected, LDLT will be advocated only when it is perceived to be better for the patient, over and above a deceased donation.

5.5.2 Culture of the population

5.5.2.1 Family Dynamics and Commitment

The culture of the Scottish population was consistently offered as a reason as to why more LDLT procedures had not been carried out in Scotland (see Box 5-5). What was meant by 'culture' was a difficult concept to explain but was predominantly found to refer to the family dynamics of the Scottish population. Patients first and foremost were perceived to simply not want to put their family at any risk of harm: *"…it may be part of eh, Scottish culture that patients don't want to put their family at risk…"* [Consultant 100].

This wish to not *"put their family through it"* [Coordinator 112] is particularly important within the area of living liver donation specifically whereby the donation dynamics are regarded as different to the more common procedure of living kidney donation. The average age of a liver transplant patient was commented to be older than a kidney transplant patient; therefore, potential liver donors were required from a younger generation, often the patient's child. This concept of 'donating up a generation' is perceived to be difficult for the patient to accept. The patient' role as parent or elder is traditionally to protect the young, not to cause them harm and risk their life.

Whilst it is commented that ‘donating up a generation’ is commonly done in other countries or within other cultures and religions, within a predominantly white Scottish population, to allow your child to risk their life for you is socially unacceptable:

> *“…It’s sort of natural, older people who’s coming to the end of their life trying to, you know, protect eh, look after young people. Living donation is often the other way round em, and that’s perhaps not the most natural thing”.*
>
> [Consultant 100].

To donate to your child is considered a natural, almost automatic action to take. As explained by one participant, LDLT is: *“…just not a British thing really. It’s not an adult-adult thing, I think it’s an adult-child thing, you know”* [Coordinator 112]. The majority of participants were sympathetic to patients’ apparent apprehension as they agreed that they would donate to their children without a second thought or *“in a heart beat, it’s a no brainer”* [Coordinator 104], whereas much more consideration would need to be given before accepting a donation from their child as this would *“morally be a huge thing for me to do”* [Consultant 105].

It was surmised that in other countries, the population is more multicultural, specifically including more Asian families or families of ethnic minorities, where to donate up a generation is both accepted and expected. For this reason more LDLTs are thought to have been carried out in places such as Toronto[1]. Such families are thought to see it as their duty to look after their elders, and for religious reasons deceased donations are rarely provided or accepted. LDLT therefore is the only real

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[1] Toronto was provided as a comparison for participants as the transplant unit at Toronto General Hospital has an established LDLT programme, recognised within the SLTU.

option and is immediately considered for any family member. This level of commitment to family is different to that seen in a predominantly white Scottish or UK population. Whilst in other cultures patients would arrive at clinic appointments with family and potential donors in tow, in Scotland, patients often attend clinics on their own and if family are present they rarely instigate discussion about the possibility of living liver donation.

One participant explained that if accompanying relatives were offered a blood test to check their suitability for donation, whilst they waited, *"you'd clear the waiting room I suspect in about 10 seconds"* [Surgeon 109]. This highlights the general feeling that the commitment of the Scottish population to helping family was limited and does not involve the same feelings of duty and obligation found in other cultures where the uptake of LDLT is greater.

Of interest is that in Chapter 4 (Considering LDLT), potential donors refute this perceived lack of duty and obligation. Potential donors were found to automatically consider LDLT, driven by feelings of obligation and duty to try and save their loved one's life. However, the reality of LDLT and how this would affect personal circumstances meant the option was not advanced upon. From the perspective of the staff at the SLTU, this inaction is interpreted as disinterest or a lack of family commitment.

However, when asked to personally contemplate the position of a donor, participants generally believed that they would like to donate to family, but similarly to the donors in Chapter 4 (Considering LDLT), the practicalities of having children would admittedly effect their decision. Such practical thinking was described as another way in which the culture in Scotland differs from other

Box 5-5: Family dynamics and commitment

…what they haven't come to terms with is a procedure that may have harm for an otherwise fit person, even if the chances of that occurring is low em, as I say, I think people compute things emotionally and would you want your daughter to die? The answer's no….so I think there's a cultural element at play here where people don't want to take risks on behalf of their family.
[Consultant 113]

…one of the major factors I think in the small number of donors coming forward has been the fact that the recipients have said no, again probably because of this transplanting up a generation gap.
[Surgeon 109]

If their kids have children that's a big no, no, its not just obviously about dying it's the fact that oh no, I'm not having my child going through that, they've got a young family to look after, they've got a life ahead of them. So that's a risk for them, so they're not keen to allow them to do it, because they've got a life, their grandkids need their parents.
[Coordinator 103]

Most of our recipients on the list are eh, are parents rather than children, so it's offering a child donation to an adult and most parents are reluctant to allow their child to take that risk.
[Surgeon 107]

We don't have such a responsibility for family in the way, you know, you speak to the patients who are Asian and their culture is completely different. You know, they say to you that's their job is to look after their parents and they would chop their head off to help them, because they feel that, you know, they've been looked after as a young person, but I would say in Scotland, we don't have that culture, we don't have that culture at all.
[Coordinator 104]

Parents have this concept that it's very important that their children out live them, and so putting their children through a risky procedure showed no benefit to them eh, it's unacceptable to a lot of people, so it's a cultural thing as well.
[Surgeon 110]

I think that the vast majority, by far, of people listed were 55 plus, in which case you're looking at realistically a child donating to a parent and the parent's wouldn't want to consider that and it's almost like a cultural… More of a cultural thing than it is elsewhere in the world where em, parents, obviously, in Korea and places like that, see it as part of a family duty to almost, to donate.
[Consultant 111]

countries. Scotland stereotypically has a reputation of being, *"not a very giving nation"* [Coordinator 103] and this was further referred to by examples of how many donors were perceived to think on a more practical level than an emotional level when considering becoming a donor:

“…we don’t feel that (duty) in Scotland. We just think well, what will happen to my wages, what will happen to my mortgage, we’re much more practical. What will happen to my benefits, these kinds of things.”

[Coordinator 106]

The Scottish population appears to possess a more selfish orientation towards living donation, and the benefits for the recipient are perhaps outweighed by the more personal implications. However, the personal implications are often in relation to other, younger family members, suggesting a selfless element to the decision making. Scottish culture simply depicts that we focus more on the young and less on older generations which is counterproductive to the acceptance of LDLT.

5.5.2.2 Donor health

In addition to the family dynamics and consequent constraints on a donor, the health of potential donors is also thought to be a cultural aspect of the Scottish population that has particularly important implications for the progress of living donation (see Box 5-6). A number of participants commented that whilst interest from family members has been instigated on occasion, their suitability to become donors has been undermined due to health problems:

“I think the ones that did some forward, the great Scottish public with their heart disease and their obesity and , you know, general poorer health, didn’t allow them to come to fruition.”

[Coordinator 104]

The health of our nation is a major concern with obesity and related conditions of heart disease, high cholesterol, fatty livers etc commonly found. Such conditions serve to increase the risk for that person if they were to proceed with an operation

Box 5-6: Donor health

I think if we could have lived in a healthier part of the world we might have increased our numbers.
[Coordinator 104]

I think people were keen to come forward for it, but I thought people would be ruled out because we're an obese nation, purely from that point of view, I didn't think there would be many people suitable for it.
[Coordinator 102]

Interviewer: …the first one didn't happen until twenty one months after it became available, so tell me a bit more about why you think that was the case?
Participant: I think because most folk in Scotland are unhealthy. Because they're fat and smoke.
[Coordinator 103]

I think the ones that did come forward, the great Scottish public with their heart disease and their obesity and, you know, general poorer health, didn't allow them to come to fruition.
[Coordinator 104]

I think it's the Scottish men and to be honest most of the ones that you see in clinic are obese, they're high cholesterol, they like their alcohol, and you know, we tell them they've got to got smoking, you've got to stop drinking before the operation and people… You'd think that's not a lot, but it is for some people, they won't do it.
[Coordinator 106]

Well people, I think people have come forward, they've just been struck out. Em, and again, because a lot of it's weight em, and they've got fatty livers.
[Coordinator 102]

…one of the important things with live liver transplantation is having quite fit donors, and, you know, Scotland is not really known for having the fittest people in the world, particularly in older people, are often hypertensive, they're on one or two medications for something and that makes something like live donor liver transplantation much riskier.
[Surgeon 109]

The second reason, I suspect, is the fact that, unfortunately, Scottish people are not terribly fit and I think this is an issue because, as I said, 90% of people who came through and went as far as having, you know, CTs and cardiac testing's, they were not appropriate on the grounds of fitness…
[Consultant 115]

and therefore the unit cannot allow them to donate. It is the unit's duty to their patients, both donors and recipients alike, to ensure that the risk is kept to a minimum. Consequently, potential donors who are not immediately refused on medical grounds are subjected to an array of medical and psychological assessments. Any element found that would likely increase the risk to the donor is confronted, and if necessary will result in the rejection of the individual as a potential donor. In Scotland this is a common occurrence predominantly due to the less than adequate fitness levels of potential donors, who are overweight and smoke, and often are reluctant to change their ways. Although it is not possible to say how many potential donors enquired about LDLT but were refused formal assessment due to immediately obvious health contraindications, of the 22 donors who did start formal assessment between April 2006 and April 2009, 27% were later turned away due to medical issues (Scottish Liver Transplant Unit, unpublished data)(see Appendix 21).

5.5.2.3 Illness and transplant perceptions

In addition to family dynamics and health, ‘culture’ also encompasses how liver disease and transplantation is perceived by the general population (see Box 5-7). Participants generally believed that patients and donors do not know enough about LDLT and are reluctant to find out. This lack of knowledge may lead to unsubstantiated ideas of what living donation involves and requires, and subsequently may have resulted in premature rejection of the possibility.

Within the white Scottish culture, deceased donation is the norm. Deceased donation is widely publicised through media and national promotions to increase registration on the NHS organ donor register. Therefore, deceased donations are perhaps seen as the most common and successful way of obtaining a transplant. LDLT on the other hand is new and has now only been done once by the transplant team at the unit. Consequently, there is presumed nervousness amongst many

Box 5-7: Illness and transplant perceptions

Because possibly coming from the patient and the relative's stand point they know that something's possible, but then the most common way of that happening is because somebody dies and donates their organ so they think that that's going to happen.
[Coordinator 104]

I wonder if they think that we're saying that to force them to donate and that they don't necessarily think that what we're telling them is, I wouldn't say true, but not the whole truth. That they will still have that option later on.
[Surgeon 107]

People are nervous aren't they? Even though you're offering it to them they knew it was new. They have access to the Internet, they know what we do and what we don't do and we tell them, do you know that we haven't done one. They've read the packs and I think a lot of people were put off. The patients on the list themselves were saying no, a lot of them were saying no. I think maybe it was because we hadn't done one, I'm not too sure.
[Coordinator 102]

I just think that for a lay population it's very difficult to appreciate, you know, what happens in liver disease, chronic liver disease. Because they could be relatively well i.e. walking around, but things, complications that happen can happen like that (clicks fingers) and that's what people… They are unpredictable. The slow, steady decline does happen but on the waiting list the people who die, you know, tend to be from unexpected acute infection or bleeds.
[Consultant 111]

I think most of them believe that, as you say, another type of organ will become available and so living donor is a last resort for them. And I just don't think they necessarily can think out, you know, the fact that they might be too sick to benefit from living donation by the time it gets to that, I think they just hope that they'll get a deceased donor, that's the impression I got.
[Consultant 105]

Em, I don't know. I think, maybe, people don't realise that, you know, when you say you have to wait a long time on the waiting list that, it's not going to happen, you know.
[Coordinator 112]

…and maybe the truth is that, that whatever it is, ten, twelve deaths a year on the waiting list is not enough to scare people into making a decision
[Consultant 100]

…you can see what happens to the patients, they think they'll kind of try their luck first, they're told deceased is better if they get one, so they wait for a deceased one.
[Consultant 108]

patients about being one of the first to opt for LDLT. It is perceived that patients would rather stick with what they know and hold out for a deceased donation as this is how it is normally done. Patients appear unwilling to *"open their minds up a bit further and think about things a bit out the box"* [Consultant 105].

It is generally recognised that patients believe a deceased donation suitable for them will arrive without the need to consider living donation. There is an expectation amongst patients that the waiting list is almost a guarantee that a deceased donation will arrive because *"you wouldn't be put on a waiting list to wait for nothing"* [Coordinator 104]. Such logical thinking suggests patients do not fully believe the team when they are told the wait on the list could be a long time. Patients, perhaps as a coping mechanism, convince themselves that a deceased donation will arrive in time and their illness perceptions give them no reason not to believe this.

It is suggested that patients don't appreciate the unpredictability of liver disease and how quickly fatal deterioration can occur. Whilst many patients feel relatively well when they are first put on the transplant waiting list, they don't always *"necessarily know how sick they are"* [Consultant 100], and consequently the estimated death rate whilst on the list does not apply to them. It is perhaps presumed that people sicker than them will be the ones that die and it is not appreciated that they too could become that sick in a short space of time. This 'unrealistic optimism' (Weinstein, 1980) whereby deterioration and death will not happen to them and a deceased donation will be found in time, may result in the opportunity to receive a transplant through living donation being missed. Patients may not fully comprehend that the unit has strict eligibility criteria for the transplant waiting list. To be 'listed' indicates that the patient has, at a minimum, reached a point where their predicted mortality within the next year is greater than 9% if they do not receive a transplant (Neuberger, Gimson, Davies, Akyol, O'Grady, Burroughs et al, 2008). Listed patients are therefore sicker than they might think. The culture of the Scottish population is either one of hope and/or misunderstanding but both are thought to have contributed to the lack of progress made with LDLT at the SLTU.

5.5.3 Discussion

A patient presenting with liver disease has their progress monitored by a liver consultant physician (i.e. a hepatologist), and if selected for transplant, will have the additional support of a transplant coordinator and surgeon. Each profession plays a significant role in the patient’s care and for each the introduction of LDLT required the acquisition of new skills and knowledge giving them a valuable perspective on the option and its subsequent progress. Whilst conducting the interviews to draw out such perspectives, and from initial analysis of the transcripts, no obvious differences in thematic content between the three groups (surgeons, consultants and coordinators) were noted and therefore the decision was made to continue analysis of the transcripts as one sample. Evidence to support each of the emerging themes was found within each of the three groups.

Participants generally agreed that although they had expected to conduct a low number of LDLT procedures within the first year of the programmes availability in Scotland, a rate as low as one in three years was not anticipated. However, upon reflection, possible reasons for this outcome were offered and, through analysis of all 17 interviews, were found to fall into the six main themes described in the results section above.

The results neatly complement the findings described in Chapter 4 (Considering LDLT). In this previous chapter, one of the key reasons why LDLT had not been actively pursued by patients was the perceived risk to the donor. In this current study risk is also regarded to be the underlying reason for the LDLT programme's slow uptake, but rather than focusing on the risk to the donor specifically, it is justification of this risk that is thought to be at the heart of the themes identified. By obtaining the perspectives of medical staff we have been able to establish exactly how and why the risk involved in LDLT has impacted its progress in Scotland.

Within the culture of the unit, the risk to the donor was an important, distinguishing feature of living donation and attempts to avoid this risk was sought through a cautious, 'soft sell' approach of the unit towards LDLT. In the current climate of reduced deaths on the waiting list and increased deceased donations, the risk to a healthy donor was considered difficult to justify, and subsequently, deceased donation was the preferred method of transplantation.

Participants also understood that risk was an important determinant of the slow uptake from the perspective of the patients and their families. The culture of the Scottish population would depict that donations from a younger generation are unacceptable, yet with LDLT, they are often the only potential candidates. The risk to a younger donor was thought to be worse in light of the likelihood of such donors having young families, personal commitments and future plans. Donors themselves were also thought to be less willing to donate to an older person for similar reasons. When potential donors did come forward to enquire about donating their less than adequate health and fitness levels only served to increase the risk involved and therefore the team would reject their offer as a risk reduction method.

Whilst the risk for the donor is deemed an important factor, patients' perceived personal risk is also thought to contribute to the slow uptake. The theme concerning the illness and transplant perceptions of patients has highlighted the presence of unrealistic optimism. Unrealistic optimism is demonstrated when a group of people collectively believe that the chance of something negative happening to them as an individual is lower than average (Weinstein, 1980). In this study, patients are reported to believe that their chance of dying before a transplant becomes available is lower than average and this deterred their pursuit of LDLT.

Unrealistic optimism is a common finding within various health domains and is thought to affect coping and treatment choices and, in addition, may impact how personal risk information is processed (Radcliffe & Klein, 2002; Treloar & Hopwood, 2008). The theme of LDLT being a possible last option, from the study with patients described in Chapter 4 (Considering LDLT), may also indicate an optimistic bias. Not only was the patient delaying the risk to the donor by only considering LDLT as a last option, but perhaps their confidence to delay was indicative of an optimistic bias that a deceased donation would arrive and that dying was not something that would happen to them. Unrealistic optimism may therefore result in patients not seeking treatment alternatives and not fully appreciating the real risks involved in waiting for a deceased donation. The extent to which unrealistic optimism is involved in LDLT and ways to overcome any detriment associated with it requires further investigation.

In this study it is suggested that patients may have picked up on unspoken "vibes" from the team that LDLT was a) not the unit's preferred method of transplant and b) that a deceased donation was likely to turn up in time and therefore the need to consider LDLT was not so strong. Although in Chapter 4 (Considering LDLT) patients and donors did not describe being directly put off LDLT by staff, it may be that subconsciously, the culture of the unit has been influential in their decision to only consider LDLT as a last option. The unit admittedly chose not to force the subject of living donation, but rather they would provide initial information and then wait for a decision to be independently made by the patient and their donor. It may be that this lack of ‘push’ was interpreted as a lack of encouragement, which in comparison to the standard and obligatory preparation of patients for a deceased donation, perhaps gave weight to an optimistic bias that a living donation would not be personally necessary for them.

In consideration of the theoretical underpinnings of this research, which stipulates that how we think influences what we do, the results can be partially explained within the framework of both the health belief model (HBM) (Rosenstock, 1966) and the theory of planned behaviour (TPB)(Ajzen, 1988). In support of the HBM, patients and donors are again thought to weigh up the costs and benefits of LDLT when trying to decide on what action to take (Chapter 4: Considering LDLT). The costs were predominantly in relation to the impact on the donor’s family and personal circumstances, which were heightened by the family dynamics of the typical Scottish patient and required younger donor. In contrast, the benefits of LDLT were underplayed by the patients’ belief that they were not that unwell and would receive a deceased donation in time. The perceived severity of the illness and susceptibility to death were therefore also important determinants of the decision to not pursue LDLT.

The behaviour of the medical staff is also influenced by the perceived costs and benefits of LDLT and can therefore be partially explained by the HBM. Since the unit introduced LDLT, the need for the procedure in Scotland is thought to have reduced resulting in the risks / costs of the procedure outweighing the benefits. LDLT was originally deemed necessary because deceased donation rates were so low that the risk of a patient dying before they received a deceased donation was high. However, changes to the transplant system have now been made resulting in an increased rate of deceased donations, which serves to heighten the perceived risk / cost to the donor and, at the same time, has reduced patients' perceived susceptibility to death whilst on the list.

In December 2006, the Organ Donation Taskforce was formed to carry out extensive research of worldwide organ donation systems in order to elicit the barriers to donations and make recommendations for improvements to the UK system (Griffiths, Verble, Falvey, Bell, Logan, Morgan et al, 2009). The UK was thought to have the worst donation rates in Western Europe and improvements were needed to reduce the unnecessary deaths on the transplant waiting list. Through subsequent research it was hypothesised that changes to the system, specifically to the identification and retrieval of suitable organs, would lead to a 50% increase in donations over the next 5 years, leading to an estimated additional 1200 transplants in the UK (Organ Donation Taskforce, 2008). Recommendations to achieve this have been implemented and an increase in the number of deceased donations has already been achieved. Consequently, the balance of costs and benefits in relation to LDLT has shifted in Scotland so that the risk to the donor cannot be confidently justified.

In respect to the Theory of Planned Behaviour (TPB), ‘perceived control’ can be considered as a crucial determinant of the unit’s behaviour, which is carrying out LDLT. Through experience with organising and conducting deceased whole and split liver transplants, the unit believe they have the skills to conduct LDLT. Such control contributed to the unit’s original intention to perform the procedure. However, only conducting one LDLT procedure in three years has been noted to be detrimental to the maintenance and development of these more specific skills, which may have served to reduce intention over the years. In addition, external factors relating to control, such as the health and fitness of potential donors, has directly impacted on the behaviour: a living liver donation can only be performed if there are healthy donors willing and able to donate.

The other two component of the TPB, namely attitude towards the behaviour and subjective norms, are also highlighted in this research. The preference towards deceased donations and the approach of the unit towards LDLT is indicative of the unit’s attitude which, as described, is influenced by the perceived need for LDLT in Scotland. The risk to the donor, under the current conditions of the deceased donation rate and waiting list mortality, is not easily justified and attitudes have changed accordingly, with the intention to perform LDLT reduced. Similarly, the medical staff who participated in this study understood why patients did not want to pursue LDLT and agreed that ‘donating up a generation’, and the family dynamics associated with this, was not a socially acceptable norm, again reducing the intention to perform LDLT.

In Japan, family dynamics are thought to influence the uptake of LDLT. In a study by Fujita and colleagues (2006), donating to extended family such as parents or siblings was regarded as a more difficult decision than if the donation was for immediate family such as children or partner. However, it was found that the Japanese donors overcame this issue due to the notion that they had no choice (Fujita, Akabayashi, Slingsby, Kosugi, Fujimoto, & Tanaka, 2006). Donors considered the patient's life to be the priority and that it was their responsibility to donate. Importantly, LDLT was considered to be the only option as deceased donations, particularly from heart beating donors have traditionally not been accepted in Japan (Fujita et al, 2006). This is due to mixed cultural and religious beliefs which includes that death cannot occur until the heart and lungs have stopped functioning, and that following death it is important to be buried with all body parts (Kaur, 1998). In Scotland, it is clear that donors do have a choice and therefore social norms have resulted in limited pressure to perform LDLT.

Although the themes described emerged in interviews with surgeons, coordinators and consultants alike, differences between the groups of participants were found with respect to the flow of the interview. It was observed by the interviewer (the author) that surgeons were particularly more inclined to be matter of fact in their response to questions and did not easily elaborate on their personal opinions. Whilst this may be characteristic of the surgeons interviewed, the circumstances of the interview and interviewer may also have been contributing factors and this is potentially a weakness of the study.

Despite familiarity with the majority of participants, contact between the interviewer and surgeons had been limited. The interviewer personally perceived the surgeons to be in a position of power and consequently, felt particularly nervous when conducting these interviews. However, nervousness was also indicated from their perspective. As leaders of the LDLT programme, the surgeons had a vested interest in finding out the reasons why LDLT had not taken off in Scotland and were perhaps anxious that the results would indicate blame on the unit and consequently harm its reputation. This may have added to the professional standpoint elicited in their responses.

In addition, arranging a time and place for the interviews was troublesome given the busy schedules of each of the participants but this was particularly problematic with surgeons. It was perceived that participating in this research was not a priority but rather a favour, conducted under their conditions. The surgeons' limited time will have affected the dynamics of the interview and this should be noted.

However, the difficulties found with the interviews may not only be attributable to level of familiarity between the interviewer and interviewee, or power relationships, but also gender differences and influences. Whilst the coordinators were all female, the surgeons were all male, each being interviewed by a female, which again may have affected the flow and ease of the interview. Consultant physicians were also predominantly male, but familiarity with the interviewer and less direct involvement in LDLT, perhaps aided the interview process.

Without changes in the perceived need for LDLT, and to the cultural dimensions highlighted in this study, it is unlikely that Scotland, in the near future, will see a great increase in the number of LDLTs conducted.

Chapter 6 Scotland’s first Living Donor Liver Transplant procedure – a case study

6.1 Abstract

Objectives: LDLT is a relatively new procedure and its impact requires further psychological evaluation. To justify the inevitable harm to the healthy donor the risk must be minimised. In January 2008, the Scottish Liver Transplant Unit conducted their first LDLT procedure and an in-depth evaluation of the impact on both the donor and their recipient’s quality of life (QOL), psychosocial wellbeing and, physical and cognitive functioning was deemed essential.

Design: A mixed quantitative and qualitative longitudinal study design was employed. Patterns of responses to each quantitative measure were reviewed and relevant themes from each interview described.

Method: Participation involved the completion of a questionnaire pack, a set of computerised neuropsychological tests, and a semi-structured interview at three time periods: prior to the operation, 6 weeks post operation and 6 months post operation. **Results**: LDLT resulted in an improvement to the recipient’s QOL from pre to 6 months post LDLT. In contrast, the donor suffered some deterioration in her QOL at 6 weeks post LDLT which, despite improving by 6 months, did not always completely return to the baseline level. Both donor and recipient experienced improvement in their levels of emotional distress. Qualitative analysis confirms and enhances explanation of the quantitative results. Whilst the recipient experienced emotional difficulties related to unrealistic expectations regarding his recovery, improvements resulted in a fresh, positive perspective to life. For the donor, although saving the recipient’s life was a positive consequence of donating, the procedure also meant sacrifices had to be made, and unmet expectations

subsequently affected her perceived QOL.

Conclusion: The results of the first couple to proceed with LDLT in Scotland provide important information that merits consideration and monitoring with future LDLT candidates.

6.2 Introduction

Living donor liver transplantation (LDLT) is one of the many advances in surgical and medical techniques developed in an attempt to increase the supply of transplantable organs and reduce the number of waiting list deaths. However, it is also the most controversial as it involves a substantial degree of risk to a healthy individual (see Chapter 1: General Introduction).

The moral and ethical implications of LDLT are a paramount consideration for any transplant unit embarking on a living donation programme. As the operation itself is of no direct physical benefit to the donor and causes substantial harm, the only potential gain for the donor is psychological, which brings its justification into question (Cronin, Millis, & Siegler, 2001; Neuberger & Price, 2003). The inevitable harm to the donor must be minimised, and only by being fully aware of the physical and psychological implications of LDLT for a donor can this be successfully achieved.

As LDLT is a relatively new surgical procedure, only conducted by a select number of transplant centres in a small number of countries, research in this area remains limited. The research conducted to date has predominantly been quantitative in nature and whilst the consensus would be that LDLT does not adversely effect the overall quality of life of donors, there has been some variation in the findings (Feltrin, Pegoraro, Rago, Benciolini, Pasquato, Frasson et al, 2008; Kim-Schluger et al, 2002; Pascher et al, 2002; Trotter et al, 2001). The introduction of qualitative research whereby the donor's views, feelings and ideas can be described from their own perspective has aided interpretation of the donor experience and has allowed important issues not addressed by quantitative studies to come to light (Cabello & Smolowitz, 2008; Kusakabe, Irie, Ito, & Kazuma, 2008; Papachristou et al, 2004). For this reason, in-depth semi-structured interviews with donors and recipients were included in this current study.

It has been established that patients with liver disease often face cognitive decline due to impaired liver function leading to an accumulation of toxins within the blood stream (Collie, 2005; O'Carroll et al, 2003; O'Carroll et al, 2008). However, the cognitive impact for donors following removal of 60% of their liver has not yet been investigated; therefore neuropsychological tests were also included in this study to establish the possibility of deficits in attention, concentration, psychomotor speed and memory. Assessing donors on a number of occasions over the course of their LDLT experience was an important aspect of this study. For donors to be appropriately supported, any deterioration or development in physical and psychosocial wellbeing across the course of the LDLT experience must be understood.

Given the degree of risk to the healthy donor, the majority of research studies to date have concentrated on the donor, but the impact on the recipient cannot be ignored. The medical outcome for the recipient following LDLT is generally considered comparable to a deceased donation (e.g. short-term patient and graft survival). However, recent research has indicated a higher rate of complications and disease recurrence following LDLT (Berg, Gillespie, Merion, Brown, Abecassis, Trotter et al, 2007; Kashyap, Mantry, Sharma, Maloo, Safadjou, Qi et al, 2009; Settmacher, Theruvath, Pascher, & Neuhaus, 2004). Whilst the option of LDLT does have benefits over a deceased donation, essentially due to its timing (see Chapter 1: General introduction), the impact of the involvement of a known living donor on the experience of the recipient is under-researched. Therefore an additional aim of this study is to gain a better understanding of receiving a living donation and the effect it has on the recipient's psychosocial wellbeing.

The Scottish Liver Transplant Unit (SLTU) commenced their LDLT programme in April 2006. Poised to investigate the functional and psychosocial impact of LDLT on both donors and recipients in Scotland, the author and colleagues faced the challenge of recruitment. When funding for the SLTU to provide LDLT was granted it was proposed that the unit would conduct approximately 27 LDLT procedures within the first three years, however, this was not fulfilled (Scottish Liver Transplant Unit, 2004). By April 2009, only one LDLT operation had taken place at the SLTU. The opportunity therefore arose to report a detailed case study on Scotland's first LDLT couple and their experience is described in this chapter.

6.3 The Couple

The recipient (RP) was a 28 year old, white male. He was diagnosed with Primary Sclerosing Cholangitis (PSC) whilst a teenager and was placed on the Scottish liver transplant waiting list in September 2007, with a MELD score of 20 (see Appendix 1). Prior to listing RP was working as an IT consultant following time spent travelling. In 2002 he met his wife (DP), whom he married in May 2007. Eight months later, DP, a 25 year old, white female, whilst studying for a degree in veterinary nursing, donated 60% of her liver to her husband. The couple had no children and were residing with DP's mother.

6.4 Primary Sclerosing Cholangitis (PSC)

Primary Sclerosing Cholangitis (PSC) is a disease which affects the bile ducts of the liver, causing them to degenerate, narrow and consequently impede the necessary flow of bile in and around the liver. Bile is produced by the liver and is essential for digestion and the removal of toxins from the body. The cause of this disease remains largely unknown however problems in an individual's immune system are mainly thought to be involved. The precise nature of these problems continues to be investigated (Cullen & Chapman, 2003; Lee & Kaplan, 1995).

PSC is a progressive disease often asymptomatic in its initial stages leading to symptoms such as fatigue, jaundice, itchiness and weight-loss as it develops (Geonzon-Gonzales, 2007). The disease is predominantly found in males and the average age at which diagnosis is given is 40 years. As the precise cause is yet to be determined, medical intervention is limited to the temporary management of symptoms with the only effective long term treatment currently being liver transplantation (Geonzon-Gonzales, 2007; Lee & Kaplan, 1995).

6.5 Hypotheses

- The recipient will show general improvement from pre to 6 weeks, to 6 months post LDLT.

- The donor will show physical and cognitive deterioration from pre to 6 weeks post donation, improving to similar pre donation levels by 6 months post LDLT.

6.6 Methodology

The couple was contacted by the interviewer (the author of this thesis) and invited to participate in a large longitudinal study to investigate the functional and psychosocial outcome of living liver donation (see Appendix 22). The interviewer introduced herself to the couple as a psychologist working for the University of Stirling, researching the experience of living organ donation. The interviewer explained to the participants that, whilst the transplant unit had agreed to support the research project, their involvement was limited to the provision of patients' contact details. RP and DP both agreed to participate and separately completed the assessment at three time periods: pre-transplant, 6 weeks post transplant and 6 months post transplant. Written consent was obtained prior to participation. Lothian Local Research Ethics Committee approved this study (letter dated 29th May 2006).

Each assessment began with completion of the psychological questionnaire package, immediately followed by completion of the computerised cognitive neuropsychological tests. Following a short break, a semi-structured interview was then conducted to allow each participant the opportunity to describe their own personal experience of the LDLT process. The whole assessment took approximately 2 hours to complete and was conducted in the participant's home.

By December 2008, the couple remained the only donor and recipient to have completed LDLT at the SLTU. The results from RP and DP's participation were, therefore, incorporated into a detailed single-case study. The couple indicated support for their data to be used within a single-case study and provided additional written consent (see Appendix 23). Additional consent was necessary as the couple's situation meant anonymity could not be guaranteed, despite every effort by the interviewer to retain it.

6.6.1 Questionnaires

The questionnaires employed measured physical limitations (SF36); daily physical and psychosocial functioning (FLP); relationships and social issues (VAS); global quality of life (WHOQOL-BREF); and anxiety and depression (HADs). Each questionnaire is described in detail in Chapter 2 (Methodology). The questionnaires took approximately 30 minutes to complete.

6.6.2 Verbal Memory

Verbal memory was assessed with the *Story Immediate* (completed before the interview) and *Story Delayed* (completed after the interview) subtests of the Rivermead Behavioural Memory Test (RBMT) (see Chapter 2: Methodology, section 2.12).

6.6.3 Computer tests

Three tests from the Cambridge Neuropsychological Test Automated Battery (CANTAB) were completed: Rapid Visual Information Processing (RVP), Reaction Time (RTI), and Delayed matching to sample (DMS). These tests specifically measure memory, attention and psychomotor speed (see Chapter 2: Methodology, section 2.11).

6.6.4 Interview

A semi structured interview schedule was developed for the purpose of this project with flexibility added to address data collection from the perspective of the donor and the recipient, and to coincide with the time point of assessment (see Appendix 24 for example). The topics covered are listed in Table 6-1. Topic formation was stimulated by the available literature and discussion between the author and colleagues. Whilst the topics and questions were not structured around one theoretical model, knowledge of psychosocial factors known to predict behaviour and recovery influenced the content of the interview schedule. For example, the interview was devised to encourage an environment whereby participants could freely describe their attitudes towards organ transplantation, the perceived norms surrounding living donation, and the cognitive representations of their condition, factors intrinsic to the Theory of Planned Behaviour (TPB) and Leventhal's Self-Regulation Model (SRM) (Ajzen, 1988; Leventhal et al, 1984).

Table 6-1: Topics to be discussed in the pre and post operation interviews

Pre-operation	Post operation (6 weeks and 6 months)
Background to current situation	The surgical experience (6 weeks only)
Decision to donate / accept donation	Current wellbeing
Perceived views of others	Body image
Body image	Relationship and social implications
Relationship and social implications	Expectations and concerns
Expectations and concerns	Attitude towards medical care
Attitude towards medical care	Reflections on experience
Anticipated reactions to all possible outcomes.	Additional comments
Additional comments	

The interview was always conducted following completion of the quantitative measures. This order was adhered to in an attempt to maximize participant insight when the opportunity to discuss the topics suggested with the quantitative measures arose within the interview. Each interview was recorded and transcribed verbatim.

6.7 Data Analysis

6.7.1 Quantitative data

The results are described in terms of the general pattern of scores. The testing of statistically significant differences between the donor and recipient, and over time, were not possible due to the conditions of a single-case study. However, results showing substantial differences are illustrated in graph form to allow visual comparisons to be made. Comparisons are made to normative data where possible.

6.7.2 Qualitative data

The interviews were transcribed and analysed by the author using Thematic Analysis as described by Braun and Clarke (2006) (see Chapter 1: General Introduction, section 1.8). An inductive, semantic approach directed the analysis (Braun & Clarke, 2006). Each transcript was coded and analysed separately. An experienced qualitative researcher also coded the data to prevent potential bias from the interviewer. The emerging themes were compared and discussed between coders allowing interpretation of the data and theme formation to be enhanced (Barbour, 2001). A third person familiar with the transcripts and the area of liver transplantation reviewed the analysis and agreed with the final generated themes and sub-themes.

From initial coding of the interview transcripts it was decided by all three reviewers that for the purpose of this chapter the decision-making process surrounding LDLT, embedded within the first interview transcripts, would be specifically considered, followed by the main changes that had occurred by each time point of the remaining interviews. The corresponding sub-themes are reported in this chapter. The transcripts of the donor and recipient were assessed separately. In keeping with proposed guidelines for quality assurance in qualitative research, extracts from the relevant interview transcripts are included in the results section to illustrate the themes developed, provide transparency, and allow the reader the opportunity to appraise the interpretations offered by the author (Elliot, Fischer, & Rennie, 1999; Yardley, 2000).

6.8 Results

6.8.1 Quantitative results

6.8.1.1 Short-Form 36 (SF36)

The results of the physical functioning domain of the SF36 are presented in Table 6-4. Prior to the operation and at 6 months post operation the donor scored above the UK norm for age matched females (norm mean = 89.12) (Ware, Kosinski, & Gandek, 2000). However, physical functioning deteriorated below the norm at 6 weeks post operation. The recipient's physical functioning improved from pre to 6 months post operation but remained below the UK norm for males his age (norm mean = 94.9) (Ware et al, 2000). Due to missing data from the recipient the level of physical functioning at 6 weeks post operation cannot be determined.

6.8.1.2 Functional Limitations Profile (FLP)

Physical dimension

The donor's health only slightly limited her daily physical abilities at 6 weeks post operation. For the recipient, the LDLT operation resulted in a substantial improvement in physical functioning associated with daily living (see Figure 6-1).

Psychosocial dimension

Again the donor, prior to the operation, was not limited in a psychosocial capacity as a result of her health but substantial deterioration was noted at 6 weeks. By 6 months the donor was not as limited as a result of her health but had not yet returned to her pre-operation levels. For the recipient, his poor health prior to the operation meant he suffered a considerable degree of limitations with regard to the psychosocial aspects of daily living. Such limitations became slightly worse by 6 weeks post operation before improving substantially by the 6 month assessment (see Figure 6-2).

Figure 6-1: Score on the Physical dimension of the Functional Limitations Profile

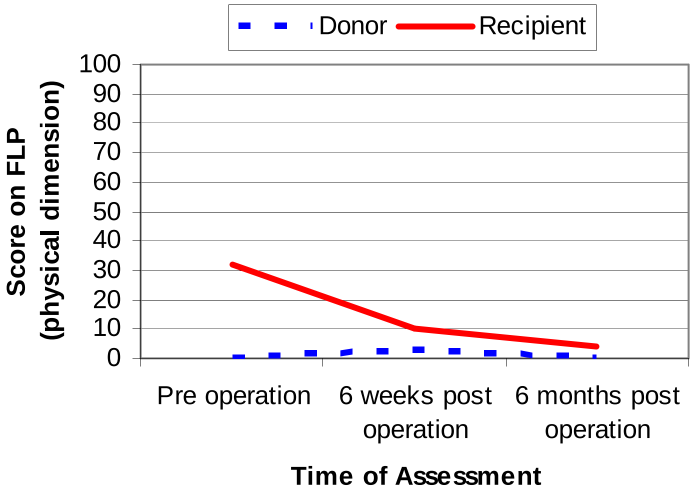
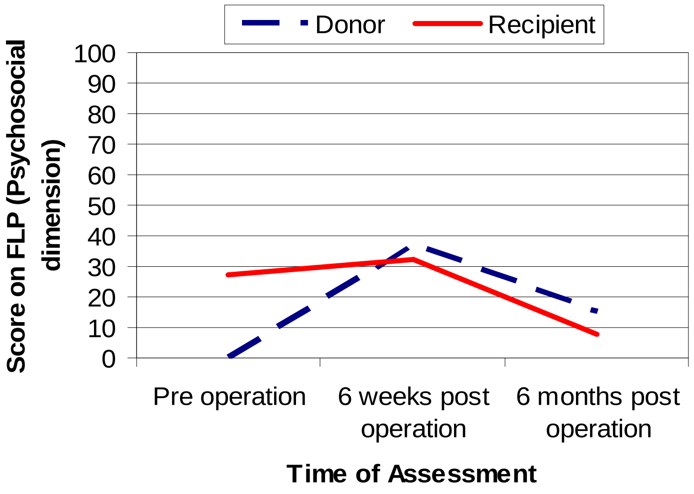


Figure 6-2: Score on the Psychosocial dimension of the Functional Limitations Profile



6.8.1.3 Visual Analogue Scales for Relationship and social issues (VAS)

The results from the visual analogue scales are listed in Table 6-2 and Table 6-3. Both the donor and recipient predominantly felt LDLT had positively impacted their relationship with one another and their relationships with other family members and friends. However, it should be noted that the recipient also perceived a degree of adverse affect on his relationship with friends and family, particularly whilst he was on the waiting list, and with his donor during recovery at 6 weeks post LDLT.

Table 6-2: Responses to questions regarding relationship issues.

Question	Participant	Pre Operation	6 weeks Post Operation	6 months Post Operation
Has relationship with donor/recipient improved? (%)[a]	Donor	65	93	97
	Recipient	58	81	77
Has relationship with donor/recipient been adversely affected? (%)[a]	Donor	1	1	0
	Recipient	2	20	7
Has relationship with family and friends improved? (%)[a]	Donor	47	84	75
	Recipient	33	48	60
Has relationship with family and friends been adversely affected? (%)[a]	Donor	3	2	0
	Recipient	33	14	11

[a] 0% = Not at all, to 100% = An extreme amount

The additional questions and results are presented in Table 6-3. Prior to the operation the donor had a reasonable level of concern for the operation and for the remaining part of her liver. Following the operation DP's worry for her liver substantially reduced, but by 6 months it had not diminished completely. This may be related to the high level of discomfort from the scar which persisted at 6 months post operation.

Table 6-3: Responses to questions regarding personal and social issues.

Question	Participant	Pre operation	6 weeks post operation	6 months post operation
Do you have concerns about the operation itself? (%)[a]	Donor	62	N/A	N/A
Do you have concerns / worry about the remaining part of your liver? (%)[a]	Donor	61	30	25
Have you suffered any financial loss? (%)[a]	Donor	N/A	74	36
Do you experience discomfort from the scar? (%)[a]	Donor	N/A	76	73
If possible would you donate part of your liver again? (%)[b]	Donor	N/A	72	58
Do you have concerns for the welfare of the donor? (%)[a]	Recipient	97	66	80

[a] 0% = Not at all, to 100% = An extreme amount [b] 0% = Definitely no to 100% = Definitely yes

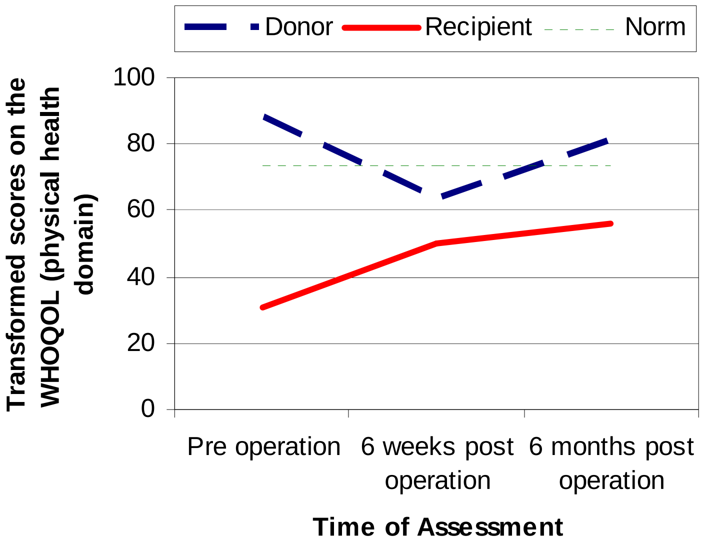
At 6 weeks post operation the donor felt fairly strongly that she would go through the experience again, but at 6 months the conviction of this response had reduced, as had the feeling that the operation resulted in financial suffering. For the recipient, his extreme concern for the welfare of the donor prior to the operation decreased post transplant, but had increased again by 6 months.

6.8.1.4 World Health Organisation's Quality of Life Scale (brief version) (WHOQOL-BREF)[2]

Physical health

As illustrated in Figure 6-3, the donor's satisfaction with her physical health status substantially reduced at 6 weeks post operation but was above established norms prior to and at 6 months post operation (Hawthorne, Herrman, & Murphy, 2006). In contrast, the recipient had limited satisfaction with his physical health prior to the procedure, but by 6 weeks this had increased and the improvement was maintained at 6 months. However, it is important to note that the recipient's satisfaction with his health was consistently below both the norm and that experienced by the donor.

Figure 6-3: Scores on the Physical Health domain of the World Health Organisation's Quality of Life Scale – Bref.



Psychological health

A similar pattern was found for the psychological health domain, illustrated in Figure 6-4. The donor's satisfaction with aspects of her psychological health was

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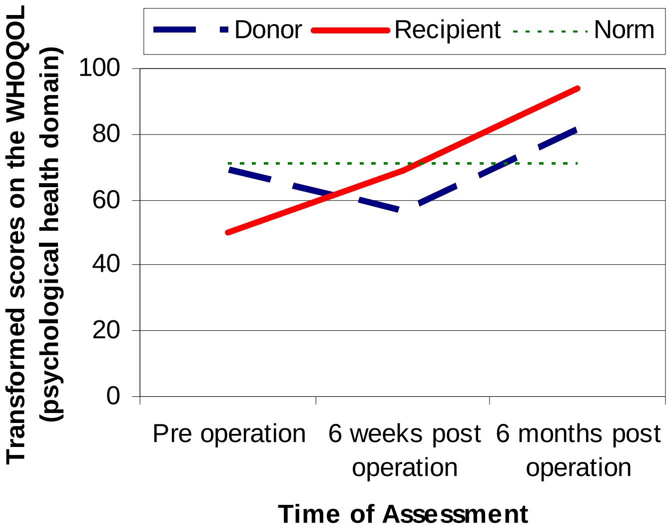
[2] Results of the WHOQOL domains have been transformed to a 0-100 scale to allow comparisons with published norms.

comparable to published norms prior to the operation and despite a dip at 6 weeks, was again above the norm at 6 months post operation (Hawthorne et al, 2006). For the recipient, his satisfaction increased over the three time points, reaching a level above the norm at 6 months.

Figure 6-4: Scores on the Psychological Health domain of the World Health Organisation's Quality of Life Scale – Bref.



Social relationships and Environment

The results for the remaining two domains are presented in Table 6-4. Both the donor and recipient experienced an increase in their satisfaction with social aspects of their lives, reaching the maximum level by 6 months post operation (norm = 71.5) (Hawthorne et al, 2006). With regard to their environment the level of satisfaction remained stable over time for the donor from pre to post transplant and was below the norm (norm = 75.1)(Hawthorne et al, 2006). Due to missing data it was unclear how the recipient scored on this domain prior to the procedure however post transplant scores were similar to that of the donor.

Table 6-4: Scores on the SF36, the remaining two domains of the WHOQOL-Bref, and the Anxiety subscale of the Hospital Anxiety and Depression Scale

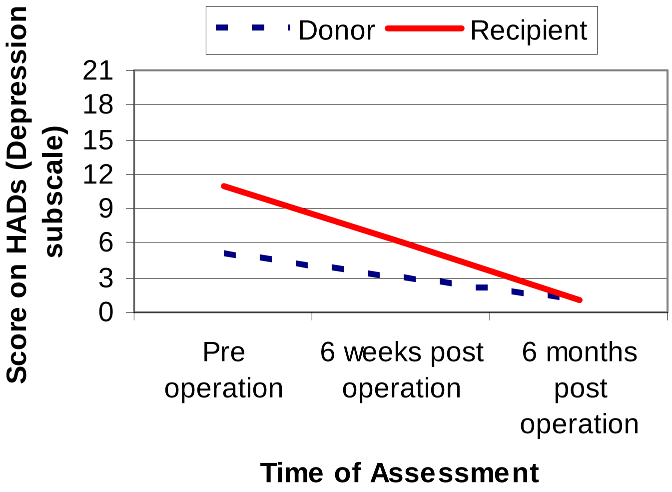
Measure	Participant	Pre Operation	6 weeks Post Operation	6 months Post Operation
Short-Form 36: Physical functioning	Donor	100	75	95
	Recipient	25	(Missing data)	85
WHOQOL (Social relationships)	Donor	75	81	100
	Recipient	69	81	94
WHOQOL (environment)	Donor	69	69	69
	Recipient	(Missing data)	69	75
HADs: Anxiety	Donor	4	4	1
	Recipient	4	2	1

6.8.1.5 Hospital Anxiety and Depression Scale (HADs)

Depression

The depression scores are illustrated in Figure 6-5. Both the donor and the recipient experienced a reduction in levels of depression over the three time periods, but this was particularly so for the recipient. According to normative UK data the recipient scored at the 98th percentile prior to the operation (Crawford, Henry, Crombie, & Taylor, 2001). In reference to the cut off scores proposed by Zigmond and Snaith (1983), this score represents “moderate” depression.

Figure 6-5: Scores on the Depression subscale of the Hospital Anxiety and Depression Scale



Anxiety

Both the donor and recipient saw a decrease in anxiety scores over the course of the LDLT experience but at all times the level of anxiety did not rise above the 'normal' range (0-7) (see Table 6-4). The highest scores for both donor and recipient, achieved prior to the operation, constituted the 34th and 42nd percentiles respectively (Crawford et al, 2001).

6.8.1.6 Cambridge Neuropsychological Test Automated Battery (CANTAB)

Scores on the computerized neuropsychological tests are presented in Table 6-5. No distinct patterns were noted in the results; however, on tests of speed and attention the donor consistently under performed in comparison to the recipient. This suggests that either the recipient is not limited in neuropsychological function as a result of his condition or that the tests used were not sensitive enough to identify such problems.

Table 6-5: Scores on CANTAB tests and the RBMT test of verbal memory

Measure	Participant	Pre Operation	6 weeks Post Operation	6 months Post Operation
RTI: 5-choice accuracy score (max = 15)	Donor	15	15	15
	Recipient	15	15	15
RTI: 5-choice reaction time[a] (milliseconds)	Donor	292.47	339.60	357.93
	Recipient	261.60	243.33	270.00
RTI: 5-choice movement time[b] (milliseconds)	Donor	399.33	438.07	444.73
	Recipient	318.33	391.53	324.07
RVP: Total hits (max = 27)	Donor	25	26	23
	Recipient	26	25	27
RVP: Mean latency[c] (milliseconds)	Donor	450.16	522.35	508.52
	Recipient	310.42	292.36	321.33
DMS: Total correct with 12000ms delay (max = 5)	Donor	5	5	5
	Recipient	5	4	5
DMS: Mean correct latency of all delays[d] (milliseconds)	Donor	3611.60	3386.00	2822.93
	Recipient	2992.13	2888.15	2375.40
RBMT: Story immediate	Donor	8	11	12
	Recipient	8	7.5	7
RBMT: Story delayed	Donor	7.5	7.5	14
	Recipient	6.5	10	9

[a] Speed at which the button is released. [b] Time taken to touch the screen following release of button. [c] Time taken to respond when a correct response was made. [d] Time taken to respond when the target was presented following a delay.

6.8.1.7 Rivermead Behavioural Memory Test (RBMT)

Raw scores from the RBMT are presented in Table 6-5. Again no distinct patterns emerged from the results, but of interest was that the donor and recipient scored similarly on both subtests at the pre operation assessment and the donor showed no decline following removal of 60% of her liver. The recipient only improved with regard to the *story delayed* subtest.

6.8.2 Qualitative results

6.8.2.1 Donor

Throughout the three interviews, DP discusses her experience of living liver donation, describing how her life has changed over the course of the procedure, from the offer to donate through to recovery. In the initial interview with DP, she had already made her decision to donate, but through our conversation more information about how that decision was made and why is gained. Following the procedure, the interviews allowed DP the opportunity to explain the personal impact of her decision and to reflect upon her recovery. Table 6-6 lists the master themes and subsequent sub-themes that emerged from each interview.

Table 6-6: Table of themes for donor

Master Theme		Sub-themes
Pre operation (72 days before)	Deciding on LDLT	Regaining control Having no choice Personal gain Support from medical team
Post operation: 6 weeks (47 days post)	Initial impact	Sacrifices made Shift in attention
Post operation: 6 months (196 days post)	Recovery	Consequences of LDLT Unrealistic expectations

6.8.2.1.1 Pre operation

Within the donor's initial interview it is evident that the decision to donate is a result of a complex web of beliefs and emotions. This analysis therefore specifically tries to describe the factors which influenced DP's decision to donate 60% of her liver to her husband.

6.8.2.1.1.1 Regaining control

Whilst DP had been aware of her husband's (RP) condition since they met, the need for a liver transplant was not expected at such an early point in their married life:

> *"So the disease, we knew it was always going to progress and eventually he would need a liver em, transplant. We didn't really think it was going to be at this point, so soon."*

It was anticipated that time was on their side and that a liver transplant would be the end result of a long period of gradual liver deterioration. There is therefore an element of surprise at the current situation, with subsequent feelings of injustice as they *"only got married in May"*.

The worsening of RP's condition was not fully appreciated when symptoms started to appear, with increased tiredness and stomach bloating being attributed to less serious explanations such as RP *"just getting fat"*. The subsequent speed and gravity of RP's deterioration was not anticipated and DP felt a loss of control over the situation: her partner's symptoms simply *"snowballed"*.

In order to regain an element of control, DP has taken action and identified a number of strategies to help alleviate some of RP's symptoms. For example, in order to control RP's ascites[3] *we got his diet stable"*, and his growing weakness and susceptibility to bed sores are managed by *"trying to sort of move him*". With effort, DP can retain some control over RP's condition and help ensure he is fit enough to

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[3] A condition whereby fluid accumulates in the abdomen.

receive a transplant when one becomes available. DP's need for control is epitomized by her offer to donate:

"Well I mean if you can do something to help. It wouldn't matter if it was (RP) or my brother or whatever, you're going to have to do something to help".

The option of LDLT puts DP in a position to potentially change the course of her husband's disease and therefore cannot be ignored. There is a sense of obligation to not sit back but rather seek out and grasp all opportunities. This is heightened by the urgency of the situation as RP's condition is set to become worse:

"…if RP gets weak, well weaker em, you know, the risks are higher so I'd rather him be put through while he still can".

From DP's experience as a veterinary nurse, she understands that as the patient becomes weaker, the risk of major surgery increases and the chances of survival are reduced. If the risk is deemed too high by the surgeons, they will not operate, therefore, for RP to receive a transplant now, whilst he is relatively well, would be to his advantage and therefore is DP's preferred plan of action. However, given that there are *"just not enough organs"* available, the timing of a deceased donation cannot be relied upon and time itself is running out:

"…as the weeks go on and he's not getting a call, he's getting worse, he can feel he's getting worse, you can see he's getting worse…"

DP is witness to the extent of RP's deterioration and the hopelessness of the situation. Without a transplant, RP can only continue to get worse, which adds weight to DP's decision to donate. DP cannot rely on other people to provide the essential liver in time and therefore feels the necessity to take control over the matter and provide the liver herself.

6.8.2.1.1.2 Having no choice

This feeling of wanting to regain some control over the situation is predominantly a result of the inadequate organ donation system in the UK:

"…we hope that he'll get like a dead donor but the way things are going and the dire state of things it's, if I'm honest it probably pisses me off that there isn't, that the system's failing (RP) and we have to do everything that we can, and if I can help him I'm damn well sure I'm going to do it…".

This quote highlights DP's anger and frustration at how the system has let both her and her husband down. Despite preferring not to donate, in the unlikelihood of her husband receiving a deceased donation in time, she is willing to cause herself significant harm, and potentially sacrifice her own life, for his benefit. The current organ donation system neither protects her husband nor DP, but rather persuades her to risk her own life. DP is determined to have her husband saved and will stop at nothing to do this.

With few alternatives, DP feels she has no real choice:

"I'm not forced in, well okay, I am not forced into doing it but I wouldn't feel I had to do it if there was enough donor pool out there".

Whilst DP understands that not donating is physically an option, emotionally the potential consequences of not donating leaves her with no alternative but to donate. A deceased donation is not guaranteed, therefore the only way DP can truly help her husband, is to compensate for the system's failings and donate part of her own liver. DP's decision to donate is made within a context of "*a risk that I suppose you've got to take*". DP's supposition suggests a sense of obligation to help her husband, which is irrespective of any risk involved. With no alternative in sight, donating is the last chance she and her husband have of living a life together.

6.8.2.1.1.3 Personal gain

RP’s condition and subsequent need for a liver transplant has not only changed RP’s life but has adversely impacted DP’s. The quality of DP’s own life is not a priority whilst her husband remains on the transplant waiting list.

> *“…life revolves around (RP), his condition and making sure he’s fit and healthy. And trying to fit my life in but, like I said, it’s been on hold since he was put on the transplant list…”*

As indicated in the above extract, DP is committed to her husband and his care is paramount. As a consequence, DP’s needs have got lost along the way and instead of living she is simply existing. To donate is therefore a way in which DP can take control of the situation, stop the disruption to her own life, and get back to normal. To not donate, on the other hand, has the potential to make her life even worse:

> *“…if we don’t do this and (RP) doesn’t get a call, what’s the alternative? I don’t have a husband? Not much of a life”.*

To donate is a chance to not only save her husband but also to restore her own quality of life. Without a sufficient supply of deceased donations and without living donation her husband’s death is likely and a subsequent loss to her own life inevitable. It could therefore be surmised that living donation is DP’s only real option. Ironically, for DP to live the life she wants she must first risk her life and donate.

DP’s focus on getting her husband better may be a selfless act on one level but on another, a selfish dimension persists as she is not only doing this for him but importantly for her own benefit too. DP wants to *“Just get my husband back”* and donating part of her liver is the means to this end:

"…but part of it's probably selfish because I get my husband back and I get a life with him, but if it was for a stranger and I did all this risk, you know, human nature is what can I get out of it?"

DP's decision to donate is tied in with the benefits she perceives for herself. She may be risking her own life, but the prospect of living a life with her husband is both justification and reward. The opportunity to get her own life back encourages her decision to donate.

6.8.2.1.1.4 Support from medical team

DP is aware of the risk involved in the living donation procedure but her faith and confidence in the transplant team allows her to keep her concerns and worries in check. Despite feeling *"a bit of a guinea pig"* with respect to being the first living liver donor at the unit, DP is not dissuaded from donating but rather is encouraged by her belief in the team and the care she and her husband have received so far.

"I have every faith in the doctors, faith in the surgeons, and I am happy with the way things are done. Every time we go up there, you know, they do, you know they're doing their best for you, and they're obviously good at what they do. I just don't think about it".

DP's confidence in the team encourages her not to think too deeply about the involved risks, which in turn minimises her concerns and reinforces her decision to donate. This confidence is supported by DP's evaluation of the *"excellent"* service received so far:

"Em, and you feel like, you know, you're getting a private treatment in an NHS hospital."

The care received by DP whilst being tested for donor suitability has exceeded her expectations and this feeling of being treated as a priority serves to increase her confidence and satisfaction with the team, supporting her decision to donate.

6.8.2.1.2 Post operation: Initial impact

DP describes the run up to the operation as a calm process. A date for the procedure had been arranged and therefore an end to the wait was in sight. In the interim period, DP continued to focus on her husband's condition, continued to receive special treatment from the transplant team, and remained confident in her decision to donate. However, the procedure resulted in a shift in DP's focus away from her husband and more towards her own recovery. At 6 weeks post donation the positive and negative impact of donation for DP was therefore described.

6.8.2.1.2.1 Sacrifices made

At 6 weeks post operation there is an overall improvement in DP's emotional quality of life which corresponds with her husband's survival. Whilst previously DP was concerned about RP's deterioration, he is now thought to be *"on the road to recovery"* and this has a complementary effect on DP's own life and emotional wellbeing:

"…I got my husband back, starting to get my life back, so I feel good."

DP has achieved her aim. As described in the pre interview analysis DP pursued living donation for her own personal gain. DP wanted a life with her husband and donating has allowed this to happen. However, in contrast to the emotional benefits of LDLT, the procedure itself has resulted in a degree of physical deterioration.

"It's not a big issue, but quality of life, physically it's less, but because I've got (RP) back my quality of life is so much better than it was…"

DP's body has felt the impact of major surgery and consequently she has changed from being a very healthy individual to being a recovering patient with symptoms of her own to contend with[4]. However, at this stage of her recovery such physical problems are *"to be expected"* and therefore do not overshadow the benefit of having her husband alive and well.

This positive perspective is further adopted with regard to the limitations such physical deterioration causes:

"I'm obviously not doing as much as I could do or would be doing, but at the same time I can sacrifice that for another month if it means I've got my husband back again".

The limitations are perceived to simply be a temporary inconvenience to DP as she anticipates a return to normal physical functioning in the near future. Being physically active is clearly an important aspect of DP's quality of life as being limited is described as a *"sacrifice,* with the loss entailed only acceptable for the greater good of having her husband with her. However, this positive perspective appears dependent on the anticipated short duration of the limitations.

A physical change that is acknowledged to be permanent is the scar and this serves as a great challenge to DP's body perception. In the interview prior to the operation, DP predicted that the scar would not bother her but the reality of its existence is an issue:

"…it is big, it goes from here to here and my body's not healing as well as it should be, (RP)'s got a lovely little pink line, whereas mine's still quite inflamed and red…"

Comparing her scar to RP's emphasizes the fact that DP is disappointed with the appearance of her own scar: whilst little and pink is *"lovely"*, inflamed and red is

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[4] Symptoms include nausea, constipation, loss of appetite, weight loss, diarrhea and stiffness.

not. Although a visible scar was expected, DP had not anticipated the extent of its appearance and it has subsequently become a concern for DP:

"…but I think that six months down the line, a year down the line it'll be, still very, very obvious and that's probably my biggest issue, is the scar, I'll need to keep it covered up."

DP feels dejected by the perceived likelihood of the scar not fading in the immediate future. DP appears embarrassed by the scar, preferring to keep it hidden from view. Whilst she was proud of her *"nice smooth skin"* and is happy with her *"nice little belly"*, the scar spoils her appearance and reduces her confidence in her body: *"I can't wear a bikini anymore"*.

6.8.2.1.2.2 Shift in attention

RP's improvement following the operation puts DP in a position to readdress her focus and give her own wants and needs much more consideration. However, it would seem that, as DP's attention has turned more towards herself, the attention from the transplant team has reduced.

DP continues to praise the transplant team for the *"superb"* service she has received since offering to donate; however, she now perceives she is less important to the team:

"…like I said it was all donor, donor, donor before the operation and then it was all recipient, recipient, recipient after the operation, I thought, I said to them I feel as if you've got my liver, now you don't need me".

Prior to the procedure DP felt that she received a lot of attention from the transplant team as their focus was on ensuring her safety and wellbeing. Whilst RP was already unwell, DP was not; therefore she was perhaps considered the team's main concern with her liver being the most important component. Following the operation, it could be argued that the liver remained of the utmost importance, but as it was now part of RP he became the focus of the team's attention. DP consequently felt abandoned and used having served her purpose.

DP felt that the regeneration of her liver should be closely monitored with frequent checkups by the transplant team. However, ironically, now that DP had her own health concerns, she was not wanted as a patient.

> *"…can I not just get some bloods done regularly enough to keep my mind at ease and he was, 'oh, no I don't want to take you as a patient' and all that sort of thing so I was a bit miffed at that…"*

Whilst before the operation the transplant team's attentiveness offered assurances to DP, this is no longer readily available post transplant, and this change in level of support has upset DP. As a couple, DP believes she and her husband remain particularly important to the transplant team as *"we're protégées, we're their babies"*, but it would appear that the balance of importance within the couple has changed. The shift of attention from DP towards RP, following the operation, was not anticipated causing DP some annoyance.

6.8.2.1.3 Post operation: Recovery

Again DP reaffirms her decision to donate but now the physical changes noticed previously are described in terms of how they affect her life, and reflections on her previous expectations are provided.

6.8.2.1.3.1 Consequences of LDLT

The consequences of LDLT have been both positive and negative. On an emotional level, DP has continued to reap the benefits of her decision to donate. Her relationship with RP has been strengthened: *"now we've got a special bond that,* *you know, not many a husband and wife share"*, and their life as a couple has been restored: *"we've got our life back*", but further progress is hindered on a physical level.

Whilst DP states that she is *"recovered"* from the surgery, pain around the scar area prevents her from moving on completely. At 6 weeks post operation, the appearance of the scar was the main concern, but now the appearance appears less of an issue compared to the physical discomfort experienced from the scar. As a direct result of the pain, DP feels restricted in her abilities and is frustrated at not being able to do everything she normally would:

"…this scar's the only thing that's holding me back, and the pain and sort of muscle spasms".

The scar, the associated pain and muscle spasms are unwelcome remnants of the recovery process and are consequently causing disruption to DP's complete return to normality. The description of her being held back first and foremost relate to the fact that the pain and spasm prevent her from taking part in "vigorous exercise", which constitutes a level of fitness DP had achieved prior to the procedure. In addition, the pain is described to be a *"daily thing"*, and therefore could be said to act as a constant reminder of DP's living donation operation, preventing her from moving on with her life and drawing a line under her experience once and for all.

This wish to move on from the experience is further highlighted by her hopes to *"be all sorted":*

"I'm hoping that this is fixed or it fixes itself and (RP) will be fixed…"

This quote refers to two problems resulting from the procedure: DP’s scar pain and her husband’s hernia. The need for these to be *“fixed”* suggests a need for an official and permanent end to the problems and to the LDLT experience. DP’s scar pain is poorly understood by both DP and the transplant team. Its cause and, consequently, its duration are uncertain. Therefore, how to ‘fix’ it is not known and instead of taking action DP is left to ‘hope’.

6.8.2.1.3.2 Unmet expectations

In connection with the persistent scar pain, is the idea of unmet expectations. In earlier interviews it was indicated that DP did not anticipate that she would still be in pain at this stage and therefore, as explained above, it is felt to be holding her back from her envisioned state of normality. However, it should be noted that the pain itself is not the issue as it is described as *“more annoying than anything”*, but rather it was not expected by DP, and more importantly, she had not been told to expect it.

> *“I think my biggest qualm is just that I wish they had said something about this, whether… It wouldn’t have made any difference I know but, but at least you’d be prepared for it.”*

Being prepared, being in control and knowing what to expect is important to DP. There is a sense of regret at not having been told about the possibility of scar pain noted in her *“wish”* that things had been different. Knowing would not have resulted in DP changing her mind about donating *“because (she) can live with this and can't live without (her) hubby”*, but rather to have known about the pain would have reduced her present concern over its existence and allowed her to alter her expectations accordingly.

Prior to the procedure DP described asking questions of the transplant team and being given information about LDLT but she was not forewarned of the lasting scar pain and she appears disappointed at this outcome:

"…it would have been nice to be have been told and known to expect it. You know, because they told me the main things, but you know, your bile leaks, your infection and things like that which didn't occur, thank God, but it would have been nice to know every sort of occurrence that may arise to, just to look out for it".

There is an indication that perhaps the team held back information not perceived by them to be as important as other complications and this occurrence had not been anticipated. When considering her decision to donate, DP's faith and confidence in the transplant team was an important influence, therefore there is now a sense of disappointment in the team for not informing her of lasting pain and she is consequently*"a bit annoyed"* by the situation.

6.8.2.2 Recipient

Over the course of the three interviews RP describes how his life has changed from his diagnosis to his recovery from a living liver transplant. At the initial, pre operation interview, RP describes the extent of his condition and the changes to his life experienced as a result of the disease. RP is undecided about LDLT at this stage and he describes the reasons behind his indecision. At the interview conducted 6 weeks after the procedure RP is able to reflect upon the transplant experience and describes the difficulties incurred during his stay in hospital. This leads to a description of the transformations resulting from LDLT, realised 6 months after the operation. The sub-themes to be discussed are listed in Table 6-7.

Table 6-7 : Table of themes for recipient

Master Theme		**Sub-themes**
Pre operation (56 days pre)	Considering LDLT	Deterioration Loss of identity Regain control Concern for wife
Post operation: 6 weeks (65 days post)	The operation	Unrealistic expectations
Post operation: 6 months (165 days post)	Recovery	A positive perspective A fresh start

6.8.2.2.1 Pre operation

At RP's first interview he, unlike his wife, remains undecided about proceeding with LDLT. The turmoil present in RP's consideration of LDLT is apparent as he describes being *"a bit torn between the two at the moment",* and he reduces the pressure of making a formal decision by putting it off until a future meeting with the transplant team. This analysis describes the factors adding to RP's confusion over how to proceed.

6.8.2.2.1.1 Deterioration

The symptoms of RP's disease started when he was 15 years old but following formal diagnosis of Primary Sclerosing Cholangitis (PSC) and subsequent *"miracle"* trial medication, he managed to maintain good health for many years. However, in March 2006 he began to feel ill again, but it was assumed by RP to be *"a hiccup, it'll go away"*. RP played down the reappearance of symptoms and proceeded to get married but his condition soon deteriorated:

> *"…my body realised, 'Right I've had enough, I need a rest' and em, that's when my condition, kind of, must … It was just like falling off a cliff, because I'd been relatively well for ten years and then mid June, probably the start of July I just started getting really, really bad, lost, like I was losing like, maybe a kilo or two a*

week. Em, I was, all my muscle was just falling off me, sort of thing, couldn't eat, had no appetite, and I, I just got sicker and sicker".

The deterioration in RP's health was unexpected, sudden and rapid. His body felt as if it was out of his control and acting against him. For years RP had successfully managed his condition and therefore to be told he needed a transplant was a *"big, big, big shock to me"*. RP had only been married 4 months and so the news was *"just devastating"*. RP felt his body and future were out of his control.

RP's mental and physical deterioration has continued with concentration and memory problems on top of jaundice, itchiness, lack of appetite and fatigue. As a consequence, RP feels *"very, very limited in what (he) can do"* and this adversely affects his quality of life:

"I don't have a life as such. I can't go to my work, I never go, I can't go and visit my friends, you know. I can't go out anywhere without knowing there's a toilet nearby…I have no quality of life at the moment."

RP sees his condition as restricting his freedom. Similar to his wife, RP feels he is currently only existing, not living, as a direct result of the disease and its progression.

6.8.2.2.1.2 Loss of identity

In connection to RP's physical deterioration is his apparent loss of identity seen predominantly through his changing physical appearance:

"… I'm a shell of my former self. I, I don't really recognise myself when I look in the mirror…right now I don't feel like I'm me."

RP neither looks nor feels like the person he knows he is. RP has previously worked hard to look after his body, doing what he could to keep fit and healthy, and used weight training to get *"a bit of bulk on me* and enhance his appearance. However, now it would seem his body has turned against him and his condition has *“cannibalized all the muscles”*, destroying him from the inside out.

A further loss of identity can be seen with regards his perceived cognitive deterioration:

“…my long term memory seems to be okay but I get quite forgetful and I forget where I put things and I mean I’m only twenty eight, it’s kind of like, it feels like I’m senile, you know.”

Being forgetful is a stereotypical characteristic of an elderly person and therefore this quote describes how RP feels old before his time. RP’s current level of cognitive functioning is unrepresentative of who he really is.

6.8.2.2.1.3 Regain control

In light of the deterioration and subsequent loss of identity, RP has fought to regain some control over his symptoms and has taken action to help slow down his rate of decline:

“Well actually I’m, I’ve just through diet and eh, kind of, I guess will power, I’ve actually made my condition a bit better…”

Whilst limited in energy RP is motivated and determined to not give in to the disease and maintain some control over his body. For physical improvement RP is *“forcing myself to eat a hell of a lot”* and to help his cognitive decline he has *“been trying to keep my brain active”* with crosswords, jigsaws, etc. RP is making a conscious effort to defer further decline, but it is the disease itself, and not just the symptoms, that needs to be treated if RP is to have full control over his life and future. RP knows a transplant is ultimately required, but the arrival of a suitable deceased donation is uncertain:

"… it's the not knowing that's hard with the waiting list, because you know the call could come today, but it might not come for six months. And with the, if we do go ahead with this it would be some sort of way you'd have a finality to it. You'd have a day and it's like, 'Right it's going to be done January, whatever or February, whatever' and then we can start to make firm plans as to, like I can be rehabbed by then, I can speak to my work and say, 'Look I'm aiming to be back at work here'. But right now I can't give anyone a time frame for anything, so I think I'm coming around to the idea a bit more."

LDLT would enable RP to regain control of the disease and put an end to this period of his life. Currently, due to the uncertainty of deceased donation, RP cannot make future plans and he is aware of the consequences this has for others. RP needs to visualize a conclusion to his current situation, and he can currently only do this with the option of LDLT.

6.8.2.2.1.4 Concern for wife

Despite the benefit of LDLT as a readily available solution, the decision to continue with this option is undermined by RP's concern for his wife:

"I thought, 'Oh that, that sounds good'. I thought, but not if my wife had to do it."

Upon hearing that LDLT could be an option, RP was encouraged by the concept but reluctant to proceed due to the detail of who would be the donor. To accept would mean his wife would have to go through major surgery, and this could be seen to counteract the benefits of a timely procedure:

"…for me the really hard part to deal with is just the thought of her being in pain, just going through a surgery in general and then having a scar afterwards and any possible pain. I mean I just don't even want to think about the fact that something … That she could have health issues arising from it, you know…"

It is evident that RP loves his wife and that he fears for her welfare if she proceeds as his donor. Serious complications are deliberately not given much thought, perhaps as a way of coping with the enormity of the situation, but their possibility is also in some ways irrelevant as it is simply the idea of DP being harmed which first and foremost acts as a barrier to RP’s acceptance of LDLT. Surgery is inevitably a painful, disfiguring procedure and RP does not want to be the cause of his wife’s suffering. His wife’s perceived vulnerability, set within the image of her *“having to lie on a table and getting cut open with a scalpel”*, is the crux of his concern and reluctance to proceed with LDLT. To refuse his wife’s offer of donation would be to protect her from such harm; however, to accept may serve to protect their future together. Consequently, the option of LDLT is not refused by RP but is considered a *“a safety net*”, and the decision he has to make is whether the time to proceed with his *“last resort”* is now.

6.8.2.2.2 Post operation: 6 weeks

During this interview, RP reiterates the turmoil he experienced on the build up to making a decision about LDLT and describes relief when a decision was finally made. RP no longer felt *“in limbo”*. However, post LDLT, he describes how his expectations for recovery were not met and the impact this had on his own emotional wellbeing.

6.8.2.2.2.1 Unrealistic expectations

RP describes his slow and gradual recovery from the procedure and how he has only recently, since being discharged home, began to feel *“like a normal person again”*. RP is disappointed by the speed of his recovery yet is accepting of it:

“I’m not where I want to be, but I’m so much better than I was, so I’m happy about that.”

Following the procedure RP suffered a number of complications[5] which was inconsistent with his expected course of recovery. Although he now appreciates the progress he has made, this was not always the case:

"I didn't think I'd have all the complications, I thought ten weeks or so after it I'd be back at work., I figured eight weeks, I'd set myself all these time rules in my head and every time I missed one in the hospital I'd get really down and emotional about it."

RP was not emotionally prepared for the complications. RP's previous positive thinking and determination with regard to his recovery could not withstand the reality of his situation and he became depressed as a consequence:

"…its probably the worst I've been mentally, I was like I think it was the post transplant blues or something DP was saying, but everything was upsetting me, all the steroids you're on make you really emotional and that and I was just thinking I'm not going to be able to get back to my job, I'm not going got be able to build this house because I won't have the money to pay for it and everything just felt too much for me…"

RP was overwhelmed by his situation and frustrated that his body and future plans remained out of his control. RP had expected to be *"bouncing off the walls and full of energy"* following his transplant but instead he remained physically limited due to the repercussions of the procedure and this served to undermine any joy and excitement from the success of the liver transplant itself. As the chance to reverse his deterioration and improve his quality of life were important factors in his decision to proceed with LDLT their continuation post operation was disappointing and caused RP substantial distress.

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[5] Complications described by DF included problems with kidney function, nerve damage to his feet and the need to have his spleen removed. A hernia at the wound site developed following his discharge from hospital which resulted in him being readmitted.

6.8.2.2.3 Post operation: 6 months

In this interview RP describes how he has continued to make a positive recovery and can see how LDLT has changed his life for the better. At 6 weeks post operation the benefit of having his life back was duly noted, but this was undermined by the slow progress being made. At six months the implications of having a new, working liver are realized and RP consequently reaffirms his belief that choosing to proceed with LDLT was *"the right decision"*.

6.8.2.2.3.1 A positive attitude

Since diagnosis, RP has tried to maintain a positive mental attitude with regard to his situation, only faltering shortly after the operation when his expectations had not been met. However, his continued progress since his release from hospital has led to a more effortless positive attitude:

> *"I'm quite sore but it doesn't stop me being happy because I'm so happy just to be here."*

RP is euphoric to be alive. Whilst he continues to have pain at the wound site, it does not dampen his spirits as he understands having his life back is more important. He admittedly *"forgets"* about the pain and overlooks the other continuing repercussions, which include a hernia, nerve damage to his feet and a structured medication regime, referring to them as *"small fry stuff*'.

RP has faced tough and challenging situations since his deterioration began and has becomes a stronger person physically and mentally as a result:

> *"I'm just so happy now, its like you could chuck anything at me and as long as my liver is working and my kidneys are working, take away any major health problems and nothing bothers me"*.

RP has faced the worse and survived and only a further risk to his life could take away from his delight. Any other medical, social or personal issues that may arise are put into perspective and are subsequently downgraded in their importance to RP. His health is precious and will always come first.

In-keeping with his more positive outlook is his continuing gratitude to all those who supported him through the LDLT experience. Such support has enabled him to get to the position where he can reflect on what is truly important:

"I've got an IOU book about this long, so I've got lots of making up to do for all the stress and everything".

Whilst the condition was out of RP's control, he feels responsible for the impact it has had on others around him and wishes to make amends for any harm caused. It is RP's turn to do something for others, and his consideration of this is an indication of how far he feels he has come. Giving something back is a celebration of his new found ability to do so.

RP's gratitude extends beyond the support provided by others to the foundations of the procedure itself:

"I just feel like the luckiest guy in the world, I just feel so, so lucky, not so much even just having (DP) do that for me, just for the fact that this could even be done in the first place, that that sort of operation is available, that the surgeons have got those talents to do that, we still haven't got our head around it."

RP has always been appreciative of his wife's offer to donate but the realization of how lucky he is to have had the option of LDLT at all is only really apparent now it is over. That LDLT is possible and was possible at Edinburgh was a lucky circumstance for RP's unfortunate situation and he is grateful to have had the opportunity.

6.8.2.2.3.2 A fresh start

RP's life turned a corner when he received a transplant and the resulting change of direction is one for the better:

"…it's the fact that I'm getting better instead of getting worse. I'm getting better, that's really hard to describe how good that feels, because I feel like my life was over and now I've started it all over again, it feels like starting afresh but better than before."

Prior to the operation RP was "just surviving" and not really living his life but the transplant has given life to his existence and his experience of deterioration and waiting can now be put behind him. RP feels like a new person.

For RP the new, fresh start to life that the transplant has signified is specifically one without Primary Sclerosing Cholangitis (PSC):

"I would say my general health, I'm the best I've been for three or four years but I can see myself once this (the hernia) is fixed, I actually feel like I'm going to be better than I've ever been because I got sick when I was a teenager, I wasn't fully grown, so pretty much the whole time I've been an adult I've had this condition, so its like the ceiling's been raised on how good I can actually feel…"

Since a young age RP has had to make allowances for the fact that he has had a damaged liver whereas now the liver in his body is healthy and therefore RP believes *"there's nothing to hold me back now"*. RP's previous level of normal functioning has always been restricted by the condition of the liver and so without it he can surpass his expectations and reach a new level of 'normal'.

Like DP, RP also described an even closer relationship with his wife following the procedure which is accentuated by the future possibilities now open to them as a couple:

"…I can't be anything but just be in absolute awe of her because of what she's done for me, but on top of that the fact that we've got this life to look forward to together

as well, its just there with me all the time. She's had a lot of stressful exams and stuff but we know in the end its all going to be worth it because we've got this life to start planning, so at the moment it still feels like, we're just waiting to get out of the gates…"

LDLT has given RP the opportunity to have a new life with his wife and he is eager to get started. RP may continue to have mixed feelings of guilt and gratitude towards his wife, but the positive result of the procedure puts any negative aspects into perspective. Control over his life has been regained and a positive future is in sight for RP and his wife.

6.9 Discussion

The patterns of responses obtained from the quantitative measures have illustrated the changes in functional and psychosocial wellbeing experienced by Scotland's first living liver donor and recipient. The use of qualitative data has allowed a more detailed interpretation of the quantitative results and has provided supplementary information about the LDLT experience.

Similar to previous research carried out with recipients of a deceased liver donation, LDLT has resulted in a marked improvement in quality of life (QoL) for the recipient (Bravata & Keefe, 2001) (O'Carroll et al, 2003). At 6 weeks and by 6 months post LDLT, the recipient demonstrated improvement from pre LDLT results in physical and psychosocial aspects. The results of the qualitative interviews further illustrate this transition as the recipient first described his physical and cognitive deterioration and its adverse impact on his quality of life and then later described feeling physically and mentally like a new person with a positive attitude and excitement about the future.

We know from the interviews that the improvement shown at 6 weeks was limited in light of the recipient's slow recovery. The difficulties and *"post transplant blues"* experienced by the recipient shortly following the transplant could not be identified by the quantitative measures alone, but they were revealed through the qualitative measures and can enhance interpretation of the results.

For the donor, as found in previous research, the procedure did not have a profound adverse effect on her QOL, and she remained above the norm on physical health at 6 months post donation (Feltrin et al, 2008; Kim-Schluger et al, 2002; Pascher et al, 2002; Trotter et al, 2001). However, at 6 weeks post LDLT, the donor was found to have experienced some deterioration in physical and psychosocial abilities and corresponding satisfaction. Whilst improvements were made by 6 months post LDLT the level did not always return to the donor's premorbid baseline levels. At 6 months the donor continued to experience a degree of psychosocial disability, as indicated on the FLP, but her satisfaction with this aspect of her life surpassed her pre-operation levels, as indicated on the WHOQOL. This highlights the important distinction between disability and quality of life: disability does not necessarily result in impaired quality of life. The interview data confirms this finding as any limitations and restrictions experienced at 6 months post LDLT were played down by the donor when considered alongside the benefits of having her husband back to a positive state of health.

Other similarities with previous studies were found regarding the donor's experience of body image changes, continuing abdominal pain, an enhanced relationship with the recipient and feeling personal benefit from donating (Kim-Schluger et al, 2002; Trotter et al, 2001). This study however, has allowed more details about these changes and their exact nature and connections to surface. It has been shown that the experience of change in body image was predominantly surrounding the appearance of the scar. However, whilst the appearance becomes less of a concern over time, the pain, due to its unexpected duration and uncertain cause, is of increased concern. Whilst we know that relationship improvements and personal benefits are possible following donation, in this study, and in others, it was the initial quality of this relationship and the anticipation of personal gain that originally motivated the donor’s decision to donate (Kusakabe et al, 2008; Papachristou et al, 2004).

Previous studies have indicated that the majority of donors would, upon reflection, donate again and this is replicated in this study (Kim-Schluger et al, 2002; Parolin, Lazzaretti, Lima, Freitas, Matias, & Coelho, 2004; Sevmis, Diken, Boyvat, Torgay, & Haberal, 2007; Trotter et al, 2001). However, by using a continuous scale the results of this study indicate that the conviction of this response can be challenged. Whilst the donor agrees that she would donate part of her liver again, she is never 100% certain of this choice but instead goes from 72% definite in her positive response at 6 weeks, to only 58% by 6 months. From the interview transcripts an explanation for her response can be offered in that she would donate part of her liver again if it were possible, because of the positive result of having her husband back, but the general impact donating has had on her body and the pain she is continuing to have around the scar site serves to increase her reluctance to go through LDLT again.

Although the Illness Perception Questionnaire-Revised (IPQ-R) was included in the questionnaire pack (see Chapter 2: Methodology), results are not reported in this study due to interpretation problems by the participants[6]. Such problems were predominantly noted in the larger study on Living Donor Kidney Transplantation (Chapter 8) but were echoed in this single-case study. For example, confusion surrounding the meaning of the term ‘condition’ used in the measure, reduced the authors confidence in participant responses and therefore the decision was made to not include the results of the IPQ-R in either chapter. Further explanation for the removal of the IPQ-R is offered in Chapter 8, (section 8.6.3) and in the General discussion (Chapter 9, section 9.9).

Important illness perceptions were, however, clearly identified within each interview and were found to be important influences on the donor and recipient’s coping strategies and quality of life. For example, the recipient’s personal control over his illness and symptoms became more and more limited as the disease progressed, but RP perceived he had a personal role to play in his condition and continued to force himself to gain weight and keep his mind active, maintaining an element of control. With regard to treatment control, it is evident that RP understood the importance of transplantation in curing his illness and this impacted his decision to accept LDLT. Likewise, it could be said that DP felt she had personal control over the course of her husband’s condition and reacted by offering to donate, the ultimate treatment option for RP.

Of particular interest was the donor and recipient’s reference to the timeline of their individual illness / condition and, in accordance with Leventhal’s Self Regulation Model, how such beliefs impacted on coping strategies and recovery (Leventhal et

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[6] Measures of recovery locus of control, optimism and self efficacy were also included in the pre LDLT questionnaire pack but are not reported due to the statistical limitations which became apparent when the study design converted to a single case study.

al, 1984). Both the donor and recipient had expectations about their recovery that were unmet. Whilst the recipient expected to feel better and full of energy immediately following the transplant, his expectations were not fulfilled and RP became depressed with the reality of his situation. However, RP regained a positive perspective and, consequently, his quality of life was perceived to improve. Likewise, the donor had not expected to still have pain and numbness at the scar site at 6 months. The pain was described as holding her back from a complete return to normality as she had to amend her lifestyle to accommodate the pain. Furthermore, her psychosocial daily functioning, as measured by the FLP, had not returned to its previous excellent baseline level at 6 months post operation. This can be interpreted from the interview data as a direct result of her continuing scar pain. The donor's recovery was therefore affected by her beliefs regarding the duration of her condition.

The results from the neuropsychological measures were disappointing. Previous research has indicated problems in cognitive functioning with liver transplant candidates, who show signs of improvement following a successful deceased donation (O'Carroll et al, 2003; O'Carroll et al, 2008). However, the recipient in this case study performed either at a similar or better level than the healthy donor at the pre-operation assessment and this continued post operation. Such results are despite the recipient's obvious weakness, fatigue, and memory problems described during the interview conducted prior to transplant. It may be that the neuropsychological measures employed in this study were not adequately sensitive, limiting our conclusions.

6.9.1 Limitations

A further limitation of this case study relates to the timing of assessments. Whilst this study is one of the few to assess patients at 6 weeks and 6 months post procedure, it is noted that an assessment closer to completion of the operation would have quantified the initial physical and psychosocial problems indicated retrospectively in the interviews. Similarly, to follow the donor and recipient after 6 months post LDLT would also have helped establish if and when a complete return to normality was achieved. A previous study assessing donors as early as 1 week post LDLT and as late as 1 year post LDLT, using the SF36, indicates that whilst significant physical deterioration resulted at 1 week, donors returned to pre donation baseline levels at 1 year (Verbesey, Simpson, Pomposelli, Richman, Bracken, Garrigan et al, 2005).

The main limitation is in relation to the characteristics of a single-case study. The relationship, age, gender, and lack of dependents are variables that are likely to have affected the course of LDLT for this couple and therefore it is not possible to generalize the results to other LDLT procedures. The strength of the case study method has succeeded in providing in-depth detailed data on the participants' beliefs, reactions and outcomes and this will serve to guide the information, advice and support offered to future LDLT candidates.

6.9.2 Advice for unit

Possible general advice that could be provided to the transplant team at the Scottish liver transplant unit (SLTU) as a result of the outcome of this case study includes:

- Prepare donor for deterioration in quality of life to remain 6 weeks post LDLT with subsequent improvement by 6 months.

- Prior to the procedure assess the donor and recipient’s expectations for personal recovery and provide them with realistic possible outcomes, including both major and minor complications (i.e. continued pain around the scar area and non immediate transformations post transplant).

- Be aware of the donor feeling used post transplant and either prepare the potential donor for a reduction in attention and/or make regular post donation medical checks compulsory.

Chapter 7 Living donor organ transplantation: the effect of message frame on an altruistic behaviour.

7.1 Abstract

Objectives: The shortage of donated organs for transplant is an ongoing public health concern. In an attempt to increase the donor pool living organ donation, has been introduced. This may be regarded as an altruistic act as the healthy donor must incur a high cost for little direct benefit to themselves: the benefit is predominantly for the recipient. Cost is an important factor as people are less willing to help another as the cost of helping increases. Therefore, cost is a potential barrier to living organ donation and it is important to understand how perceptions of cost can be influenced. Using framing theory, it is proposed that low cost behaviours would be more influenced by a gain frame and high cost behaviours by a loss frame. This study compared the influence of gain and loss framed messages on willingness to donate an organ from a low cost (kidney donation) and a high cost (liver donation) perspective.

Design: A 2 (frame: gain vs. loss) by 2 (organ cost: liver vs kidney) by 2 (involvement: involved vs not involved) between-group study involving a UK sample of 87 healthy participants was conducted.

Method: Participation involved completion of a short questionnaire after reading a vignette inviting participants to consider living kidney or living liver donation.

Results: Results indicated that gain frames increased the likelihood of an altruistic act towards kin for low cost donations (kidney donation) only. For high cost behaviours (liver donation) there was no significant effect of frame.

Conclusion: The results have implications for the generalisation of framing theories and the promotion of living kidney and living liver donation.

7.2 Introduction

The shortage of donated organs for transplant is an ongoing public health concern. As supply continues to fall well short of demand, many patients on the transplant waiting lists are consequently dying before a suitable organ is found (Abouna, 2008). In an attempt to improve the situation and increase the availability of organs fit for transplant, medical procedures have been developed which allow a healthy, living person to donate an organ.

Living organ donation involves a person donating an organ (e.g. a kidney) or part of an organ (e.g. lobe of a liver). This is in contrast to a standard cadaver donation which occurs following death. The living donation procedure originally required that there be a genetic relationship between the donor and the recipient mainly to minimize possible rejection of the foreign organ within the recipient. However, advances in immunosuppressant medication have allowed non-kin donations. To donate an organ to a family member, friend or stranger may be regarded as a classic altruistic act as the donor puts themselves at great risk for no direct benefit to themselves but rather for the purpose of benefiting another person. Whilst altruistic donation of an organ can be to non-kin, these are more likely to be to kin and as such this study examines kin based donation.

Kin selection theory is one dominant theory for the evolution of altruism, which may explain helping towards kin (Hamilton, 1964). Kin selection theory proposes that the extent of help provided is based on a ratio of the cost to the individual donor relative to the benefit to the recipient as a function of the degree of genetic relatedness between the donor and recipient (Hamilton, 1964: see Lehmann & Keller, 2006; Bshary & Bergmüller, 2008; Nowak, 2006 for reviews). An important parameter in the above is the cost to the donor, indeed the Arousal: Cost-Reward model suggests, and is supported by data, that people are less willing to help as cost increases (Dovidio, Piliavin, Gaertner, Schroeder, & Clark, 1991; Penner, Fritzsche, Craiger, & Frefield, 1995). This model also suggests that personal cost is more important to decision making than the cost of not helping the recipient (Dovidio et al, 1991). Therefore, donors should be less willing to donate to a relative as the cost of donation increases. If this is the case, donors will be less willing to consider certain high cost donations such as live liver donation and more willing to consider low cost donations such as a kidney donation. Consequently, there is a need to explore theoretical models that help us to gain a better understanding on how information about costs (and benefits) of donation may be expressed to potential donors to overcome the barrier that high cost donation will entail. Indeed, from a theoretical perspective it is important to know if the strong evolutionary force of costs can be influenced in the context of kinship donation. Furthermore, the extent to which the costs/risks are understood by potential donors was questioned in Chapter 3 (Attitudes towards LDLT), and in Chapter 4 (Considering LDLT) the risk to the healthy donor itself was found to be the main deterrent towards the uptake of living liver donation specifically (McGregor et al, 2008; McGregor, Swanson, Hayes, Forsythe, & O'Carroll, 2009; Neuberger & Price, 2003). It, therefore, becomes important to know if interventions that focus on perceptions of costs/risk can be used to increase understanding of risk and possible acceptance of living organ donation. To this end the experiment reported here explores how message framing within the context of living kidney (low cost) and living liver (high cost) donation influences the expressed willingness to donate to a relative. This is the first ever experimental application of framing to an altruistic behaviour directed towards a specific other. It, therefore, has implications for (1) the generalisation of framing theories, (2) the extent to which the effect of cost on altruistic behaviours is immutable or can be changed by a simple cognitive framing intervention and (3) practical recommendations for transplant services.

7.2.1 Costs and benefits

Living organ donation is performed for the purpose of benefiting the recipient but involves a corresponding cost for the healthy donor. Whilst Living Donor Liver Transplantation (LDLT) and Living Donor Kidney Transplantation (LDKT) have similarities in principle, they differ in terms of the estimated risk of death for the donor. LDKT has a donor mortality rate of approximately 1 in 3000, whilst, in contrast, LDLT donors are thought to have a 1 in 200 chance of dying as a result of the donation (see Chapter 1: General Introduction for more details on LDLT and LDKT).

As the risks/costs of a donation are a key feature that will be discussed between both potential recipients, donors and clinicians, theoretical models of decision making that focus on risk as a key element are of particular importance in this context. Theoretical models concerning framing effects explicitly incorporate the concept of risk as an explanatory variable moderating the relationship between how information is presented and cognition and behaviour (Kahneman & Tversky, 1979; Rothman & Salovey, 1997; Ferguson & Gallagher, 2007). As such, the experiment reported here applies framing theory to understanding people’s willingness to become a liver of kidney donor or recipient.

7.2.2 Framing effects

Message framing effects refer to the different reactions or behaviours elicited when information is presented either as gains (e.g. 40% chance of survival) or losses (e.g. 60% chance of death) (Kahneman & Tversky, 1979). People are risk seeking (prefer to take a gamble over a certainty) when information is presented as losses and risk averse (prefer a certainty over a gamble) when presented with gains (Kahneman & Tversky, 1979). Developing this concept to the domain of health promotion, Rothman and Salovey (1997) suggested that frame valence is moderated by the perceived risk associated with the health behaviour. The basic prediction is that a loss frame advantage will be observed for risky behaviours. That is, people will be more likely to adopt a high risk behaviour (e.g. health screening, whereby an individual has an increased chance of detecting a serious health problem) if the message is loss framed. Conversely, low risk behaviours (e.g. sun screen use whereby an individual acts to prevent a future health problem) should show a gain frame advantage. There is now considerable evidence to support this basic prediction (Ferguson & Gallagher, 2007). Based on this theory, the simple prediction tested here is that people will be more willing to proceed with living kidney donation (low risk) when presented with gain frames and living liver donation (high risk) when presented with a loss frame. However, the application of framing in previous studies is based on self-directed perceptions and ultimately focused on personal benefits (clear health screen, prevention of cancer etc.). The current study is novel in that it is set within the context of an altruistic other-directed health behaviour where there is a complex mix of benefits and cost to the self, set firmly with the context of benefit to the other. In this case the cost-benefit, or risk analysis, is not just selfishly about personal beneficial outcomes but about the beneficial outcome for another. People may be happy to experience higher level of personal risk (high cost) if it is going to benefit another. However, the Arousal: Cost-Reward model suggests that personal costs loom large when making altruistic decisions (Dovidio et al., 1991). Thus the application of altruistic health behaviour allows consideration of a number of new predictions and extensions to framing theory which are detailed below.

7.2.3 Altruism and Framing Effects

Previously, framing studies in the health domain have focused on individual-self-directed behavioural change such as screening attendance, smoking cessation, vaccination etc. (Küberger, 1998; Rothman & Salovey, 1997). However, a large part of the activity of health services is based on engaging people to behave on behalf of others (e.g., organ donation, blood donation, charitable donations, volunteer work). There are a series of studies that have examined framing effects with respect to helping groups of strangers or kin (Wang, 1996a; Wang, 1996b; Wang, Simons, & Bredart, 2001). These show that the preference for risk seeking increases in the presence of kin. However, these studies do not focus on the decision to help a single relative in the health domain.

To date, there is only one paper that has applied framing to a health related altruistic behaviour (Ferguson, Farrell, & Lawrence, 2008). Ferguson et al (2008) applied framing to the willingness to donate blood and drew a parallel between cost to the donor and personal risk to the donor, with blood donation seen as a high risk behaviour. Following on from Rothman and Salovey (1997) it was predicted that loss framed information would promote willingness to donate blood. However, no framing effects were found. There are a number of possible reasons for this. First, theoretically, costs within an altruistic scenario may not directly equate to personal risk as they are based within the context of benefits to others and not just the self. Behaviours where personal risk is high, such as in health screening, also have the potential for personal benefit (e.g., a negative result or early detection). For organ donation the personal benefit for the donor is less obvious than the recipients' benefit. As such, while the cost is high, direct personal benefit remains low. The Altruism: Cost-Reward hypothesis suggests that personal cost dominates the decision making, therefore when cost is high the potential donor is unwilling to donate (Ferguson et al, 2008). Conversely, for low cost helping, even when personal benefit is low, any additional information provided may help to highlight personal benefits, especially if that information is gain framed, and this should encourage helping. Thus, in contrast to the Rothman and Salovey's (1997) model, it is hypothesized that for altruistic helping a framing effect will only be observed for low cost donation and this will be a gain frame advantage. For the recipient of an organ this relationship is different, while there is a cost associated with any transplant, the personal benefits are higher, indeed the cost of not having the transplant outweighs any cost associated with the transplant. As such, it is predicted that any effect of cost should be observed only for a scenario that focuses on donation as opposed to receiving an organ.

Second, within the Ferguson et al (2008) study the frames focused on gains and losses associated with personal emotions and rewards (egoism) from donation, or gains and losses associated with helping others (altruism). As such, the frames did not focus on specific behavioural gains and loses, such a death and survival rates, which are often used in framed messages (Rothman & Salovey, 1997).

Third, the Ferguson et al (2008) paper focused on blood donation which focuses explicitly on altruism towards a stranger which cannot necessarily be explained by standard evolutionary models. Therefore, the present experiment is set within the context of one important model of human altruism, kin selection, where cost-benefit ratios are central (Bshary & Bergmüller, 2008). This experiment, therefore, examines willingness to make a high cost (liver) and low cost (kidney) live organ donation (or to be a recipient of a donation) amongst relatives, and tests if this cost-willingness relationship is moderated by the use of gain or loss framed information.

7.2.4 Issue Involvement

A final key variable that is known to enhance framing effects is issue involvement (Millar & Millar, 2000). Specifically, involvement is believed to increase the amount of central processing that individuals will pay to the information provided (Petty & Cacioppo, 1986). Within the context of blood donation, Ferguson et al (2008) equated issue involvement to the degree of commitment to donate. In the context of organ donation in the UK this would be equivalent to registering to be an organ donor. Therefore, we established whether or not participants were currently on the NHS organ donor register.

7.3 Hypotheses

1. Following Rothman and Salovey (1997): Participants will be more willing to consider donating a liver (high risk) when a loss frame is used and more willing to consider donating a kidney (low risk) when a gain frame is used.

2. Following Arousal: Cost-Reward Model: Participants will be less willing to donate a liver (high risk) than a kidney (low risk). A framing effect will only be found with kidney donation.

3. Message framing effects will be stronger for participants currently on the NHS organ donor register.

7.4 Method

7.4.1 Pilot study

Despite both involving the donation of an organ from a healthy individual, as described in the introduction, living kidney and living liver donation differ on a number of levels which makes living kidney donation a relatively low cost procedure for a donor and by comparison, living liver donation a high cost procedure for a donor. Prior to commencing the main study, it was considered important to confirm this low cost/high cost distinction between the two types of organ donation within a sample of non-medical professionals. This would enable the hypothesis that willingness to donate and receive a living organ donation will differ as a function of cost to be tested in the main study.

7.4.1.1 Design

A one-way between subject design was employed within this study. Participation involved the independent completion of one of two short questionnaires. Both questionnaires followed an identical format differing only in respect to the subject matter i.e. living kidney donation (N = 36) or living liver donation (N = 31). The kidney and liver questionnaires were blindly distributed to participants.

7.4.1.2 Participants

Students from the University of Nottingham were asked to participate and 67 agreed, completed and returned the questionnaire. The male to female ratio in the kidney and liver groups were 34:1 and 28:1 respectively (gender was not disclosed on 3 questionnaires). The average age of participants was 20.5 years (SD = 1.78, Range 19-28) for the kidney group and 21.06 years (SD = 4.01, Range 19-42) for the liver group. The front page of each questionnaire included information about the study and stated that consent to participate was determined following the return of a completed questionnaire.

7.4.1.3 Measure

The questionnaires consisted of a short vignette giving general information about either living kidney or living liver donation, followed by 10 questions regarding the recipient and then the same 10 questions regarding the donor. Both sets of questions followed the same format*: How likely is it that the recipient/donor will, as a result of the living donor liver transplant procedure…* 1) *have good health?;* 2*) have improved health?;* 3) *have deterioration in their health?*; 4) *live longer?*; 5*) have future liver/kidney complications?*; 6) *have pain?*, and 7) *die?* Questions 9 to 11 asked about the level of overall perceived personal cost of living kidney/liver donation for the recipient/donor; the level of overall perceived personal benefit of living kidney/liver donation for the recipient/donor, and the perceived riskiness of living kidney/liver donation for the recipient/donor, respectively. All questions required responses to be made a 7 point scale (e.g.1 = Not at all likely to 7 = extremely likely).

7.4.1.4 Results

The perceived risk to the donor was significantly higher for the liver group (M = 5.2, SD = 0.96) compared to the kidney group (M = 4.31, SD = 1.17); t (64) = -3.35, p = 0.001. There was no significant difference with regards the perceived risk to the recipient. This confirms that LDLT is perceived to be a riskier procedure for the donor than LDKT, and each may therefore legitimately be described as high risk and low risk respectively.

A health consequence score was calculated by subtracting the participants' response to question 3 (*How likely is it that the donor will, as a result of the living donor kidney / liver transplant procedure, have deterioration in their health?*) from responses to question 2 (*How likely is it that the donor will, as a result of the living donor kidney / liver transplant procedure have improved health?*). Positive scores consequently indicated a relative improvement in health and a negative score, a relative deterioration in health. Results show that the health consequence score for a living liver donor (M = -2.17, SD = 1.97) was significantly lower than that for a living kidney donor (M = -1.19, SD = 1.86); t (64) = 2.06, p = 0.04. This confirms that the LDLT donor is perceived as significantly more likely to have their health compromised compared to a LDKT donor. Therefore, to consider liver donation as high cost and living kidney donation as low cost is a valid distinction. When considering a medical procedure, the effect on a person's health may be a more salient consideration than the global costs and benefits of the procedure. From an overall perspective both procedures were described in the vignette to involve an operation for a healthy individual for the benefit of the recipient. Therefore no significant differences between groups were found for the two questions on general costs and benefits but rather a significant difference was found when the health of the donor was specifically addressed. The results were not influenced by gender of the participants.

7.4.2 Main Study

7.4.2.1 Design:

A 2 (frame: gain vs. loss) by 2 (organ cost: liver vs kidney) by 2 (involvement: involved vs not involved) between-subjects design was employed. Participants were randomly allocated to one of four groups corresponding to the frame and organ: gain/liver (n = 21); loss/liver (n = 24); gain/kidney (n = 22), and loss/kidney (n = 20). A questionnaire specific to each group was designed following the format described below. A total of 50 questionnaires of each design were printed, randomly collated together and blindly distributed to students at the University of Stirling. Course credit points were awarded to students on completion of the questionnaire. Participants returned self completed questionnaires either to their lecturer or directly to the author via the university internal mail system. Issue involvement was classified according to whether or not participants indicated that they were currently on the NHS organ donor register. Ethical approval was granted by the Departmental Ethics Committee (letter dated, March 17th 2008).

7.4.2.2 Participants:

Of the 200 questionnaires prepared 114 (57.0%) were collected by potential participants and 87 (76.32%) completed questionnaires were subsequently returned. Participants consisted of 9 males and 69 females (indication of gender was missing from 9 questionnaires) with an average age of 23.02 years (SD = 6.64; range = 18-48)[7]. For demographic details of each group by organ and frame see Table 7.1.

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[7] Mann-Whitney tests indicated that there were no significant difference as a function of sex on any of the main study outcome variable (all Z test < -.025 and all p values > .923).

Table 7-1: Participant demographic details by group

	Liver		Kidney	
	Gain	Loss	Gain	Loss
N	21	24	22	20
Age in years (SD)	24.14 (6.94)	22.21 (5.92)	23.43 (7.22)[a]	23.15 (6.86)
Age range	19-46	18-48	19-45	19-44
Gender (M:F)	3:16[b]	3:20[c]	1:16[d]	2:17[e]

[a]1 participant failed to indicate age. [b,c,d,e] 2, 1, 5, and1 participant failed to indicate gender respectively.

Table 7.2 lists additional group characteristics. The groups significantly differed on one variable: the proportion of participants in the kidney group who had heard of LDKT was significantly different to the proportion in the liver group who had heard of LDLT. A consent form to be read and signed was attached to the front of the questionnaire but removed prior to marking to ensure anonymity.

Table 7-2: Additional participant characteristics

	Liver		Kidney	
	Yes	No	Yes	No
Are you currently on the NHS organ donor register?	47.7%	52.3%	48.8%	51.2%
Before taking part in this study had you ever heard of living liver/kidney donation? *	66.7%	33.3%	90.2%	9.8%
If yes, on a scale of 1 to 7, how much do you know about living liver/kidney donation? (mean (SD))	3.33 (1.30)		3.30 (1.27)	
Is someone in your close friends or family currently on an organ transplant waiting list?	0%	100%	4.8%	95.2%
Has anyone in your close friends or family ever received an organ transplant?	13.3%	86.7%	2.4%	97.6%

* $p<0.05$

7.4.2.3 Framing manipulation

Participants individually read a short vignette corresponding to the organ and frame characteristics of their assigned group. Each vignette was designed to initially persuade participants to consider the information from the point of view of becoming a potential donor to a relative (see Box 7.1 and Box 7.2 for the LDLT and LDKT vignettes respectively).

Box 7-1: Vignette for LDLT group

Your relative has been diagnosed with end stage liver disease (non-alcohol related) and you have been informed that they have been placed on the liver transplant waiting list. A liver transplant is the only treatment for their disease.

Your relative is provided with an information pack detailing the option of living donor liver transplantation. Living donor liver transplantation allows a healthy family member to donate approximately 60% of their liver to a relative in need. Both the part that remains in the donor and the part that is received by the patient will grow again to its original size.

The other option is a deceased donation whereby your relative will be on the transplant waiting list until, hopefully, a liver suitable for them is donated from a person who has just died.

With living donor liver transplantation, it is estimated that for every 200 people who donate part of their liver to a relative on the transplant waiting list,….

For those in the **gain frame** group the last sentence is completed with:

……..199 will survive the procedure.

For those in the **loss frame** group the last sentence is completed with:

……..1 will die as a result of the procedure.

Participants were asked to imagine themselves as ‘a relative of a person with kidney/liver disease’ and answer a question on their willingness to donate. In addition, participants were asked to imagine themselves as ‘a patient with kidney / liver disease’ and answer a similar question regarding their willingness to accept a living donation. Participants were asked to consider actions from the perspective of being a donor and a recipient to gauge their cost-benefit judgments and calculate an altruism index (AI) (see section 1.4.2.4.3 below). The order in which each role was to be imagined was counterbalanced within the design of the questionnaire.

Box 7-2: Vignette for LDKT group

Your relative has been diagnosed with end stage kidney disease and you have been informed that they have been placed on the kidney transplant waiting list. Until a new kidney is found for them, they will need to go on dialysis three days a week. During dialysis they will be attached to a large machine that performs the function of a kidney for them.

Your relative is provided with an information pack detailing the option of living donor kidney transplantation. Living donor kidney transplantation allows a healthy family member to donate one of their kidneys to a relative in need. The kidney that is donated and the kidney that remains in the donor will each function as adequately as two healthy kidneys.

The other option is a deceased donation whereby your relative will be on the transplant waiting list until, hopefully, a kidney suitable for them is donated from a person who has just died.

With living donor kidney transplantation, it is estimated that for every 3000 people who donate one of their kidneys to a relative on the transplant waiting list,…

For those in the **gain frame** group the last sentence was completed with:

……..2999 will survive the procedure.

For those in the **loss frame** group the last sentence was completed with:

……..1 will die as a result of the procedure.

7.4.2.4 Measures

7.4.2.4.1 Manipulation Checks

To assess if the vignette manipulations were successful, the following questions were asked: *Do you find the information presented above positive or negative?* , and *Do you feel the information presented above emphasised the costs or benefits of living kidney/liver donation?* Response options were positive or negative and costs or benefits respectively.

In addition, the following questions were asked: *How easy was the above information to read?*: *How easy is the above information to understand?*, and *How* *easy is the above information to remember?* All responses were made on 1 to 5 scales.

7.4.2.4.2 Behavioural intentions

Participants were asked about their intention or willingness to become a living donor or to receive a living donation. Within the SLTU, the first step towards becoming a donor is to speak to a member of the medical team to obtain more information about the process and confirm donor eligibility (e.g. compatible blood type). Therefore the following question was presented to participants: *How likely would you be to talk to the doctors about donating one of your kidneys / part of you liver to your sick relative?'* All questions were answered on a 7 point scale (1 = Not at all likely to 7 = Definitely likely).

Participant's intention to be a recipient of a living donation was assessed with the question: *How likely would you be to talk to the doctors about opting for living donor kidney / liver transplantation?* All questions were answered on a 7 point scale (1 = Not at all likely to 7 = Definitely likely).

7.4.2.4.3 Altruism

Using the responses from the above two questions, an altruism index (AI) was calculated by subtracting the willingness to be a recipient from that to be a donor. A positive score indicates that people are more willing to donate than to receive (altruistic) and a negative value indicates a greater willingness to receive than to give (a selfish orientation).

7.4.2.5 Results

A series of 3-way between-group ANOVAs were conducted to establish the impact of message frame, type of organ, and issue involvement on intention to donate, intention to receive, and altruism.

7.4.2.5.1 Manipulation checks

The proportion of participants in the gain frame group who believed the information was positive was significantly higher than the proportion of participants in the loss frame group (χ^2 (1) = 5.59, p = 0.02). Within the gain frame group 95.2% believed the information was positive compared to 74.4% of the loss frame group.

The proportion of participants within the gain frame group and the loss frame group, who believed the information presented in the vignette emphasised the benefits were significantly different (χ^2 (1) = 10.97, $p < 0.01$). A total of 97.6% in the positive group believed the information emphasised the benefits compared to 68.2% in the negative frame group.

The vignette itself was considered easy to read (M = 4.24, SD = 0.84); easy to understand (M = 4.34, 0.79), and the information within the vignette was perceived to be easy to remember (M = 3.97, SD = 0.87). In addition, the information presented within the vignette was considered to be fairly accurate (M = 3.66, SD = 0.61). Opinions regarding the kidney vignette and the liver vignette were not significantly different. As such, any differences are not attributable to other textual factors.

7.4.2.5.2 Behavioural intentions

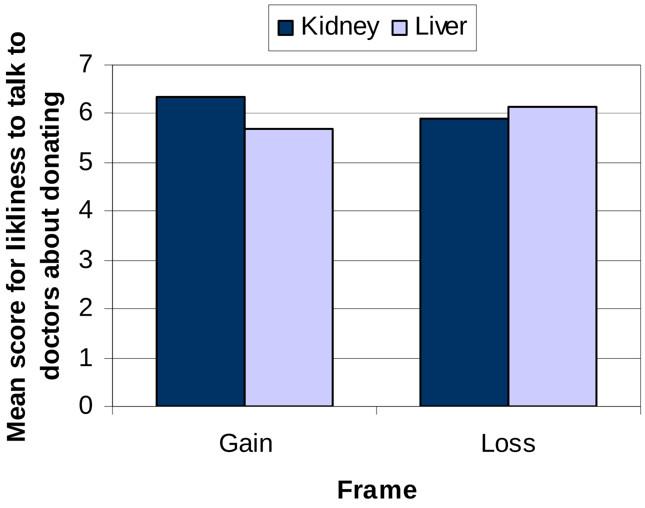
With regards willingness to become a living donor, there was a statistically significant main effect for NHS registration, F(1, 77) = 8.66, $p < 0.01$, $\eta p^2 = 0.10$.

Those currently on the NHS organ donor register were significantly more likely than those not currently on the NHS organ donor register to talk to the doctors about donating to a sick relative (M = 6.34, SE = 0.17 and M = 5.66, SE = 0.16 respectively). There was no significant main effect of organ or frame.

There was a significant 2-way interaction between organ and frame, F(1,77) = 4.68, p = 0.03, $\eta p^2 = 0.06$. Decomposing this interaction showed that for those exposed to a gain frame, the kidney (low risk/cost) group (M = 6.36, SD = 0.95) were more willing to donate compared to the liver (high risk/cost) group (M = 5.67, SD = 1.24) (t (41) = 2.07, p = .04, $\eta^2 = 0.10$) (see Figure 7-1).

With respect to willingness to be a recipient of a living organ transplant there were no significant main or interactive effects for frame, involvement or organ type. As such, all significant effects relate to altruistic decisions to donate and not to receive.

Figure 7-1: Behavioural Intention: How likely would you be to talk to the doctors about donating? (Organ*Frame)

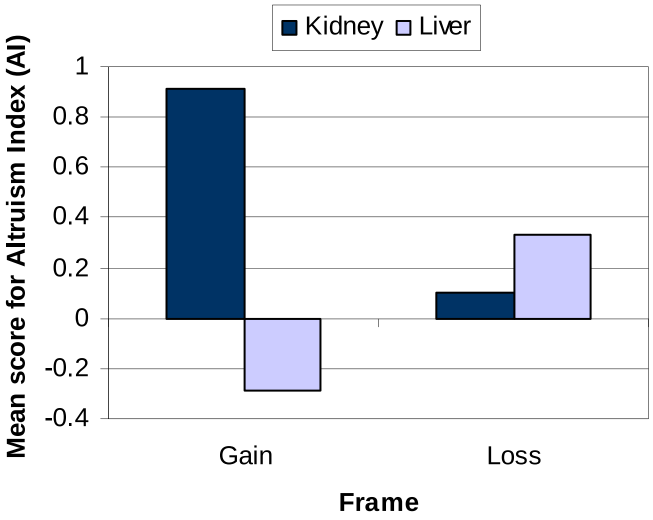


7.4.2.5.3 Altruism

For the Altruism Index (AI) there was a significant main effect for NHS organ donor registration F (1, 77) = 7.86, p = .006, $\eta p^2 = 0.09$. Those currently on the NHS organ donor register showing a higher and positive AI compared to those not currently on the register, who demonstrated a negative AI (selfish orientation). There was no significant main effect of organ or frame.

A significant 2-way interaction between frame and organ was found, F (1,77) = 5.07, p = .03, $\eta p^2 = .06$. Decomposing this interaction showed that within the gain frame, the kidney (low risk/cost) condition (M = 0.91, SD = 1.51) had a significantly increased altruistic tendency compared to the liver (high risk/cost) condition (M = -0.29, SD = 1.68), t (41) = 2.46, p = .018, $\eta^2 = 0.13$). There were no other significant differences within the interaction (see Figure 7-2).

Figure 7-2: Altruism Index (Organ*Frame)



7.5 Discussion

This is the first study to show that altruistic choice towards kin was influenced by the type of donation (high versus low cost donation) and how the information about the donation is framed. However, the results showed that it was only low cost donations that were influenced by gain frames, such that for low cost behaviours (kidney donation) the use of gain frames increases willingness to donate and altruistic tendency (more willing to donate than to receive) towards kin. For high cost behaviours (liver donation) there was no significant effect of frame.

On the surface these results show partial support for Rothman and Salovey’s (1997) theory if risk is equated completely with cost. In accordance with this theory, a gain frame advantage was found for the low risk/cost donation of a kidney, although the predicted loss frame advantage for a high risk/cost donation of a liver lobe was not found.

The hypothesis relating to the Arousal: Cost-Reward model was also only partially supported. The difference in willingness to donate a liver and a kidney was not significantly different but a framing effect was found with the low risk procedure only.

This partial framing effect is consistent with our theorizing that costs within an altruistic scenario are not directly equated to personal risk. Behaviour with personal risk (such as health screening) also has the potential for personal benefit but the personal benefit is less obvious with organ donation. As such, when cost is high (and benefit low) it is argued that cost dominates the decision making and external information has no effect (Ferguson et al, 2008). For low cost helping, even when personal benefit is low, the additional information may help to highlight benefits (especially if it is gain frame as this highlights risk avoidance and moves the person towards acting in the direction of a low risk behaviour) and this should encourage helping. The pattern of results supports this. When cost is high people’s altruistic choices may require different frames such as those that emphasize more egoistic outcomes (Ferguson et al, 2008). Conversely, for the recipient where the cost of inaction is much greater than action (having the transplant) then the effect of frame is less relevant here as the contrast between the two alternatives is very stark.

The results have significant implications for the promotion of both living kidney donation and living liver donation to the general public, and needs to be investigated further. Receiving a living donation has advantages over a deceased donation (i.e. less time on the waiting list) therefore the correct promotion of living donation as an option to patients and potential donors is important. However, despite the general similarities of the two procedures (i.e. the risk to a healthy donor), the results of this study suggest their promotion may require quite different foci if the number of potential living donors, willing to look into donation, is to be optimised.

A consistent finding is the main effect of NHS organ donor registration. Participants who were on the organ donor register, stated that they would be more likely to talk to doctors about donating and considered the overall risk to the donor to be lower, when compared to those not on the NHS organ donor register. This perhaps suggests that a more positive attitude towards organ donation *in general* can lead to more positive perceptions of living donation. Therefore, the continued promotion of deceased organ donation should be encouraged as it may subsequently promote favourable attitudes towards living organ donation. However, an alternative explanation could be that individuals who are more favourable towards living donation are already registered.

7.5.1 Limitations

Within this study, despite the fact that the majority within each group had heard of the corresponding procedure, actual knowledge about the procedure was relatively low and, therefore, perceptions of risk/cost may not have been easily considered. In addition, the majority of participants within each group did not know of someone on a transplant waiting list nor did they know someone who had had a transplant (see Table 7-1). This suggests that the topic of living organ donation was not a particularly relevant subject matter to the majority of participants. Prior experience and relevance have been shown to influence behaviour and perceptions by allowing the person to process the information presented more in-depth and consequently leave them susceptible to framing effects (Detweiler, Bedell, Salovey, Pronin, & Rothman, 1999; Gerend & Shepherd, 2007; Rothman & Salovey, 1997). As this sample had minimum prior experience with living organ donation, and the subject was perhaps of little relevance to them, the information presented may not have been processed to a great level. Although signing up to the NHS organ donor register was taken as an indication of a higher level of involvement in the topic of organ donation, this may not have been sufficient to impact framing effects. Consequently, the hypothesis of an interaction effect between NHS organ donor registration and frame was not supported.

One of the main limitations with this study is with regards the number of participants within each of the groups and the unequal gender balance. A further large-scale study, involving a more equal proportion of males to females, would increase the power of the tests and allow gender effects to be analysed further.

7.5.2 Conclusion

The main findings from this study are that, a gain framed message offers more encouragement for a low risk behaviour than a high risk behaviour. Specifically, a gain framed message encourages kidney donation more than liver donation. However, the opposite is not true for a loss framed message. In addition, a gain framed message also enhances the altruistic tendency for a potential kidney donor compared to a potential liver donor. Potential kidney donors were more willing to donate than to receive following a gain frame than potential liver donors. The benefits of using a gain frame when promoting living kidney donation have consequently been highlighted but similar benefits can not be expected when a gain frame is used to promote living liver donation.

This study has added to the message framing literature by focusing on a health related altruistic behaviour. However, within the context of living organ donation it is not just the cost-and benefits to the self that need to be considered but also those of the recipient. Future work should include how donors perceive the cost and benefits to the recipient and if this is moderated by framing effects. One possibility would be if the benefits to the recipient of the donation are perceived to be low then it may be important to highlight the cost to the recipient of no donation, in which case a loss frame should be more effective.

Living donation is often regarded as the best form of treatment for patients with end stage renal or liver disease and therefore its effective promotion is vital. It is important that every potential donor and recipient are fully aware of the risks and benefits of living donation and are not dissuaded from investigating the procedure simply because of how the information is presented.

Chapter 8 An assessment of the functional and psychosocial impact of Living Donor Kidney Transplantation (LDKT) upon donors and recipients.

8.1 Abstract

Objectives: Each year the number of living donor kidney transplants (LDKT) performed in the UK increases justified by the survival benefits for the recipient and low mortality and morbidity risk for the donor. However, the risk to the donors' quality of life, psychosocial wellbeing, and functional and cognitive abilities remains uncertain. This study therefore provides a comprehensive psychological evaluation of LDKT in both donors and recipients.

Design: A total of 22 recipients and 20 donors participated in this study. A mixed 2 (group) x 3 (time) ANOVA assessed changes within and between groups over time. Correlations assessed relationships between baseline predictor variables (locus of control, optimism and self efficacy) and 6 month outcome.

Method: Participation involved the completion of a questionnaire pack including measures of physical and functional ability, quality of life and mood, in addition to a set of computerised neuropsychological tests, at three time periods: prior to the operation, 6 weeks post operation and 6 months post operation.

Results: Neither donors nor recipients experienced significant changes on any measures when comparing baseline to 6 month follow-up. However, at 6 weeks donors' experienced significant deterioration in physical abilities and recipients with regards to depression. Baseline predictor variables did not reliably predict outcome.

Conclusion: Donors experienced some short lived physical deterioration, returning to a pre donation level by 6 months after the procedure. However, by 6 months post procedure, recipients were yet to show significant improvement from pre transplant

levels in the majority of variables measured, indicating that recovery from kidney failure is not complete within the first 6 months of receiving a new kidney.

8.2 Introduction

The shortage of donated organs following death not only affects patients on the liver transplant waiting list but also those awaiting a kidney transplant. Living donor kidney transplantation is consequently now routinely offered as an alternative therapy for many patients with end stage renal disease. Unlike LDLT, LDKT is an established procedure having first been performed in 1954 between identical twins. Since this time developments in immunosuppressant medication and surgical techniques have allowed the procedure to advance to the extent that unrelated individuals can now donate. This has consequently led to an increase in the number of living kidney donations performed each year with living donation now constituting more than one third of all kidney transplants annually performed in the UK alone (NHS Blood and Transplant, 2009). Within the renal unit at the Royal Infirmary of Edinburgh (RIE) specifically, between April 2008 and March 2009, 19% of all kidney transplants were conducted using a living donor (NHS Blood and Transplant, 2009).

The expansion of living kidney donation is supported by the additional benefits to the recipient over and above that of a deceased donation. Similar to LDLT, LDKT allows the condition of the kidney to be thoroughly checked prior to transplant, the operation can be scheduled to occur at a time suitable for the donor and the recipient, when both are in good health, and the time between removal of the kidney and transplant into the recipient can be kept to a minimum (i.e. reduced cold ischemic time). In addition, living donation can reduce the amount of time the recipient must spend on the transplant waiting list and may even be organized in such a way that the recipient can avoid dialysis (Asolati & Matas, 2003; Griva et al, 2002; Matas et al, 2003).

The benefit of LDKT not only lies in the preparation but also with respect to clinical outcomes. Previous research has indicated that patient and graft survival is superior following a living donation as opposed to a deceased donation, irrespective of the recipients' genetic relationship with the donor (Gjertson & Cecka, 2000; Matas et al, 2003). It would appear therefore that the main disadvantage to living kidney donation is the risk to the healthy donor. The risk of death for a kidney donor is considered low, estimated to be 1 in 3000, and although complication rates vary over transplant centres, they too are considered acceptable (Hartmann, Fauchald, Westlie, Brekke, & Holdaas, 2003; Matas et al, 2003; Sommerer, Morath, Andrassy, & Zeier, 2004). However, less is known about the risk LDKT has on the donor's quality of life, cognitive functioning, and psychosocial well being.

Quality of life has become an increasingly important outcome measure following surgical procedures and is a particularly important variable with regards to living donation where it is essential that any risk to the healthy donor is fully justified. Kidney transplantation is generally thought to not only extend the life of recipients but also enhance the recipients' quality of life, irrespective of the type of donation (Christensen, Raichle, Ehlers, & Bertolatus, 2002; Franke, Heemann, Kohnle, Luetkes, Maehner, & Reimer, 2000; Griva, Jayasena, Davenport, Harrison, & Newman, 2009; Griva et al, 2002). Previous research has also indicated that the majority of donors themselves either maintain or show improvement in their quality of life post donation, often scoring similar to or above that of the general population

(Cabrer, Oppenhaimer, Manyalich, Paredes, Navarro, Trias et al, 2003; Giessing, Reuter, Schonberger, Deger, Tuerk, Hirte et al, 2004; Ibrahim, Foley, Tan, Rogers, Bailey, Guo et al, 2009; Isotani, Fujisawa, Ichikawa, Ishimura, Matsumoto, Hamami et al, 2002; Johnson, Anderson, Jacobs, Suh, Humar, Suhr et al, 1999; Padrão & Sens, 2009). However, negative physical and psychosocial implications of living donation have also been reported for a number of donors and cannot be ignored (Clemens, Thiessen-Philbrook, Parikh, Yang, Karley, Boudville et al, 2006; Lumsdaine et al, 2005; Reimer, Rensing, Haasen, Philipp, Pietruck, & Franke, 2006; Smith, Trauer, Kerr, & Chadban, 2003; Virzí et al, 2007). Rather, such results call for further research into the psychosocial and physical impact of living kidney donation and the identification of factors that can predict clinical and quality of life outcomes.

Previous research has indicated that levels of optimism can predict recovery following coronary heart bypass surgery, and strength of internal/eternal locus of control over recovery has been found to predict speed of recovery following a stroke (Partridge & Johnston, 1989; Scheier et al, 1999). In addition, it has been found that higher self efficacy was related to greater psychological wellbeing in patients with arthritis (Barlow et al, 1996). Therefore, measures of optimism, locus of control and self efficacy were included in this study to assess their relationship with functional and psychosocial recovery following living kidney donation and transplantation.

Patients with end stage renal disease have been found to show variable degrees of cognitive impairment, although the exact cause of this deterioration remains unclear. One general explanation proposes that it is the result of a build up of neurotoxins in the blood, caused by the inadequate filtration rates of diseased kidneys (Pliskin et al, 2001). This explanation is supported by improvements in cognitive functioning following a kidney transplant (Griva et al, 2006; Kramer et al, 1996). This is an important finding, as cognitive abilities such as memory and attention impact an individual’s daily functioning and consequently affect their quality of life. However, it has not yet been established if donors also experience cognitive deterioration as a result of their body’s early adjustment to having only one kidney. This study therefore incorporates tests of psychomotor speed, memory, concentration and attention to assess, for the first time, the impact of living donation on the cognitive functioning of healthy donors.

In light of the benefits of LDKT to recipients and the relatively low cost to the healthy donor, LDKT is often considered the treatment of choice for patients with end stage kidney disease. However, if potential donors are to be encouraged and appropriately supported, it is essential that the experience of current donors and recipients are closely evaluated both before and after donation.

Many previous studies involving living kidney donors and recipients have limitations with regards to the use of a cross sectional research design and dependence on the SF36 as a measure of quality of life. The SF36 measures health related quality of life, depicted by what a person can and cannot do, however, quality of life is not only related to a person’s health but includes satisfaction with physical, psychosocial and environmental factors. Therefore this study improves upon previous research by incorporating both a global measure of quality of life and a measure of physical limitations, promoting a more comprehensive evaluation of donors and recipients. Measures of functional and cognitive abilities, and psychological well being, are also included. A longitudinal design is also utilised to allow an evaluation through the living donation experience, from pre to post operation. Providing potential donors with relevant, evidence based information on the likely functional and psychosocial impact of living donation is essential to ensure truly informed consent of donors which itself will contribute to the minimisation of risk.

8.3 Hypotheses

The hypotheses for this study are:

1. Recipients will show improvement in all outcome measures from pre to 6 weeks to 6 months post transplant.

2. Donors will show initial physical, functional and neuropsychological deterioration from pre to 6 weeks post donation, improving to baseline levels by 6 months.

3. The psychological variables, optimism, locus of control and self efficacy, measured pre LDKT, will be predictive of 6 month outcome in both donors and recipients.

8.4 Methodology

The LDKT coordinator at the renal transplant unit at the Royal Infirmary of Edinburgh (RIE) agreed to provide the researcher with the contact details of any potential donors, and their recipients, who volunteered to be assessed by the unit for donor suitability. Names were also provided by coordinators in Aberdeen, Dundee and Inverness whose patients would, if suitable, receive the procedure at the RIE. A letter of invitation explaining the research project and what participation would involve was sent to each potential donor and recipient (see Appendix 22). The author then called within 7 days following the expected delivery date of the letter to answer any questions and arrange participation. Consent forms were sent in advance of an arranged date of participation (see Appendix 23). Recruitment continued between January 2007 and June 2008. Lothian Local Research Ethics Committee approved this study (letter dated 5th October 2006).

All assessments were carried out by the researcher who had had no contact with the participants prior to recruitment for this study. Where possible each assessment was face-to-face and took place either within a research room within the hospital (not attached to the renal transplant unit), in their own homes, or in another convenient place familiar to them e.g. office. To encourage participation arrangements sometimes had to be made to minimise the time required for the assessment e.g. questionnaire returned by post so they could be completed at a more convenient time by the participant.

8.4.1 Design and Analysis

This study was a 2 group (recipient and donor) by 3 time (pre operation, 6 weeks post and 6 months post operation) design. A mixed Analysis of variance was used to assess changes in responses across time and between donors and recipients. Independent and paired t-tests were then conducted where appropriate and correlations assessed relationships between psychological variables and outcome.

8.4.2 Measures

Each assessment consisted of two parts beginning with completion of a questionnaire pack, followed by a set of computerised neuropsychological tests. A measure of verbal memory was also incorporated into the neuropsychological assessment. A full description and justification of the measures used can be found in the Methodology chapter (Chapter 2) and internal consistency for the current sample, for each measure where a scale was employed, is listed in Table 8-1. Each assessment lasted approximately 1 hour.

Table 8-1: The internal consistency of each scale employed

Scale / measure	Cronbach alpha coefficient		
	Pre operation	6 weeks post operation	6 months post operation
SF36: Physical functioning	0.92	0.90	0.88
FLP: Physical health	0.70	0.39	0.78
FLP: Psychological health	0.59	0.72	0.85
WHOQOL-BREF: Physical health	0.85	0.86	0.86
WHOQOL-BREF: Psychological health	0.85	0.77	0.71
WHOQOL-BREF: Social relationships	0.59	0.44	0.73
WHOQOL-BREF: Environment	0.79	0.84	0.86
HADs: Depression	0.65	0.76	0.71
HADs: Anxiety	0.80	0.85	0.82
RLOC	0.80	-	-
LOTR	0.77	-	-
GSES	0.84	-	-

SF36 = Short Form 36; FLP = Functional Limitations Profile; WHOQOL-BREF = World Health Organisation Quality of Life Scale –Brief version; RLOC = Recovery Locus of Control; LOTR = Life Orientation Test Revised; GSES = Generalised Self Efficacy Scale

8.4.3 Participants

A total of 44 donor and recipient couples were invited to participate in this study. The participation rate for donors was 72.3% (n = 32) and 77.3% for recipients (n = 34) with 22 recipients and 20 corresponding donors participating over the three time periods. Only the results from those who completed all three time periods are reported here. The recruited donors and recipients who did not complete the study did so due to the recipient receiving a deceased donation (n = 2), being unsuitable for LDKT (n = 2), not completing LDKT within the necessary timeframe (n = 6), family problems (n = 1) or relocation (n = 1). Details of the donors and recipients who participated at both pre and post LDKT are presented in Table 8-2. Initial assessments with donors were conducted an average of 166.68 days prior to donation (SD = 72.75, Range = 8-265), and recipients were assessed an average of 157.18 days prior to transplant (SD = 81.18, Range = 9-310). Donors and recipients did not significantly differ on any of the listed demographic variables. The reason for a new kidney varied amongst recipients but included congenital, auto-immune, infective, cardiovascular, and metabolic conditions. No recipients died within the course of this study. Of those who refused the invitation to participate, reasons were predominantly in relation to insufficient free time.

Table 8-2: Descriptive details of participants

		Donors (N = 20)	Recipients (N = 22)
Age (SD; range):		53.50 (11.38; 27-76)	46.55 (13.39; 22-76)
Gender:	Males	8 (40%)	13 (59.1%)
	Females	12 (60%)	9 (40.9%)
Marital status (N):	Married	17	15
	Single	1	3
	Divorced	1	2
	Living with partner	1	2
Children:	Yes	18 (90%)	17 (77.3%)
	No	2 (10%)	5 (22.7%)
Years of education (SD, range):		15.47 (4.06; 10-25)	14.41 (3.62; 10-22)
Relationship (N):	Husband	2	5
	Wife	4	3
	Brother	2	3
	Sister	4	3
	Mother	2	1
	Father	4	0
	Daughter	1	2
	Son	0	4
	Friend	1	1
Treatment:	Haemodialysis	-	8 (38.1%)
	Peritoneal dialysis	-	10 (47.6%)
	Pre-dialysis	-	3 (14.3%)

8.5 Results

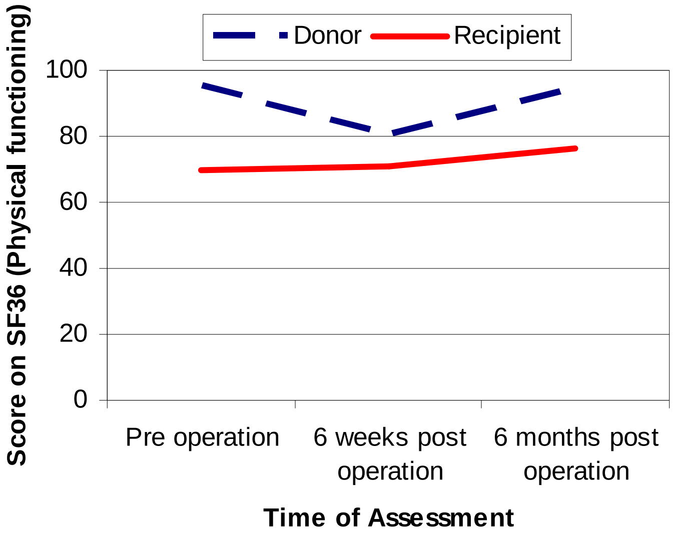
The data collected from the pre operation assessments, the 6 weeks post operation assessments and the 6 month post operation assessments are referred to as Time 1, Time 2 and Time 3 respectively. Normality of distribution was assessed for both groups across each variable at each time point and whilst some results indicated a normal distribution others did not. This was to be expected given the small sample size within each group. Only the WHOQOL-Environment scores, CANTAB RVP total hits scores, CANTAB DMS mean latency scores, and RBMT story immediate scores were normally distributed for both groups at each time point. For the remaining variables, transformations to correct normality were unsuccessful and therefore for these variables both parametric and nonparametric analyses were employed. For each variable the results of the parametric analyses (i.e. ANOVA) are reported and any post hoc comparisons were interpreted conservatively with a reduced alpha level, employing Holm's sequential Bonferroni method (Holm, 1979; Ridout, Astell, Reid, Glen, & O'Carroll, 2003). For the variables that included non normal distributions, the results of nonparametric testing were additionally reported only when different to the parametric results.

Whilst the results for each variable are listed, significant interactions are of particular interest to this study and are illustrated in the figures 8.1 to 8.3. However, the aim of this study also specified evaluation of the course of results for donors and recipients separately; therefore, comparisons across each time point for each group were conducted irrespective of a significant interaction, and are reported when significant.

8.5.1 Short Form 36 (physical functioning)

Results revealed that the main effect of group was significant $F(1, 34) = 10.45$, $p = 0.03$, $\eta p^2 = 0.24$, as was the main effect of time $F(2,68) = 6.08$, $p = 0.04$, $\eta p^2 = 0.15$ (means and standard deviations are provided in Table 8-3). Of particular interest was the obtained significant interaction $F(2, 68) = 3.73$, $p = 0.03$, $\eta p^2 = 0.1$. This indicates that the change in scores on physical functioning over each of the three time periods differs for donors and recipients (see Figure 8-1).

Figure 8-1: Scores on the Physical functioning domain of the SF36



Decomposing the interaction showed that donors experienced a statistically significant decrease in physical functioning from time 1 to time 2; $t(16) = 2.77$, $p = 0.01$, $\eta^2 = 0.32$, which significantly increased again by time 3; $t(16) = -3.59$, $p = 0.002$, $\eta^2 = 0.30$. Scores at time 1 and time 3 did not significantly differ. Whilst recipients showed a trend towards improvement in physical functioning over the three time periods this did not reach significance. However, donors scored significantly higher than recipients at time 1 ($t (34) = 4.16$, $p < 0.001$, $\eta^2 = 0.34$) and at time 3 only ($t (34) = 3.47$, $p = 0.002$, $\eta^2 = 0.26$).

Consistent results were found with nonparametric tests with an additional significant improvement in scores between time 2 and time 3 for recipients ($z = -2.04$, $p = 0.04$).

Table 8-3: Table of means (and standard deviations) for each quality of life measure

Measure	Group	Time 1 M (SD)	Time 2 M(SD)	Time 3 M(SD)
SF36: Physical functioning	Donors	95.29 (6.73)	79.71 (22.88)	94.41 (7.48)
	Recipients	70.00 (25.55)	70.79 (20.70)	76.32 (21.33)
FLP: Physical health	Donors	0.25 (0.73)	2.47 (4.03)	0.53 (1.55)
	Recipients	4.11 (4.97)	7.03 (8.79)	6.37 (11.35)
FLP: Psychological health	Donors	1.43 (3.61)	8.02 (12.15)	1.38 (3.22)
	Recipients	11.71 (11.69)	12.59 (16.68)	9.57 (18.06)

8.5.2 Functional Limitations Profile (FLP)

8.5.2.1 FLP Physical

There was a significant main effect of group, F(1, 37) = 6.98, p = 0.01, $\eta p^2 = 0.16$ indicating that donors and recipients differed with regards to how much their health effected their daily physical abilities, irrespective of time of assessment (means and standard deviations are provided in Table 8-3). Inspection of the means suggests, not surprisingly, that donors consistently had less physical limitation than recipients. There was no significant main effect of time and no significant group by time interaction.

Despite no significant main effect of time, closer inspection of each group across the three time periods revealed that donors demonstrated a significant deterioration in their daily physical abilities from time 1 to time 2 (t(19) = -2.81, p = 0.01, $\eta^2 = 0.42$) which improved again (although not significantly) at time 3, back to a level not significantly different to the pre donation (time 1) level. Recipients did not significantly differ from time 1 to time 2, or to time 3.

8.5.2.2 FLP Psychosocial

Again there was a significant main effect of group F(1, 38) = 7.14, p = 0.01, ηp^2 = 0.16 indicating that donors and recipients differed in the degree to which their health effected the psychosocial aspects of their daily living (means and standard deviations are provided in Table 8-3). Inspection of the means indicate that donors consistently had fewer psychological limitations than recipients. There was no significant main effect of time and no significant group by time interaction.

However, closer inspection of the results of each group indicates that donors experienced a significant deterioration in the psychological aspects of daily life from time 1 to time 2 (t(19) = -2.62, p = 0.017, η^2 = 0.22), which significantly increased again by time 3 (t(18) = 2.64, p = 0.017, η^2 = 0.28), to a level similar to that obtained at time 1. For recipients there was no significant change between times 1, 2 and 3.

8.5.3 Visual Analogue Scales: Relationship and social issues

There was a statistically significant main effect of time, with regards to improvement in relationships between donor and recipient (F(2,74) = 11.32 , p < 0.01 , ηp^2 = 0.23), and with family and friends (F (1.53, 56.58) = 7.73, p = 0.003, ηp^2 = 0.17). There was no significant main effect of group and no significant group by time interaction in either variable. From inspection of the means (provided in Table 8-4) we can see that the improvement in both relationships increases from pre to post transplant.

Table 8-4: Table of means (and standard deviations) for each relationship variable

Measure	Group	Time 1 M (SD)	Time 2 M(SD)	Time 3 M(SD)
VAS: Has relationship with donor/recipient improved? (%)[a]	Donors	31.53 (30.73)	45.95 (31.63)	45.46 (32.15)
	Recipients	31.10 (27.16)	54.70 (37.42)	60.78 (31.74)
VAS: Has relationship with donor/recipient been adversely affected? (%)[a]	Donors	4.05 (3.7)	3.05 (3.06)	7.5 (11.75)
	Recipients	14.10 (26.16)	9.65 (17.53)	8.34 (14.72)
VAS: Has relationship with family and friends improved? (%)[a]	Donors	23.79 (27.67)	38.42 (33.19)	39.75 (30.58)
	Recipients	24.25 (30.46)	43.80 (32.50)	44.15 (29.80)
VAS: Has relationship with family and friends been adversely affected? (%)[a]	Donors	9.79 (17.28)	6.31 (10.16)	10.02 (15.89)
	Recipients	8.95 (20.78)	12.65 (25.38)	14.86 (25.59)

[a] 0% = Not at all, to 100% = An extreme amount

Closer inspection of the results indicates that the degree of improvement felt by recipients in their relationship with the donor increased from time 1 to time 2 ($t(19) = -3.32$, $p < 0.01$, $\eta^2 = 0.37$), and to time 3 ($t(19) = -3.99$, $p = 0.01$, $\eta^2 = 0.46$) . Times 2 and 3 did not significantly differ. A similar pattern was found with recipients' relationship with other family and friends. A significant increase in degree of improvement was found between times 1 and 2 ($t(19) = -2.46$, $p = 0.02$, $\eta^2 = 0.24$) and time 1 and 3 ($t(19) = 2.75$, $p = 0.01$, $\eta^2 = 0.29$). For donors, the degree of improvement in relationships with the recipient, friends and family did not significantly change over the three time points.

Nonparametric tests verify all but one of the results: there was an additional significant improvement for donors between time 1 and time 3, with regards to their relationship with the recipient (z = -2.48, p = 0.01).

Table 8-5: Table of means (and standard deviations) for each social variable

Measure	Group	Time 1 M (SD)	Time 2 M(SD)	Time 3 M(SD)
VAS: Concern for donor? (%)[a]	Donors	N/A	N/A	N/A
	Recipients	78.05 (30.13)	67.29 (33.57)	65.45 (36.22)
VAS: Concern for operation? (%)[a]	Donors	34.45 (27.35)	N/A	N/A
	Recipients	N/A	N/A	N/A
VAS: Do you have concerns/worry about the remaining kidney? (%)[a]	Donors	22.79 (23.97)	16.26 (26.14)	17.43 (21.50)
	Recipients	N/A	N/A	N/A
VAS: Have you suffered any financial loss? (%)[a]	Donors	N/A	21.74 (30.44)	17.05 (28.15)
	Recipients	N/A	N/A	N/A
VAS: Do you experience discomfort from scar? (%)[a]	Donors	N/A	36.68 (31.22)	32.17 (36.06)
	Recipients	N/A	N/A	N/A
VAS: If possible would you donate one of your kidneys again? (%)[b]	Donors	N/A	87.39 (18.31)	89.84 (13.11)
	Recipients	N/A	N/A	N/A

[a] 0% = Not at all, to 100% = An extreme amount [b] 0% = Definitely no to 100% = Definitely yes

The results for the remaining, VAS questions are provided in Table 8-5. Prior to the operation the recipients concern for the donor was higher than the donor’s concern was for themselves. Although the recipients concerns for the donor decreased over the transplant experience this was not significantly so and remained relatively high throughout. Similarly, the donor’s concern for their remaining kidney decreased following the operation but this was not statistically significant and in contrast was relatively low throughout. Between 6 weeks and 6 months post transplant there was no statistically significant differences in perceived financial loss or discomfort from the scar. When donors were asked if they would donate again if it were possible, there was a strong positive response that was maintained at 6 months post operation.

8.5.4 World Health Organisation’s Quality of Life scale – Bref (WHOQOL-BREF)

8.5.4.1 Physical health

There was a statistically significant main effect of group, $F(1, 35) = 23.30$, $p < 0.001$, $\eta p^2 = 0.40$, and of time, $F(1,66, 58.07) = 3.62$, $p = 0.04$, $\eta p^2 = 0.09$ indicating that donors scored differently from recipients, irrespective of time of assessment and that the time of assessment significantly affected test scores. The group by time interaction was not significant. At each time point donors consistently had a higher level of satisfaction with their physical health than recipients (see Table 8-6).

Closer inspection of each group indicates that for donors a significant deterioration occurs from time 1 to time 2 ($t(18) = 3.07$, $p = 0.007$, $\eta^2 = 0.34$) but this improves and returns to a similar pre donation level at time 3. Recipients showed no significant differences between times 1, 2, and 3.

Non parametric tests support the majority of these findings although, contrasting results were found for the main effect of time: levels of satisfaction with physical health did not vary significantly across the three time points, $\chi 2\ (2, N = 37) = 4.36$, $p = 0.113$. However, when groups were analysed separately results confirmed that of the ANOVA. In addition, the improvement in donors' physical health satisfaction from time 2 to time 3 was significant (Z =-2.09, p = 0.04).

Table 8-6: Table of means (and standard deviations) for WHOQOL-BREF variables

Measure	Group	Time 1 M (SD)	Time 2 M(SD)	Time 3 M(SD)
WHOQOL-BREF: Physical health	Donors	18.79 (0.98)	16.70 (3.34)	18.00 (2.35)
	Recipients	14.77 (2.83)	14.50 (2.29)	15.32 (2.71)
WHOQOL-BREF: Psychological health	Donors	16.41 (1.45)	16.70 (2.33)	16.63 (2.03)
	Recipients	15.40 (2.76)	16.60 (1.75)	15.60 (2.04)
WHOQOL-BREF: Social relationships	Donors	17.11 (2.60)	16.74 (2.64)	17.04 (2.69)
	Recipients	16.00 (2.81)	15.82 (2.45)	16.84 (3.05)
WHOQOL-BREF: Environment	Donors	17.67 (1.32)	17.28 (2.29)	17.86 (1.65)
	Recipients	16.53 (2.47)	16.71 (2.57)	16.63 (2.41)

8.5.4.2 Psychological health

There was no main effect of time or group, and the group by time interaction did not reach statistical significance. Scores did not significantly change across the three time periods for either group (see Table 8-6).

8.5.4.3 Social relationships

There was no main effect of time or group, and the group by time interaction did not reach statistical significance. Scores did not significantly change across the three time periods for either group (see Table 8-6).

8.5.4.4 Environment

There was no main effect of time or group, and the group by time interaction did not reach statistical significance. Scores did not significantly change across the three time periods for either group (see Table 8-6).

8.5.5 Hospital Anxiety and Depression scale (HADs)

Table 8-7: Table of means (and standard deviations) for HADs variables

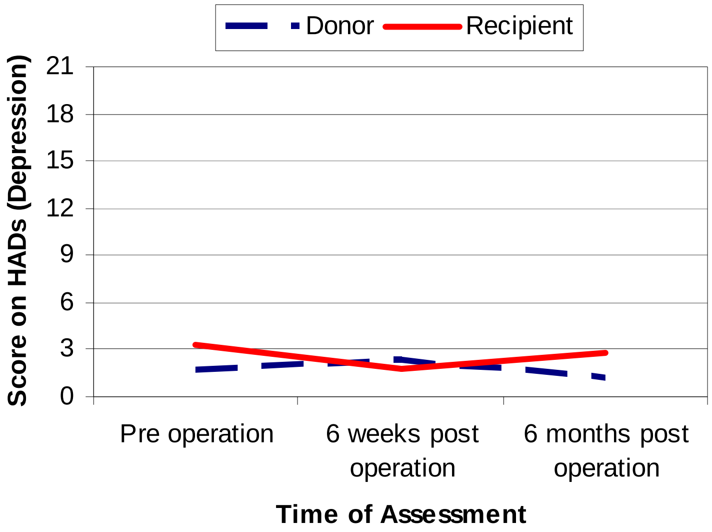
Measure	Group	Time 1 M (SD)	Time 2 M(SD)	Time 3 M(SD)
HADs: Depression	Donors	1.68 (1.46)	2.26 (2.54)	1.16 (1.61)
	Recipients	3.33 (2.67)	1.76 (1.84)	2.81 (2.46)
HADs: Anxiety	Donors	4.53 (2.82)	3.47 (3.82)	3.47 (2.39)
	Recipients	4.19 (2.34)	3.57 (2.73)	4.14 (3.28)

8.5.5.1 Depression

There was a significant group by time interaction ($F(2,76) = 1.37$, $p = 0.004$, $\eta p^2 = 0.14$) (see Figure 8-2). Decomposing this interaction showed that depression scores for donors did not differ significantly over the three time periods but for recipients depression scores were significantly higher at time 1 than at time 2 ($t(20) = 2.98$, $p <0.01$, $\eta^2 = 0.31$) and significantly increased again at time 3 ($t(20) = -2.75$, $p = 0.01$, $\eta^2 = 0.27$). The difference in depression scores at time 1 and time 3 were not statistically significant. There were no significant main effects of time or group.

Independent t-tests found that recipients were significantly more depressed than donors at time 1 ($t(38) = -2.39$, $p = 0.02$, $\eta^2 = 0.13$), and time 3 ($t(38) = -2.53$, $p = 0.02$, $\eta^2 = 0.14$. It is important to note that at no point did the depression scores for either donors or recipients fall outside the proposed “normal” range (scores 0-7) (Zigmond and Snaith, 1983).

Figure 8-2: Scores on the Depression subscale of the HADs



Non-parametric tests indicate that the levels of depression were significantly different over the three time periods χ^2 (2, N = 40) = 6.97, p = 0.031, although confirm the results of the decomposed parametric interaction and between group comparisons.

8.5.5.2 Anxiety

There was no significant main effect of time or of group, and the group by time interaction did not reach statistical significance. Scores did not significantly change across the three time periods for either group (see Table 8-7).

8.5.6 Cambridge Neuropsychological Test Automated Battery (CANTAB)

8.5.6.1 RTI: 5-Choice reaction time (Time taken to release button)

There was no significant main effect of time, or of group, and the group by time interaction did not reach statistical significance. Scores did not significantly change across the three time periods for either group (see Table 8-8).

8.5.6.2 RTI: 5-Choice movement time (Time taken to touch stimulus)

There was a significant main effect of group only, $F(1,35) = 5.43$, $p = 0.03$, $\eta p^2 = 0.13$. From inspection of the means (see Table 8-8), recipients were slower than donors at each of the three time points. Scores did not significantly change across the three time periods for either group.

8.5.6.3 RVP: total hits (number of correct responses)

There was a significant main effect of time only ($F(1.65, 57.87) = 7.18$, $p = 0.003$, $\eta p^2 = 0.17$). The total number of targets correctly responded to increases over the three times periods in both groups (see Table 8-8). However, closer inspection of the results indicate that only donors show significant changes over time with a significant increase from time 1 to time 3 ($t(17) = -3.95$, $p < 0.01$, $\eta^2 = 0.48$) and time 2 to time 3 ($t(17) = -2.55$, $p = 0.02$, $\eta^2 = 0.28$). Recipients did not show any significant changes over the three time periods.

8.5.6.4 RVP: mean latency (speed of response when correct)

There was no significant main effect of time, or of group, and the group by time interaction did not reach statistical significance. Scores did not significantly change across the three time periods for either group (see Table 8-8).

Table 8-8: Table of means (and standard deviations) for each CANTAB variable

Measure	Group	Time 1 M (SD)	Time 2 M(SD)	Time 3 M(SD)
RTI: 5-choice reaction time (milliseconds)	Donors	347.23 (48.04)	357.97 (44.94)	356.40 (52.21)
	Recipients	355.49 (54.70)	361.80 (39.98)	363.58 (84.85)
RTI: 5-choice movement time (milliseconds)	Donors	377.53 (63.43)	414.61 (80.35)	396.65 (63.15)
	Recipients	454.18 (68.70)	444.39 (85.43)	430.40 (71.58)
RVP: Total hits	Donors	19.28 (4.35)	20.17 (5.37)	22.39 (2.89)
	Recipients	16.68 (5.28)	19.32 (5.38)	19.63 (5.26)
RVP: Mean latency	Donors	462.02 (59.44)	455.35 (65.80)	473.16 (68.49)
	Recipients	473.49 (115.03)	459.55 (109.98)	476.55 (150.06)
DSM: Correct delays at 12000ms	Donors	4.28 (0.75)	4.78 (0.43)	4.33 (0.77)
	Recipients	4.47 (0.70)	4.21 (1.18)	4.32 (0.82)
DSM: Mean latency	Donors	3441.57 (776.93)	2998.27 (776.95)	2905.13 (719.81)
	Recipients	3247.67 (932.83)	3064.65 (841.30)	3279.09 (1170.99)

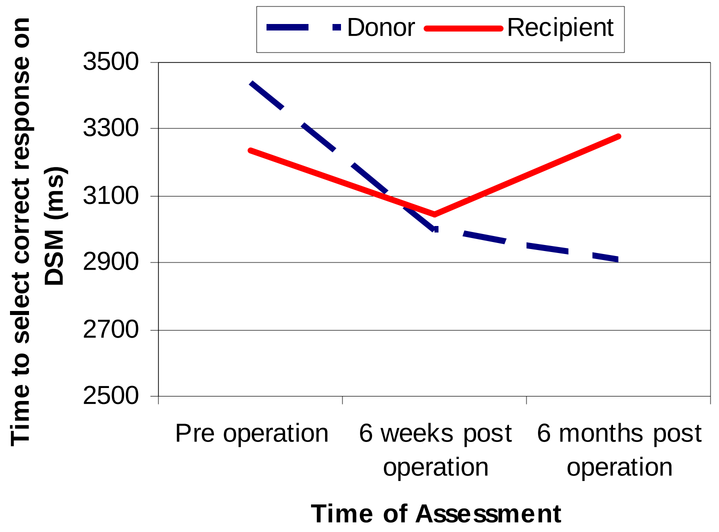
8.5.6.5 DSM: correct delays at 12000ms (number of correct responses following longest delay)

There was no significant main effect of time, or of group, and the group by time interaction did not reach statistical significance. Scores did not significantly change across the three time periods for either group (see Table 8-8).

8.5.6.6 DSM: mean latency (speed of response when remembered correctly)

There was a significant main effect of time, F(1.6, 56.06) = 5.04, p = 0.02, ηp2 = 0.13 , and in addition a statistically significant group by time interaction, F(1.6, 56.06) = 3.69, p = 0.04, ηp2 = 0.1(see Figure 8-3).

Figure 8-3: Time (ms) to select correct response on Delayed Matching to Sample



Decomposing the interaction revealed that for donors the average speed for correct responses at time 1 was significantly slower than at time 2 (t(17) = 3.85, $p < 0.01$, η2 = 0.47) and at time 3 (t(17) = 4.24, $p < 0.01$, η2 = 0.51). There was no significant difference between time 2 and time 3. No significant differences were found over the three time periods for recipients and no significant differences were found between the two groups at any time point (see Table 8-8).

8.5.7 Rivermead Behavioural Memory Test (RBMT)

8.5.7.1 Story Immediate

There was a significant main effect of time only (F(2,76) = 3.57, p = 0.03, ηp^2 = 0.09). Scores generally increased from pre to post LDKT. Closer inspection indicates that recipients show significant improvements in memory from time 1 to both time 2 (t(21) = -2.65, $p < 0.05$, $\eta^2 = 0.25$) and time 3 (t(20) = -2.59, $p < 0.05$, $\eta^2 = 0.25$). Scores at time 2 and time 3 did not differ significantly. Donors did not show significant improvement (see Table 8-9).

Table 8-9: Table of means (and standard deviations) for each RBMT variable

Measure	Group	Time 1 M (SD)	Time 2 M(SD)	Time 3 M(SD)
RBMT: Story Immediate[a]	Donor	6.87 (3.32)	7.66 (3.26)	7.55 (3.27)
	Recipient	5.93 (2,52)	7.60 (2.67)	7.88 (3.13)
RBMT: Story Delayed[a]	Donor	5.58 (2.84)	6.16 (2.64)	6.95 (2.36)
	Recipient	5.17 (2.33)	6.19 (2.55)	6.83 (3.10)

[a] Possible range of scores = 0-21

8.5.7.2 Story Delayed

Again, there was a significant main effect of time only (F(2,76) = 5.30, p = 0.007, ηp^2 = 0.12). Scores increased over the three time periods. Closer inspection revealed no significant improvements between each time period for both donors or recipients (see Table 8-9).

8.5.8 Predictor variables

The measures of Recovery locus of control (RLOC), Optimism (LOTR) and General Self Efficacy Scale (GSES) were incorporated into the study at time 1 in order to assess their ability to predict functional and psychosocial outcomes following LDKT. The means and standard deviations of each measure are presented in Table 8-10.

Table 8-10: Table of means (and standard deviations) for each predictor variable

	Group	Recovery Locus of Control (RLOC)	Life Orientation Test Revised (LOTR)	Generalised Self Efficacy Scale (GSES)
Time 1 M (SD)	Donors	37.75 (4.36)	17.32 (3.04)	32.05 (3.70)
	Recipients	32.45 (5.54)	16.23 (3,52)	31.45 (3.17)

In order to test the predictive validity of these variables a recovery score was first calculated for the variables SF36 Physical functioning, FLP Physical, FLP Psychological, WHOQOL Physical, and WHOQOL Psychological separately. Each recovery score was calculated by subtracting scores at time 3 from scores at time 1, thus controlling for baseline differences. Non-parametric correlations were then conducted between the computed recovery scores and results for the RLOC, LOTR and GSES.

For donors, a significant negative correlation was found between the LOTR score and the difference in scores for the WHOQOL Physical ($\rho = -0.40$, $n = 18$, $p < 0.05$), and the RLOC score and the difference in scores for the WHOQOL Psychological ($\rho = -0.42$, $n = 19$, $p = 0.04$). Higher levels of optimism are related to more improvement on the WHOQOL Physical measure whilst a stronger internal locus of control is related to more improvement on the WHOQOL Psychological measure (see Appendix 24).

For recipients, different significant correlations were observed. A significant positive correlation was found between the RLOC score and the difference in scores for the FLP psychological ($\rho = 0.53$, $n = 21$, $p <0.01$). In addition, positive correlations were found between the LOTR score and the difference in scores for the SF36 ($\rho = 0.47$, $n = 19$, $p = 0.02$), and the WHOQOL Psychological ($\rho = 0.46$, $n = 21$, $p = 0.02$). A significant negative correlation was found between LOTR score and the difference in scores for the FLP physical ($\rho = -0.54$, $n = 21$, $p <0.01$) (see Appendix 25). These results indicate that, counter to the hypothesis, higher levels of optimism are related to an increased level of physical limitation, more deterioration in daily physical functioning and more deterioration in satisfaction with psychological health. GSES was not significantly correlated with any of the outcome variables for donors or recipients.

8.6 Discussion

8.6.1 Hypothesis 1: Recipients will show improvement in all dependent variables from pre to 6 weeks to 6 months post transplant

The results of this study do not support the first hypothesis, as recipients only showed significant improvement from pre to post transplant with regards to a verbal working memory test (RBMT: Story immediate), and with regards to perceived improvement in relationships with the donor, family and friends. The significant improvement in both variables was made by 6 weeks post LDKT and was maintained at 6 months. This is contrary to previous studies which have indicated that kidney transplant leads to improvements in many aspects of quality of life, psychosocial wellbeing, and cognitive functioning (Franke et al, 2000; Griva et al, 2009; Griva et al, 2006; Lumsdaine et al, 2005; Virzí et al, 2007). The decision to place a patient on the kidney transplant waiting list is made based on the belief that a transplant will increase the patients' chances of survival and offer significant improvements to their quality of life. Therefore, the present results are striking in that by 6 months post kidney transplant recipients were yet to experience significant improvements to their quality of life compared to when they were receiving dialysis.

Previous studies in support of significant improvement vary with regards to the time since transplant, therefore it is possible that 6 months post transplant is too soon for improvements to quality of life to be noted and appreciated by recipients. Virzì et al (2005) reported significant improvement on various aspects of health related quality of life at 6 months post transplant when using the SF36, but similar to the current study significant improvement on the physical functioning domain specifically did not occur. The level of physical limitation experienced by recipients prior to transplant may require a longer time frame before signs of significant improvement can be observed.

In contrast to the current study, Lumsdaine et al (2005) found a significant improvement in the WHOQOL physical domain score at 6 weeks post operation which continued to increase to a level comparative with UK norms at 1 year post transplant. Lumsdaine et al (2005) completed analysis on 35 recipients which may suggest that the current study had insufficient power to detect similar significant differences on the WHOQOL and other variables.

An interesting finding was observed for depression. Whilst the level of depression noted for recipients was unchanged from pre to 6 months post transplant, significant deterioration was observed at 6 weeks post transplant. However, it should be noted that at no time point did recipients have scores which exceeded the “normal range” of between 0 and 7. Recipients were more depressed than donors prior to the operation and significantly improved to a level similar to donors by the initial post transplant assessment. However, from 6 weeks to 6 months post transplant, the level of depression for recipients significantly increased again. Following transplant, despite freedom from dialysis, patients must contend with a lifelong, strict medical regime: at a minimum, patients need to take immunosuppressant medication twice daily, 12 hours apart, normally on an empty stomach. This medication is necessary to preserve the survival of the kidney by preventing the recipient’s body from rejecting the foreign object that is the transplanted kidney, but its necessity may adversely impact psychological wellbeing. At 6 weeks, the initial relief and joy felt from having freedom from dialysis may overcompensate for any difficulties experienced with the new medical regime, and current or anticipated medication side effects (e.g. trembling, hair loss, and diabetes from immunosuppressants and weight gain from steroids), representing a “honeymoon period”. By 6 months, living without dialysis has become routine and yet a complete return to a normal life does not occur as the medication issues continue. The results therefore may indicate that by 6 months after the operation a cognitive shift leads to a more prominent focus on the restrictions and side effects of the medication, and as a result the initial improvement in levels of depression may recede. As previously suggested, 6 months post transplant may be too soon to fully appreciate changes to quality of life, but additionally, it may be that by 6 months further challenges, such as organ rejection, changes to medication, or the consequences of an increased susceptibility to infection and disease due to a lowered immune system, are faced that temporarily override any objective improvements.

A previous study assessing predictors of depression in kidney transplant patients suggests that coping preferences influence changes in depression from pre to 12 months post transplant (Christensen et al, 2000). Christensen and colleagues (2000) described how patients have to cope with the growing independence from health care providers as time from transplant increases. Recipients who had a high preference for active coping strategies were more likely to show a reduction in their depression scores over time whilst patients with a low preference, and therefore a more passive coping strategy, were likely to show an increase in depression scores from pre to 12 months post transplant (Christensen et al, 2000). In this current study coping style was not assessed, but variation in coping styles within the current sample may offer a possible explanation for changes in depression scores from pre to 6 months post transplant.

In addition, Griva et al (2002) found that recipients of a living kidney donation experienced higher level of guilt than recipients receiving a deceased donation, when measured an average of 8.6 years after transplantation. Although this particular emotional response was not measured in the current study, it is possible that such a negative emotion was reflected in the measure of depression. An explanation of the results could be that again, once the initial euphoria of a successful transplant diminished, the realisation of the sacrifice made for the recipients' benefit became more apparent thereby causing an increase in levels of depression. This interpretation is speculative and the factors involved in the course of emotional wellbeing warrants further research.

8.6.2 Hypothesis 2: Donors will show initial physical, functional and neuropsychological deterioration from pre to 6 weeks post donation, improving again by 6 months.

The results offer some support for hypothesis 2: donors show no significant deterioration in quality of life, cognitive functioning and psychosocial wellbeing from pre to 6 months post donation. In addition, as predicted, from pre to 6 weeks post donation, significant deterioration on a number of variables was observed: SF36 physical functioning, FLP Physical, FLP psychological, and WHOQOL physical. Deterioration was most notable with measures of physical ability which corresponds with previous research. For example, Virzì et al (2007) observed deterioration in the SF36 physical functioning domain from pre to 6 months post donation whilst Smith et al (2003) found a significant reduction in the physical component score of the SF36 from pre to 4 months post donation[8]. However, unlike previous research, in the current study, the deterioration was short lived, as scores had returned to a premorbid level by 6 months.

Deterioration was also noted with respect to both the physical and psychological aspects of functional limitations. Whilst limited in general physical functioning, the more specific physical day to day tasks were also negatively affected as were psychosocial aspects including general alertness and interest in hobbies etc. However, such deterioration represented only temporary changes as each returned to pre-morbid levels by 6 months. In addition, satisfaction with physical health had deteriorated at 6 weeks which corresponds with the results of Lumsdaine et al (2005), although whilst Lumsdaine observed a return to pre donation levels at one year post donation, the current study's design allowed similar improvements to be documented at the earlier stage of 6 months.

It is likely that the pre donation health check carried out by the transplant team at the RIE ensures that donors who are selected are in a particularly good state of health so as to be able to recover from any physical deterioration inevitably experienced with major surgery by 6 months, and/or that appropriate supports are available within the transplant unit at the RIE to promote recovery post donation. Regardless, it should be made clear to potential donors that physical deterioration is likely at 6 weeks after surgery, and can be at a level similar to that of the recovering recipient.

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[8] Exact scores for the physical functioning domain are not documented but the physical functioning domain has been documented as one of the most highly correlated with the general physical measure (**Ware,** 2000).

With regards to the neuropsychological variables, it was hypothesised that donors would show deterioration in performance at 6 weeks, as a consequence of losing a kidney, before returning to a pre-donation level by 6 months. However, a significant change at 6 weeks post donation was only noted for one variable: DSM: mean latency (measure of psychomotor speed). The direction of the significant change was not as anticipated: donors showed an improvement on psychomotor speed at 6 weeks post donation. The result cannot easily be explained but may indicate a possible practice effect for donors, and observations by the author would certainly suggest a determination by donors to exceed previous scores on all tests. However, a further explanation may be with regards to the timing of the assessments. It is possible that neuropsychological deterioration does occur, but is short lived and resolved within a 6 week period.

8.6.3 Hypothesis 3: The psychological variables, locus of control, optimism and self efficacy, measured pre LDKT, will be related to recovery in both donors and recipients.

The results showed limited support for the third hypothesis. For donors, self efficacy failed to correlate with any of the outcome variables and optimism and locus of control only correlated with one outcome each. Whilst a high level of optimism was related to a greater improvement in satisfaction with physical health (WHOQOL physical), a strong internal locus of control was related to a greater improvement in satisfaction with the psychological aspects of quality of life (WHOQOL psychological).

These results were not replicated in the sample of recipients. For recipients, a stronger internal locus of control was related to a larger degree of improvement in ability to carry out psychosocial aspects of daily living (FLP psychological). In addition, optimism was related to many functional and psychosocial outcomes following LDKT however, the results were not consistent with the predicted direction of relationship. Previous research has indicated that an optimistic outlook leads to better outcome following many medical or surgical procedures such as heart bypass surgery, and treatment for breast cancer (Scheier et al, 1999; Schou et al, 2005). In addition, a study by Goetzman and colleagues found that optimism within patients awaiting an liver, lung or bone marrow transplant predicted good mental health post transplant but not physical functioning (Goetzmann et al, 2007). However, within the current study, optimism was not related to improved recipient outcome. Higher levels of optimism prior to transplant were found to be related to a higher degree of deterioration in physical functioning (SF36), a higher degree of deterioration in daily physical abilities (FLP physical), and a higher degree of reduced satisfaction with psychological health (WHOQOL psychological). Such paradoxical results cannot be easily explained and may represent spurious findings.

However, the results may also be indicative of an association between poor outcome and unrealistic optimism (Weinstein, 1980a). Being optimistic may have led to the individual's quality of life being over estimated at time 1 so that at time 3, the reality of the situation was perceived to be all the more detrimental. In addition, having unrealistic optimistic expectations for the course of personal recovery, when not realised, may also have contributed to poorer outcome. Such possible associations are speculative and require further investigation.

8.6.4 Limitations

The first limitation noted is with regards to the duration of follow-up. The lack of significant improvement experienced by recipients may suggest that 6 months post

LDKT is perhaps too soon to detect such changes. However, a previous study has noted significant improvement at only 6 weeks post LDKT therefore an additional explanation, and further limitation of the study, is with regards to the relatively small sample of participants who completed assessments over all three time periods (Lumsdaine et al, 2005). This will have resulted in reduced power and therefore "real" effects may not have been detected. The restricted duration of the PhD degree programme meant that not all participants could complete the post LDKT assessments and this itself is a limitation of the study. Those who began participation but continue to await the LDKT procedure may eventually experience different outcomes to those who completed LDKT within 5/6 months from their first assessment. Future studies could consider the impact of a prolonged wait between the decision to pursue LDKT and its occurrence on donor and recipient outcomes.

The use of multiple outcome measures may also have increased the likelihood of type 1 errors, whereby significant results are indicated despite no real differences between two groups or data points. This may explain the spurious findings of this study, such as the recipients' significant improvement in immediate recall (RBMT story immediate) when no significant improvements in other memory or neuropsychological tests were found. It is important to emphasise that a more conservative alpha level was employed with post hoc tests in an attempt to control for type 1 errors (Holm's sequential Bonferroni method) however an even more conservative alpha level may have further challenged the significant findings.

The particularly low reliability scores of the physical health domain of the FLP and the Social relationships domain of the WHOQOL-BREF at time 2 require comment.

It is not possible to explain this outcome as the higher scores at time 1 and time 3 supports the reliability of the measures. It may however suggest that 6 weeks following major surgery, items relating to physical health and social relationships may be interpreted slightly differently to when the situation is more settled. For example, with regards to the social relationship domain, inspection of the scale indicates a slightly more acceptable alpha level of 0.52 with removal of the question regarding satisfaction with support from friends. This would leave satisfaction with sex life and personal relationships as the scale items. At time 2, during the initial recovery process, the distinction between personal and sexual relationships, and friendships is perhaps more apparent. Whilst explanations are speculative it is important to be aware of the low reliability scores when interpreting the main results.

A limitation of response bias may also apply to this study as potential donors and recipients who declined the invitation to participate may have suffered more in their functional and psychosocial wellbeing, or may have witnessed greater improvement. However, it should be noted that the response rate obtained for this study was a respectable 72.3% for donors and 77.3% for recipients.

Illness perceptions are thought to influence a person’s recovery and quality of life but this could not be investigated in the current study due to problems of interpretation. The use of the IPQ-R was abandoned due to consistent questioning from participants with regards to the meaning of the listed items. A recent study by Griva and colleagues (2009) has also highlighted possible interpretation difficulties with the original IPQ. It was suggested that the difference in meaning intended by the words “illness” and “treatment”, essential for completion of the measure were not easily distinguishable in the context of end stage renal disease and transplantation (Griva et al, 2009). In the current study the meaning of “treatment” was not clearly understood as recipients at the pre LDKT stage included both dialysis and transplantation as “treatment” and each provoked different response to items. In addition, the recipients found questions pertaining to the expected duration of their “illness” difficult as responses were dependent on whether or not they actually received the transplant.

In this study, the word “illness” in each item was replaced with a more specific term for donors and recipients respectively i.e. “my condition / kidney condition following the donation operation / transplant”, but questions surrounding the meaning persisted. The IPQ-R post transplant specifically was noted to pose confusion. For example, donors felt the treatment questions did not apply to them as by 6 weeks post donation medication was neither prescribed nor required, and donors and recipients alike did not understand the intended meaning of the replaced phrase. The word “condition” was considered synonymous with illness or disease as opposed to a current state of health, and post LDKT recipients felt they no longer had an illness whilst donors had never had a one.

The IPQ was devised to be a generic measure to allow use with all patient groups but recently this perceived advantage has been described as a limitation of the measure (French & Weinman, 2008). Interpretation of the items is thought to differ across various patient groups and may not address all aspects important to the specific group under investigation. Subsequently, the use of supplementary methods that allow for the specific perceptions of a select patient group to be elicited is advocated. If interventions and supports are to be successful, it is necessary that they are tailored to the needs of the specific patient group therefore ways to increase understanding of patient beliefs beyond what is achievable by the IPQ is required in the future (French & Weinman, 2008).

8.6.5 Conclusion

The prospective nature of this study has allowed a clearer evaluation of the living donor kidney transplant and donation experience. In relation to the hypotheses the main conclusions are as follows:

- First, recipients predominantly did not show significant improvements in quality of life, psychosocial wellbeing, and functional and cognitive abilities within the first 6 months post transplant. Significant improvement was noted at 6 weeks post transplant for a short working memory task, and with regards to the degree of improvement in relationships only.

- Second, donors showed significant deterioration at 6 weeks post donation in measures of physical functioning; ability to conduct daily physical activities; ability to conduct daily psychosocial activities, and satisfaction with physical health, all of which returned to a level similar to pre-donation results by 6 months.

- Third, locus of control and optimism measured pre LDKT were related to some aspects of recovery. Higher levels of optimism within donors was related to a larger degree of improvement in satisfaction with physical health from pre to 6 months post LDKT, and a stronger internal locus of control was related to a larger degree of improvement in satisfaction with psychological aspects of quality of life from pre to 6 months post LDKT. Self efficacy was not related to level of recovery. A paradoxical finding was observed with recipients whereby higher levels of optimism were related to greater deterioration in physical functioning, daily physical abilities and satisfaction with psychological health.

The results of this study suggest that LDKT, with regards to quality of life, psychosocial wellbeing, and functional and cognitive, is a relatively safe procedure for donors as any negative significant changes were temporary and returned to a pre-donation level by 6 months post operation. However, in this study LDKT only resulted in a significant improvement for recipients with regards to a short test of working memory and their perceived relationship with the donor, and other family and friends. There was no significant change on any other measure from pre to 6 months post LDKT which does not support the procedure’s anticipated benefit to the recipient’s quality of life within the first 6 months. Careful consideration should be given to the results and subsequent interpretations in light of the small sample size, reduced statistical power, use of multiple measures and a relatively short follow-up period.

Chapter 9 General Discussion

9.1 Overview

This final chapter provides a general discussion of the findings obtained throughout this thesis and their contribution to current knowledge. Implications for theory, clinical practice and future research are proposed, and reflections upon the observed limitations are considered.

9.2 Introduction

The reality of living on the liver transplant waiting list has recently been brought to public attention in the UK by Frank Deasy, a TV writer and producer, diagnosed with liver cancer. In his article for the Observer newspaper, the frustration of waiting and his powerlessness to obtain the treatment he desperately needed were eloquently described (Deasy, 2009). Whilst Deasy waited for a new liver, the benefits of receiving a liver transplant were also publicised by Stephen Jobs, chief executive of Apple Inc. Having taken time out from his position within the company, it transpired that Jobs had done so to receive a liver transplant. Upon returning to work, he took the opportunity to publicly express his gratitude to the donor, whose death had saved his life (Arthur & Johnson, 2009). However, Frank Deasy was not as fortunate and died a week after his article was published, leaving a wife and three young children (McVeigh, 2009).

Such high profile cases highlight the current, worldwide situation that is a result of the shortage of livers donated following death. Whereas some people are lucky enough to receive a liver in time, others are not. Living Donor Liver Transplantation (LDLT) was introduced as an alternative treatment to prevent deaths on the liver transplant waiting list, but it is not medically appropriate for all patients and, as this thesis shows, it is not always accepted by eligible patients and their families.

Given the relative novelty of the LDLT procedure worldwide, and specifically in the UK, there is very limited psychological research within the area. Therefore, the central aim of this thesis was to extend current knowledge by evaluating the functional and psychosocial impact of LDLT on both donors and recipients. However, the very slow uptake of the procedure in Scotland generated further important research aims that became integral to this thesis. The introduction of LDLT at the Scottish Liver Transplant Unit (SLTU) in 2006 was originally described by the then Minister of Health, Mr Andy Kerr, as a “lifeline” for patients on the liver transplant waiting list in Scotland, and yet, there has been a reluctance to grab hold of this lifeline (Gray, 2005). Consequently, an additional aim of this thesis was to elicit the reasons for this reluctance and to identify what factors contributed to the decision to decline LDLT. Establishing the reasons behind the slow uptake is an essential basis for the development of strategies to increase acceptance of LDLT.

Whilst previous research has assessed aspects of quality of life and the decision making process of LDLT donors, perhaps comparing results to donors who were unsuitable for LDLT, or between donors who did and did not suffer any complications, there has never been an attempt to understand why many donors and recipients actively decline the option (e.g. Walter, Bronner, Pascher, Steinmüller, Neuhaus, Klapp et al, 2002; Walter, Bronner, Steinmüller, Klapp, & Danzer, 2002). Chapters 3, 4, 5 and 7 of this thesis address this existing lacuna in current research.

9.3 The Influence of Perceived Risk

The concept of risk became a core theme throughout this thesis. The decision to investigate living donation predominantly derived from awareness of the risk of death and complications involved for the healthy donor. Within living donation, the safety of the donor is of paramount concern yet if risk is to be minimised, knowledge of the functional and psychosocial impact of living donation is required, in addition to rates of mortality and morbidity. Therefore, to conduct a comprehensive psychological evaluation of the impact of LDLT upon donors and their recipients was the main aim of this thesis, but, ironically, it was this very risk to the donor that prevented such an evaluation in Scotland taking place. Chapter 4 (Considering LDLT) describes how the risk to the donor specifically deterred the pursuit of LDLT by potential recipients.

In Chapter 4 it was highlighted that for patients to agree to LDLT meant agreeing to cause harm to, and possibly the death of, their loved one and this was not a decision they could easily make. Anticipated feelings of guilt if anything was to happen to the donor as a result of their attempts to help the patient could only be avoided if LDLT was refused. However, whilst the risk to the donor dissuaded them, the risk to their own mortality meant that LDLT could not be completely ruled out by patients, but rather would be considered as a last option. It was understood that if the patient had no other choice potential feelings of guilt would be minimised, and the risk to the donor would be more easily justified. For the potential donor, it was the risk of the patient dying before receiving a deceased donation that resulted in their immediate reaction to offer to donate. However, the risk to themselves, as the donor, reduced enthusiasm to donate by enhancing concern for their own personal situation. It was not simply the risk of death or complications itself, but rather how this would practically impact on their life and therefore on the life of their families. For example, having young children, or starting a new job, curbed initial enthusiasm for the procedure (see Chapter 4: Considering LDLT) (McGregor, Swanson, Hayes, Forsythe, & O'Carroll, 2009).

Despite the influence of risk in the decision to reject LDLT, it is important to note that risk itself is a poorly understood concept. This was the conclusion found in Chapter 3 (Attitudes to LDLT) and supported previous findings (Neuberger et al, 2003). The results described in Chapter 3, suggested general support for the introduction of LDLT but the majority of the general public either could not answer the risk related questions or would only allow relatives to donate to them if there was no risk involved (McGregor et al, 2008). Risk is an inevitable factor in any operation and an understanding and acceptance of this is essential to the success of any LDLT programme.

As risk is poorly understood, and yet is the main reason for the decline of the LDLT option, in Chapter 7 (The effect of message frame) we tried to understand more about how risk is perceived. If interventions could be recommended to improve understanding of risk, risk may cease to be such a strong barrier and allow more open consideration of the acceptance of LDLT.

Within the discussion of the results described in Chapter 3 (Attitudes to LDLT) a possible influence of message frame was proposed. It was suggested that had the risk options contained in the devised questionnaire been presented to participants in terms of survival (e.g. 199 in 200 survive) as opposed to death (e.g. 1 in 200 die), different responses may have been obtained. Therefore, in Chapter 7, the influence of message frame on perceptions of risk was directly tested. A review of previous framing studies concurred that a more favourable outcome following positive frames compared to negative frames was a common finding (Levin, Schneider, & Gaeth, 1998). However, the study described in Chapter 7 (The effect of message frame) was the first to consider the effect of message frame within the context of living organ donation, an altruistic act for a known other, and therefore tested the consistency of the above finding. Results suggest that presenting information using a positive/gain frame encouraged willingness to become a donor when the risk to the donor was relatively low, i.e. when the donation of a kidney was considered. When the risk to the donor was high, as in the donation of a liver, frame had no effect. The risk or cost to the donor was considered so high with living liver donation that additional information in the form of frame had little impact. This could perhaps be true for other forms of external information so that regardless of the benefits of LDLT, the cost to the donor predominates and the option is prematurely ruled out before further processing of relevant information occurs. This highlights to the transplant team the importance of taking time to explain the disadvantages and advantages of LDLT, and of giving consideration to necessary supports and actions to help reduce the perceived risk and cost to potential donors. It is important that donors are not unnecessarily prevented from pursuing this life-saving procedure.

Chapter 5 also described how, from the perspective of the medical staff at the SLTU, the risk to the donor was an influencing factor to the low uptake of LDLT. Chapter 5 describes a further unique study as previous investigation into the views of medical professionals about LDLT have been of a survey design and have approached general views about LDLT as opposed to the running of a specific LDLT programme (Cotler et al, 2003; Ríos, Conesa, Ramírez, Galindo, Martínez, Pons et al, 2005). No other study with medical professionals has queried why LDLT is not always accepted by eligible recipients and donors. The results echo previous findings in relation to support from staff for the option of LDLT, in principle, and offer more insight into the moral dilemma faced by surgeons, as indicated in Cotler and colleagues (2003).

The results of Chapter 5 (Views of medical staff) highlight how both the culture of the unit and of the Scottish population were both influential to the slow course of the LDLT programme developed at the SLTU. The risk involved with LDLT was indicated to be the main deterrent to its uptake in Chapter 4 (Considering LDLT) but Chapter 5 allowed this risk to be considered in a wider context. The recent changes and improvements to the deceased donation allocation system, has meant that currently fewer patients are dying on the waiting list. This, in addition to the embedded culture of the Scottish population whereby donations offered by a younger generation are not generally accepted by recipients of a comparatively older generation, do little to encourage the procedure and acceptance of the risk. The results, in light of the fact that only one LDLT procedure has been carried out at the unit in over three years, question the future of LDLT in Scotland. However, as patients continue to be referred for transplant and a waiting list continues to exist, the National Services Division, who commissioned the LDLT programme, has agreed for the unit to continue to offer the option of LDLT to those who do wish to pursue it, with funding reviewed on an annual basis (Scottish liver Transplant Unit, unpublished data).

9.4 Overcoming perceived risk

Chapter 6 describes the experience of the first and only patient in Scotland, along with their donor, to overcome the risk involved and proceed with LDLT. In this instance the recipient and donor were relatively unique in that both were of the same generation, were young, and were partners with no dependents. In relation to the findings of Chapter 4 (Considering LDLT), the recipient in Chapter 6 (Scotland’s first LDLT) described similar views, but was of the opinion that he had now arrived at his last option and finally accepted the need for LDLT. Similarly, the donor in Chapter 6 showed immediate commitment to try and save the recipient’s life, but on this occasion consideration of her personal circumstances did not extend beyond the situation involving the recipient. The nature of the donor and recipient’s relationship, and having no children, employment or mortgage burdens, limited the possible concerns that could deter the donor’s pursuit of LDLT. The risk to the donor was acknowledged, but on this occasion, the donor saw the risk of her husband dying and her own life being destroyed without him as greater. Similarly, the recipient also saw LDLT as a positive move.

Whilst the recipient admittedly had concerns for his donor, he also perceived LDLT as an opportunity to regain control of his and his wife’s future.

Risk was also overcome by living kidney donors and recipients. Recruitment for the LDKT study described in Chapter 8 was more successful than for the LDLT study suggesting that the perceived risk involved for the kidney donor was a weaker deterrent. The results confirm the minimal risk to the donor; no significant deterioration was experienced by donors on any physical, cognitive, or psychosocial measures from pre to 6 months post LDKT. Deterioration in physical abilities (SF36), satisfaction with physical health (WHOQOL Physical), and physical and psychological aspects of daily living (FLP physical and FLP psychological) at 6 weeks post donation were significant but were relatively modest and short lived, returning to a normal level by 6 months. This was an expected outcome as donors’ had experienced major surgery which will inevitably have significant consequences, irrespective of the reason for the operation, but the return to baseline, pre surgery levels by 6 months promotes confidence in this specific procedure.

The results for the recipients of LDKT, as discussed in Chapter 8 (The impact of LDKT), were not as expected. Whilst recipients did not suffer deterioration following the LDKT procedure they also did not show the anticipated significant improvements from pre to 6 months post operation, which questions justification of the risk to the donor. Medically the donation may be warranted due to the suspension of dialysis, but if donors are to continue to put themselves at risk, and see the process as worthwhile, psychosocial benefits to the recipient also need to be noted. However, that is not to say significant improvement would not be apparent at another later time point. The opportunity to reassess donors and recipients on an annual basis would be of benefit to address the overall continuing safety of the procedure and to offer recipients a possible timeline for the indications of significant post transplant improvement.

9.5 Quality of life of donors

The quantitative findings from Chapter 6 (Scotland's first LDLT), although limited in their conclusion, offer general support for the psychosocial and functional safety of LDLT. However, areas of concern are also apparent. Previous studies have predominantly made use of the SF36 and therefore tentative comparisons can be made on this measure. A recent study by Erim et al (2008) found that donors scored above the norm on the physical dimension of the SF36 prior to the LDLT operation, as did Verbesey at al (2005). Kim-Schluger et al (2002) and Miyagi et al (2005) found that the donor scored above the norm at an average of 10 months post LDLT and 4.5 years post LDLT respectively. The results from Chapter 6 (Scotland's first LDLT) echo these findings as the donor scored above the UK norms prior to the operation and continued to do so at 6 months post donation. In addition, the deterioration in the donor's physical functioning described in Chapter 6 has also been found in other studies. Chan et al (2006) found a significant deterioration by 1 month which improved again by 6 months; and Erim et al (2007) also saw a significant decrease from pre to 3 months post LDLT. Physical deterioration is perhaps to be expected following major surgery but the current findings add weight to the need to inform potential donors of physical deterioration associated with donating, and that by 6 months failure to return to pre donation levels of physical ability may still be apparent.

Of much more limited use in research with donors are the measures HADs and WHOQOL-BREF, therefore comparison of results is minimal. In Chapter 6, the mean score for donors on the HADs was consistently within the "normal" range and decreased post donation. This supports the positive results of previous research by Erim and colleagues (2007, 2008) who found HADs scores to be similar to a healthy control group prior to donation with a decrease in scores by 3 months post LDLT (Erim, Beckmann, Kroencke, Schulz, Tagay, Valentin-Gamazo et al, 2008; Erim et al, 2007).

Walter et al (2003) found that donor scores on all 4 domains of the WHOQOL-BREF were higher than norms prior to the operation and 6 months post, yet the physical health and environment domain scores had significantly deteriorated from pre donation levels. A similar pattern was found in Chapter 6 (Scotland's first LDLT) for the donor's physical health domain whereby although above the norm at 6 months, the level remained below that obtained at pre-donation.

The donor selection process operating within each transplant unit should ensure that donors are in peak health prior to donation in an attempt to minimise risk involved and maximise the procedure's chance of success. For this reason, donors are commonly found to score above the national norms, or a sample of healthy controls, pre donation and Scotland's first LDLT donor was no exception. In Chapter 6 (Scotland's first LDLT), the donor was subjected to numerous health examinations prior to donation (e.g. MRI [9]scan, ECG[10]) and was only permitted by the transplant team to donate based on their results. Prior to the operation, scores on the WHOQOL Physical health domain and SF36 Physical functioning domain were above the norm confirming the donor's physical suitability.

A similar screening process is adopted for kidney donors and therefore scores above the norm are also common pre and post LDKT (Ibrahim et al, 2009; Lumsdaine et al, 2005). In Chapter 8 (The impact of LDKT), analysis of scores did not include formal comparison to norms but additional research indicates that donor mean scores were

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[9] Magnetic Resonance Imaging

[10] Electrocardiogram

above the US national norms on the SF36 (mean 84.15) pre and post LDKT (Ware et al, 2000). UK norms covering the necessary age range were not available.

9.6 Qualitative data

Despite the limited statistical conclusions from the quantitative section, the qualitative section of Chapter 6 (Scotland's first LDLT) fulfilled the aim of establishing a more in-depth understanding of the personal experience of LDLT. Similarities with previous interview studies were observed. In Chapter 6, a number of themes emerged as integral to the decision to donate, one of which was the donor's relationship with the recipient, her husband. The recipient's life was dependent on the donors, therefore to protect her own life it was necessary for the donor to save the recipient's. This concurs with a previous study by Kusakabe et al (2008). Kusakabe and colleagues (2008) interviewed donors post donation about their LDLT experience (mean time since donation was not recorded) and found that many donors had offered to donate for their <u>own</u> benefit. Their motivation was not simply to save the recipient but to have the recipient live for the donor's own benefit and those of their family (Kusakabe et al, 2008). This selfish aspect to donation is also observed with blood donation, whereby an increased intention to donate blood is found when the donor expects to benefit from the act in addition to the recipient (Ferguson et al, 2008). The true altruistic nature of blood donation was questioned in the study by Ferguson and colleagues (2008) and implications for the future promotion of blood donation were highlighted. Following the qualitative results reported here, and in Kusakabe et al (2008), a similar conclusion could be suggested of the offer to donate part of your liver. Promoting a 'selfish' aspect to becoming a living liver donor, whereby the benefits of being a donor are highlighted, such as a decrease in distress and improved relationships with the recipient and other friends and families (as described in Chapter 6: Scotland’s first LDLT), could increase intentions to donate amongst potential donors and requires further investigation.

Papachristou et al (2004) also touched upon the motivation of personal gain when analysing the transcripts of donors prior to LDLT. Five ideal types of donors were concluded from their analysis, one of which being “the relationship-orientated donor”. Within this ‘type’ the donor sees donation as an opportunity to maintain an important, positive relationship with the recipient (Papachristou et al, 2004). From the results of the interviews with DP, described in Chapter 6, it is clear that DP falls within this category. Papachristou et al (2009) went on to interview donors 6 months after their donation and found that donating did not change the donor’s positive relationship with the recipient but rather enhanced it (Papachristou, Walter, Schmid, Frommer, & Klapp, 2009). Again this was suggested in the results of Chapter 6 where a positive outcome of the donation was the strengthened emotional bond between the donor and recipient.

Further similarities with the results of Chapter 6 (Scotland’s first LDLT) can be seen with Cabello et al’s (2008) study of donors between 7 and 16 months post donation. The themes elicited from donor interviews included the donors’ commitment to the recipient and consequent determination to see the process of LDLT through (Cabello & Smolowitz, 2008). Such commitment and determination was evident in the interviews with DP but unlike previous studies, her motivation to donate was evidently within the context of not having a choice, due to the limited supply of deceased donations. This finding has implications for the issue of coercion.

Whilst measure’s can be taken to detect and minimise coercion from other individuals, the existence of implicit pressure to donate requires attention from the transplant team. It is important that donors are aware of the choice they have and do not feel under pressure to donate against their wishes. Whilst an element of pressure may be needed to motivate donors through the LDLT experience, and is inevitable given the emotionally charged situation presented in liver transplantation, defining when such pressure becomes coercion is a difficult yet important undertaking of the Donor Advocate Team, whose purpose is to safeguard the welfare of the potential donor.

The interviews with Scotland's first donor and recipient have not only indicated probable factors important to a potential donor's decision making but have also demonstrated the difficult decision recipients must make. By listening to the donor and recipient's personal accounts of the LDLT experience, benefits and problems not anticipated by the author were highlighted, such as the recipient's impression of a fresh start and the donor's continuing, unexplained scar pain. This benefit of qualitative data is also noted in the results of the studies with patients and their families (Chapter 4), and staff (Chapter 5). The finding that LDLT is believed to be a last option, and the cultural influences on the progress of the LDLT programme are interesting and important findings not anticipated by the author, and therefore may have been missed in a purely quantitative thesis.

9.7 Theoretical implications

The results of this thesis can readily be interpreted in relation to Leventhal's self regulation model (SRM) (Leventhal et al, 1984). The SRM stipulates that an individual is motivated to maintain their health status and monitor their condition, taking action when necessary to correct any deviation from their normal, expected state (see Appendix 2 for an illustration of the model). The way in which an individual cognitively and emotionally perceives a health threat influences the action or coping strategy employed, which can subsequently affect recovery.

From the perspective of Scotland's first LDLT recipient, being informed of the need for a liver transplant was a major health threat which he needed to regain control of, and accepting a living liver donation was a way to do this, a way to cope with the impending threat of further deterioration. The decision to opt for this specific coping strategy could be regarded as an active response to the health threat, whilst to make the decision to refuse LDLT and wait for a deceased donation could be regarded as a passive response. Such passive coping was a strategy adopted by many patients interviewed in Chapter 4 (Considering LDLT) and this was in line with their perceived sense of optimism, as depicted in Chapter 5 (Views of medical staff). Patients were perceived to believe that a deceased donation would arrive in time and that their current condition was better than it was therefore the need to react to the health threat was not urgent. However, appraisal of this passive coping strategy if deterioration occurred, could eventually lead to the option of LDLT being sought, a last resort when other coping strategies had failed to improve the patients health. This is the course taken by Scotland’s first LDLT recipient. His hope that a deceased donation would become available depleted over time, hence he agreed to his wife’s donation and accepted LDLT as his last option.

Scotland’s first LDLT recipient talked about his emotional reaction to learning of his condition. He described shock when told of the severity of his condition and concern when he realised his donor could be his wife. This shock was influenced by his belief that the symptoms he had been experiencing prior to transplant diagnosis were just *“a hiccup”* and nothing serious, which itself led him to perceive his condition as temporary. Consequently, the option of LDLT was not accepted straight away but rather was reviewed as he perceived that his condition was deteriorating. For patients who chose not to pursue LDLT, their emotional response to the situation was perhaps more prominent in light of their belief that they were not that ill. Their great concern for the risk to the donor and anticipated feeling of guilt if anything was to happen to their donor, impacted their decision to avoid LDLT (see Chapter 4: Considering LDLT).

As suggested by the SRM, the way in which Scotland's first recipient perceived his condition also affected his recovery. Having believed that the LDLT procedure would cure his condition, the recipient expected to be *"bouncing off the walls"* post transplant but instead he suffered complications, which posed a further threat to his health, resulting in a depressive mood. This was rectified with the adoption of a determined, positive attitude, a coping strategy which enhanced his recovery by 6 months.

The components of the SRM and their interconnections were not only evident when speaking with patients but also when Scotland's first LDLT donor described her experience. For the donor, the threat to her own status quo was the further deterioration of her husband and the offer to donate was a way for her to return to normal with a healthy husband, and reduce her distress surrounding the uncertainty of the deceased organ donation system. The offer to donate possessed a selfish aspect as she was driven to regulate her own quality of life. The potential donors described in Chapter 4 (Considering LDLT) were also driven to offer LDLT as they perceived it had the ability to save their loved one's life, but the anticipated consequences of the procedure meant LDLT was not pursued. In contrast, Scotland first LDLT donor did not have dependents, a mortgage or other such responsibilities and subsequently proceeded with the liver donation. The donor believed any adverse consequences of the procedure would be short lived, and this served to encourage her decision to donate. However, such beliefs negatively affected the donor's perceived quality of life post donation as the ongoing pain around the scar area and the continued, obvious appearance of the scar itself were not anticipated and, therefore, were not compatible with her previous illness perceptions.

The qualitative interviews have highlighted support for the SRM when applied to the area of living liver donation but the strength of relationship between components are currently speculative and require direct quantitative testing in future studies. The importance of the cognitive and emotional representations of the illness or health condition in encouraging consideration of LDLT and predicting recovery of patients requires further investigation if a positive outcome for future donors and recipients is to be appropriately supported.

9.8 Implication for clinical practice

The results of the case study of Scotland’s first LDLT couple, described in Chapter 6, provide the SLTU with an initial evidence base from which future LDLT donors and recipients at the unit can receive realistic information. Preparing donors and recipients for the LDLT experience should include measures to prevent or reduce the negative psychological outcomes described by the donor and recipient which predominately centred on unmet expectations e.g. not being told of the possibility of continuing pain post operation.

It is also clear that efforts should be made to try and fully explain the concept of risk to potential recipients. Medical professionals and the general public have a different understanding and acceptance of risk and this needs to be appreciated when the professionals consult with patients (Chapter 3: Attitudes towards LDLT). Identifying ways in which risk can be better understood by the general public and consideration of LDLT can be encouraged, in light of the cultural context of Scotland and the UK (see Chapter 5: Views of medical staff), is a challenge for future research and needs to be considered by medical professionals involved in transplant.

9.9 Direction for future research

Other future research aims have become apparent through this thesis. Two proposed reasons why LDLT has only been conducted once at the SLTU since its introduction in April 2006 are patients’ concern for the risk to their healthy donor and the poor health of many potential donors. This consequently highlights areas of further psychological research into human behaviour and decision making. Deceased donation poses no risk to the donor and is the preferred method of transplant by patients and medical staff alike (Chapters 4 and 5). Therefore, ways in which to increase the availability and acceptability of deceased donation remains a challenge for psychologists.

An additional challenge relates to improving the health of the general public. Not only would health improvements increase the availability of potential donors for those patients who wish to pursue LDLT, but it would also help to reduce the demand for liver transplantation. Whilst some forms of liver disease are caused by autoimmune disorders, others develop as a result of behaviours such as unprotected sex, intravenous drug abuse, extensive alcohol consumption, and obesity. Consequently, understanding the detrimental behaviour that leads to certain types of liver disease is an important challenge for health psychologists concerned with the prevention of liver disease, liver failure and subsequent liver transplants.

In reference to living donation specifically, future research investigations could include participation from altruistic donors. Although currently LDLT at the SLTU requires that the donor and recipient have a pre-existing relationship, the Human Tissue (Scotland) Act (2006) paved the way for a stranger to anonymously donate a kidney to a patient on the transplant waiting list. Since the introduction of the Act, the renal transplant unit at the RIE have conducted 5 altruistic living kidney donations (unpublished data) and 15 were conducted in the UK between 2008 and 2009 (NHS Blood and Transplant, 2009). Although the physical outcome for altruistic donors should be similar to that for known donors, the psychosocial impact of donating to, or receiving from, someone you do not know and never meet requires further investigation if it is to continue to be an accepted way to increase the supply of kidneys. The protection of donors is paramount and continuation of altruistic donation requires the need for psychological investigations of the LDKT experience with this population.

9.10 Limitations

When this thesis was originally planned its main aim was to evaluate the recipients and donors who enlisted on the new Scottish LDLT programme. However, the very small number of participants who have thus far completed the LDLT procedure in Scotland subsequently altered the structure of the thesis. Despite being an obvious limitation to the main aim, the low uptake is an outcome in itself and has resulted in informative, novel research.

The very slow uptake of the LDLT procedure also limited the study described in Chapter 3 (Attitudes to LDLT) as the assessment of any changes in attitude towards LDLT by the general public and General Practitioners over time was subsequently postponed. It was anticipated that two years following the introduction of LDLT in Scotland would be sufficient to repeat the study and assess any attitudinal changes as a result of LDLT publicity. However, the decision was made to postpone this part of the research until LDLT activity increased in Scotland. As this did not occur within the time frame of the thesis, the second part of this specific study was not achieved.

Chapter 8 (The impact of LDKT) highlighted further limitations with regards to sample size and time constraints as not all participants completed LDKT in time to allow evaluation post LDKT, and the maximum post LDKT evaluation of 6 months limited interpretation of the results (Chapter 8: The impact of LDKT). In addition, a further limitation highlighted in the LDKT study was the measure of illness perceptions, a problem also referred to in Chapters 6 (Scotland’s first LDLT). Inclusion of the IPQ-R was originally conceptualised as an integral part of the study, but it became evident that the wording of the items posed difficulties for the population being researched and it was subsequently withdrawn from analysis. The authors of the IPQ-R have advocated the adaptation of the scale to coincide with the illness being investigated, but despite much deliberation over the specific wording to be used it would appear that the choices of “My condition following the donor operation…” and “My kidney/liver condition since the transplant…” were problematic, causing the participants confusion over the intended meaning (Moss-Morris et al, 2002). In retrospect, a pilot run of the measure could have been administered with a sample of kidney and liver recipients, and kidney donors, to assess the validity of the amended measure prior to use in the main studies.

9.11 Conclusion

Data collection for this thesis was completed in November 2009 and at that time, three and a half years after the programme commenced, the number of LDLT procedures conducted at the SLTU remained at one. Since LDLT was introduced at the SLTU, liver transplant units in Birmingham and Leeds have also developed a LDLT programme, but as far as the author is aware no psychological research is ongoing or planned in either unit. This thesis therefore represents the first functional and psychological investigation of LDLT donors and recipients within the UK. According to published statistics, as of March 2009, Leeds had performed five LDLT operations and Birmingham one, although it is unclear how many were adult to adult procedures and details of donor and recipient outcomes are not yet publicly available (NHS Blood and Transplant, 2009).

It is the belief of the author that, as has recently been suggested, there is great need for a central, National transplant registry that includes documentation of LDLT procedures, with short and long-term outcomes for living liver donors (Rudge, 2009). The results of this thesis would strongly advocate the inclusion of psychological measures within such a registry. Only by collating data from all active LDLT programmes, both NHS and privately funded, using consistent measures and reporting techniques, can a true estimation of physical and psychosocial risk and outcome be established and monitored, realistic expectations provided, and the overall safety of donors prioritised. The Adult-to-Adult Living Donor Liver Transplantation (A2ALL) cohort study established in the USA is perhaps an example of that required in the UK, whereby data from numerous transplant centres are collated, contributing to retrospective and prospective studies, and providing donors and recipients with precise information about the risks and benefits involved (Ghobrial et al, 2008). It is not known how much psychological data is collected within the A2ALL study but publications to date would suggest it is minimal, and yet should be included if the overall safety of donors is to be optimised.

9.12 What does this thesis add?

1. This thesis was the first to establish support for the Scottish general public towards the introduction of LDLT, as an option for those on the transplant waiting list (Chapter 3: Attitudes towards LDLT).

2. This thesis highlighted a difficulty with the understanding of risk by the general public (Chapter 3: Attitudes towards LDLT).

3. For the first time, the views of patients who had chosen not to pursue LDLT were sought and an enhanced understanding of why this was the case was achieved. Despite a risk of personal mortality, for patients on the liver transplant waiting list, the possibility of a life-saving procedure with a high risk to a family member is not a readily acceptable treatment option (Chapter 4: Considering LDLT).

4. Many patients wrongly perceive LDLT to be a last possible option. This result was fed back to the staff at the SLTU and it was suggested that the prerequisites for LDLT (e.g. time to assess donor suitability, and the relatively good health of the recipient) should be made more explicit to patients (Chapter 4: Considering LDLT).

5. The views of family members in their role as potential donors were also sought for the first time and the difficult position they encounter when LDLT is an option was highlighted. Whilst motivated to save their loved one's life, the practical and personal implications of donating have to be considered (Chapter 4: Considering LDLT).

6. This thesis was also the first to interview medical staff involved in the Scottish LDLT programme about their views on the slow uptake of the procedure. As a result, the risk to the donor, as a deterrent to LDLT, has been put into a wider context. Interviewed staff believe deceased donation is preferential due to the elimination of donor risk, and with a reduced perceived need for LDLT, the unit have advocated a conservative approach to its promotion as an option for patients. Reluctance to accept a donation from a donor from a younger generation, patients optimism that a deceased donation will be received, and the poor health of potential donors have additionally impacted the slow uptake of the procedure (Chapter 5: Views of medical staff).

7. This thesis provides the first quantitative report on the functional, cognitive and psychosocial outcome of living donation in Scotland, and is the first report of the procedure as provided on the UK NHS (Chapter 6: Scotland's first LDLT).

8. This thesis provides the first qualitative report on the experience of living donation within Scotland, and is the first report of the experience as provided on the UK NHS (Chapter 6: Scotland's first LDLT).

9. This study was the first to consider the impact of message framing upon living organ donation and results have implications for the generalisation of framing theories. The influence of message framing on the promotion of living donation is

not comparable across LDLT and LDKT. Whilst a gain frame message increased the likelihood of a person donating a kidney, when a liver donation was proposed, there was no significant effect for frame. (Chapter 7: Impact of LDKT).

10. LDLT and LDKT donors experience some functional and psychosocial deterioration at 6 weeks post donation but largely recover by 6 months post donation. These results add to the current, limited psychological literature on living donation (Chapter 6: Scotland’s first LDLT and Chapter 8: Impact of LDKT).
11. With regards to LDKT, the anticipated benefit to recipients may not be quantifiable until after 6 months post operation (Chapter 8: Impact of LDKT).

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Appendix 1: Glossary of Terms

Altruistic donations
This is when a living person donates an organ or part of an organ to a patient awaiting a transplant. The donor and the recipient are, and remain, complete strangers. The Human Tissue Act 2004 / (Scotland) 2006 removed some of the restrictions that previously prevented organ donation between strangers.

Cold Ischemic/ Ischemia Time
This term generally refers to the amount of time between the removal of an organ from a donor to the time it is transplanted into the recipient. A short ischemic time is better for the condition of the organ.

Deceased / cadaveric donation
This is when an organ provided for transplant is obtained from an individual following their death. It is also referred to as a cadaveric donation. Deceased donation can be classified into two groups distinguished by cause of death: heart beating and non heart beating.

Donor Advocate Team (DAT)
The DAT at consists of a consultant physician, a consultant psychiatrist, a transplant social worker and a transplant coordinator. Their purpose is to protect the welfare of the potential donor by establishing that the donor is fully informed and understands the procedure and the risks involved, is psychologically suitable to donate, and is free from coercion. The members of the DAT are not involved in the care of the recipient therefore can put the needs of the potential donor first. The DAT advises the transplant team as to whether or not the potential donor can and should be accepted as a donor (Unpublished protocol).

Heart beating donation
This is a deceased donation whereby the donor has been certified brain stem dead. All brain activity has ceased and a machine is the only means by which the heart continues to beat. When the machine is switched off the heart stops beating and the organs are removed for transplant immediately. As blood was provided to the organs up to the point of their removal the quality of the organs is preserved ready for transplant (Ridley, Bonner, Bray, Falvey, Mackay, Manara et al, 2005).

Marginal livers
Livers that are not in perfect condition and are at high risk of poor function are accepted for transplant. Such livers can include split livers and livers from non-heart beating donors but also livers from older donors (above 60 years of age), or from donors with a known disease. It was previously felt that such livers were not suitable for transplantation but research indicates good results and therefore marginal livers are now being accepted for appropriate patients (Attia, Silva, & Mirza, 2008).

Model for End-Stage Liver Disease (MELD) score
The MELD score provides an indication of the severity of a patients' liver disease and can predict the likelihood of 3 month survival without a liver transplant. The score ranges from 6 to 40 with a higher score meaning higher priority for transplant. The score is calculated using objective clinical measures: serum creatinine level, serum

bilirubin level, and international normalised ratio (INR) of prothrombin time (Wiesner, Edwards, Freeman, Harper, Kim, Kamath et al, 2003). Such measures consider impairment in kidney functioning, the liver's ability to produce bile, and the liver's production of blood clotting factors respectively.

Non-heart beating donation
This is a deceased donation whereby the donor has been declared dead as a result of a cardiac arrest. A heart beat cannot be reinstated. The organs must be removed within a certain time frame from the point of death so as to ensure the quality of the organs for transplantation. The quality of the organ is affected by the duration without blood flow therefore since the legalisation of "brain-stem death", heart beating donations have become the preferable source of organs. However, non heart beating donation is being utilised again in light of the shortage of donated organs (Ridley et al, 2005).

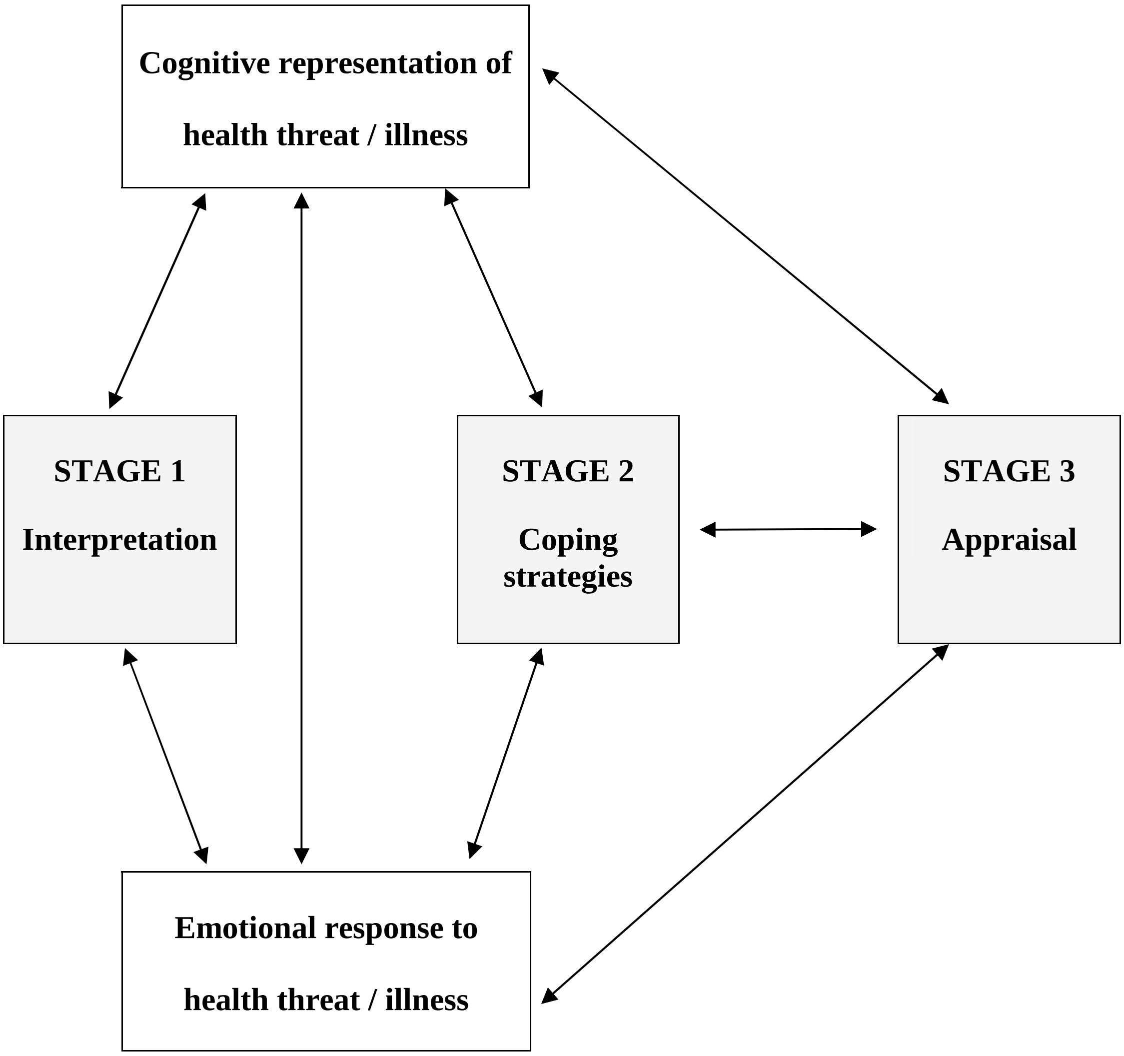
Northern Liver Alliance
The Northern Liver Alliance is a network involving liver transplant units in Edinburgh, Leeds and Newcastle. The three units work together so that a patient in need of a liver transplant in any of the three units, whose condition is considered "top band" (i.e. MELD score of 25 or greater) gets first choice of an organ retrieved from either of the three centres. The alliance increases the donor pool for particularly ill patients within the three centres.

Organ Donation Taskforce
A team of medical professionals, along with members of the general public and media, established in 2006 for the purpose of identifying the barriers and facilitators to organ donation. A systematic review conducted by the taskforce highlighted three main barriers requiring changes: donor identification and referral, donor co-ordination, and donors organ retrieval processes (Organ Donation Taskforce, 2008).

Presumed consent
This denotes a system whereby organ donation following death would occur for every individual unless they had, during life, registered their refusal for this process. Presumed consent is also referred to as an "opt out system". Presently, within the UK an "opt in system" is employed whereby individuals who wish to donate following death must indicate this preference by joining the NHS organ donor register. Consent for organ removal is not presumed. A change to the current UK system, towards presumed consent, has been advocated as a way to increase the number of deceased donations but the merits of a change continue to be debated in political and public spheres (Rithalia, McDaid, Suekarran, Myers, & Sowden, 2009).

Split liver donation
This is a deceased donation whereby the liver is dissected to allow the left lobe to be donated to a child, or small adult recipient, and the larger right lobe to an adult recipient (Neuberger & Gimson, 2007).

Appendix 2: Leventhal's Self Regulation Model (SRM)



Appendix 3: The Short Form 36 (Physical functioning domain) (SF36)

The following questions are about activities you might do during a typical day.
Does **your health now limit you** in these activities? If so, how much?
Please circle one number on each line.

		Yes, limited a lot	Yes, limited a little	No, not limited at all
1.	Vigorous activities, such as running, lifting heavy objects, participating in strenuous sports	1	2	3
2.	Moderate activities, such as moving a table, pushing a vacuum cleaner, bowling or playing golf	1	2	3
3.	Lifting or carrying groceries	1	2	3
4.	Climbing several flights of stairs	1	2	3
5.	Climbing one flight of stairs	1	2	3
6.	Bending, kneeling or stooping	1	2	3
7.	Walking more than one mile	1	2	3
8.	Walking half a mile	1	2	3
9.	Walking one hundred yards	1	2	3
10.	Bathing or dressing yourself	1	2	3

Appendix 4: Functional Limitations Profile (FLP)

When reading each of the following statements think of yourself **today** and consider if the statement describes you. **Only tick the box if (a) you agree with the statement AND, (b) you feel it is due to the state of your health.**

Mobility: These next statements describe how you get about the house and outside. Only tick the box if you agree with the statement, **and it is due to the state of your health.**			
1.	I only get about in one building.		
2.	I stay in one room.		
3.	I stay in bed more.		
4.	I stay in bed most of the time.		
5.	I do not use public transport now.		
6.	I stay at home most of the time.		
7.	I only go out if there is a lavatory nearby.		
8.	I do not go into town.		
9.	I only stay away from home for short periods.		
10.	I do not get about in the dark or in places that are not lit unless I have someone to help.		

Recreation and pastime: The following statements describe the activities you usually do in your spare time, for relaxation, entertainment or just to pass the time. Again, think of yourself **today**. Only tick the box if you agree with the statement, **and it is due to the state of your health**.			
11.	I spend shorter periods of time on my hobbies and recreation.		
12.	I go out less often to enjoy myself.		
13.	I am cutting down on some of my usual inactive pastimes; for example, I watch TV less, play cards less, or read less.		
14.	I am not doing any of my usual inactive pastimes; for example, I do not watch TV, play cards, or read.		
15.	I am doing more inactive pastimes instead of my other usual activities.		
16.	I take part in fewer community activities.		
17.	I am cutting down on some of my usual physical recreation or more active pastimes.		
18.	I am not doing any of my usual physical recreation or more active pastimes.		

Alertness: These statements describe your general alertness **today**. Only tick the box if you agree with the statement, **and it is due to the state of your health.**			
19.	I am confused and start to do more than one thing at a time.		
20.	I have more minor accidents; for example, I drop things, I trip and fall, or I bump into things.		
21.	I react slowly to things that are said or done.		
22.	I do not finish things I start.		
23.	I have difficulty reasoning and solving problems; for example, making plans, making decisions, or learning new things.		
24.	I sometimes get confused; for example, I do not know where I am, who is around, or what day it is.		
25.	I forget a lot; for example, things that happened recently, where I put things, or to keep appointments.		
26.	I do not keep my attention on any activity for long.		
27.	I make more mistakes than usual.		
28.	I have difficulty doing things which involve thought and concentration.		

Ambulation: The following statements describe walking and use of stairs. Remember, think of yourself **today**. Only tick the box if you agree with the statement**, and if it is due to the state of your health**.			
29.	I walk shorter distances or often stop for a rest.		
30.	I do not walk up or down hills.		
31.	I only use stairs with a physical aid; for example, a handrail, stick or crutches.		
32.	I only go up and down stairs with assistance from somebody else.		
33.	I get about in a wheelchair.		
34.	I do not walk at all.		
35.	I walk by myself but with some difficulty; for example, I limp, wobble, stumble or I have a stiff leg.		
36.	I only walk with help from somebody else.		
37.	I go up and down stairs more slowly; for example, one step at a time or I often have to stop.		
38.	I do not use stairs at all.		
39.	I get about only by using a walking frame, crutches, stick, walls, or hold onto furniture.		
40.	I walk more slowly.		

Appendix 5: Illness Perception Questionnaire – Revised (IPQ-R) (Donor post transplant version)

		Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree
1	My condition following the donor operation will last a short time.					
2	My condition following the donor operation is likely to be permanent rather than temporary.					
3	My condition following the donor operation will last for a long time.					
4	This condition following the donor operation will pass quickly.					
5	I expect to have this condition following the donor operation for the rest of my life.					
6	My condition following the donor operation is a serious condition.					
7	My condition following the donor operation has major consequences on my life.					
8	My condition following the donor operation does not have much effect on my life.					
9	My condition following the donor operation strongly affects the way others see me.					
10	My condition following the donor operation has serious financial consequences.					
11	My condition following the donor operation causes difficulties for those who are close to me.					
12	There is a lot which I can do to control my symptoms.					
13	What I do can determine whether my condition following the donor operation gets better or worse.					
14	The course of my condition following the donor operation depends on me.					
15	Nothing I do will affect my condition following the donor operation.					
16	I have the power to influence my condition following the donor operation.					
17	My actions will have no affect on the outcome of my condition following the donor operation.					
18	My condition following the donor operation will improve in time.					

		Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree
19	There is very little that can be done to improve my condition following the donor operation.					
20	My treatment will be effective in curing my condition following the donor operation.					
21	The negative effects of my condition following the donor operation can be prevented (avoided) by my treatment.					
22	My treatment can control my condition following the donor operation					
23	There is nothing which can help my condition following the donor operation.					
24	The symptoms of my condition following the donor operation are puzzling to me.					
25	My condition following the donor operation is a mystery to me.					
26	I don’t understand my condition following the donor operation.					
27	My condition following the donor operation doesn’t make any sense to me.					
28	I have a clear picture or understanding of my condition following the donor operation.					
29	The symptoms of my condition following the donor operation change a great deal from day to day.					
30	My symptoms come and go in cycles.					
31	My condition following the donor operation is very unpredictable.					
32	I go through cycles in which my condition following the donor operation gets better and worse.					
33	I get depressed when I think about my condition following the donor operation.					
34	When I think about my condition following the donor operation I get upset.					
35	My condition following the donor operation makes me feel angry.					
36	My condition following the donor operation does not worry me.					
37	Having this condition following the donor operation makes me feel anxious.					
38	My condition following the donor operation makes me feel afraid.					

Appendix 6: Recovery Locus of Control (RLOC)

These are statements other people have made about their recovery following organ donation. Please will you indicate the extent to which you agree or disagree with each statement in the right-hand columns.
Please respond to each statement with regards to **your recovery following your liver donation operation**.

		Strongly agree	Agree	Uncertain	Disagree	Strongly disagree
1.	How I manage in the future depends on me, not on what other people can do for me.					
2.	It's often best just to wait and see what happens.					
3.	It's what I do to help myself that's really going to make all the difference.					
4.	My own efforts are not very important, my recovery really depends on others.					
5.	It's up to me to make sure that I make the best recovery possible under the circumstances.					
6.	My own contribution to my recovery doesn't amount to much.					
7.	Getting better now is a matter of my own determination rather than anything else.					
8.	I have little or no control over my progress from now on.					
9.	It doesn't matter how much help you get, in the end it's your own efforts that count.					

Appendix 7: Visual Analogue Scales (VAS) (Donor post operation version)

Please read each of the following questions and indicate on the scale provided where your views lie by marking the line with a cross e.g.

Not at all ——————————————————————✕—————— An extreme amount

1. Has your relationship with the recipient improved following donation?

Not at all ————————————————————————————— An extreme amount

2. Has donation had an adverse affect on your relationship with the recipient?

Not at all ————————————————————————————— An extreme amount

3. Has your relationship with other family members/friends improved since the donation of part of your liver?

Not at all ————————————————————————————— An extreme amount

4. Has the donation of part of your liver had an adverse affect on your relationship with other family members and friends?

Not at all ————————————————————————————— An extreme amount

5. Have you suffered any financial loss due to the donation of part of your liver?

Not at all ————————————————————————————— An extreme amount

6. Do you experience discomfort from the scar following liver donation?

Not at all ————————————————————————————— An extreme amount

7. Do you worry about the remaining part of your liver?

Not at all ————————————————————————————— An extreme amount

8. If it were possible, would you donate part of your liver again?

Definitely No ————————————————————————————— Definitely Yes

Appendix 8: World Health Organisation Quality of Life Scale – Bref (WHOQOL-BREF)

This questionnaire asks how you feel about your quality of life, health, or other areas of your life. Please answer all the questions. If you are unsure about which response to give to a question, please choose the one that appears most appropriate. This can often be your first response.

Please keep in mind your standards, hopes, pleasures and concerns. We ask that you think about your life in the last two weeks. For example, thinking about the last two weeks, a question might ask whether or not you feel you have received the support from others that you need.

You should circle the number that best fits how much support you got from others over the past two weeks. So you would circle the number 4 if you got a great deal of support from others as follows:

	Not at all	Not much	Moderately	A great deal	Completely	
Do you get the kind of support from others that you need?	1	2	3	[✓ 4]	5	

You would circle number 1 if you did not get any of the support that you needed from others in the last two weeks.
Now please read each question, assess your feelings, and circle the number on the scale for each question that gives the best answer for you.

		Very poor	Poor	Neither poor nor good	Good	Very good
1	How would you rate your quality of life?	1	2	3	4	5

		Very Dissatisfied	Dissatisfied	Neither satisfied nor dissatisfied	Satisfied	Very satisfied
2	How satisfied are you with your health?	1	2	3	4	5

The following questions ask about how much you have experienced certain things in the last two weeks.

		Not at all	A little	A moderate amount	Very much	An extreme amount
3	To what extent do you feel that (physical) pain prevents you from doing what you need to do?	1	2	3	4	5
4	How much do you need any medical treatment to function in your daily life?	1	2	3	4	5
5	How much do you enjoy life?	1	2	3	4	5
6	To what extent do you feel your life to be meaningful?	1	2	3	4	5

		Not at all	A little	A moderate amount	Very much	Extremely
7	How well are you able to concentrate?	1	2	3	4	5
8	How safe do you feel in your daily life?	1	2	3	4	5
9	How healthy is your physical environment?	1	2	3	4	5

The following questions ask about how completely you experience or were able to do certain things in the last two weeks.

		Not at all	A little	Moderately	Mostly	Completely
10	Do you have enough energy for everyday life?	1	2	3	4	5
11	Are you able to accept your bodily appearance?	1	2	3	4	5
12	Have you enough money to meet your needs?	1	2	3	4	5
13	How available to you is the information that you need in your day-to-day life?	1	2	3	4	5
14	To what extent do you have the opportunity for leisure activities?	1	2	3	4	5

		Very poor	Poor	Neither poor nor good	Good	Very good
15	How well are you able to get around?	1	2	3	4	5

The following questions ask you to say how good or satisfied you have felt about various aspects of you life over the last two weeks.

		Very dissatisfied	Dissatisfied	Neither satisfied nor dissatisfied	Satisfied	Very satisfied
16	How satisfied are you with your sleep?	1	2	3	4	5
17	How satisfied are you with your ability to perform your daily living activities?	1	2	3	4	5
18	How satisfied are you with your capacity for work?	1	2	3	4	5
19	How satisfied are you with yourself?	1	2	3	4	5
20	How satisfied are you with your personal relationships?	1	2	3	4	5
21	How satisfied are you with your sex life?	1	2	3	4	5
22	How satisfied are you with the support you get from your friends?	1	2	3	4	5
23	How satisfied are you with the conditions of your living place?	1	2	3	4	5
24	How satisfied are you with your access to health services?	1	2	3	4	5
25	How satisfied are you with your transport?	1	2	3	4	5

The following question refers to how often you have felt or experienced certain things in the last two weeks.

		Never	Seldom	Quite often	Very often	Always
26	How often do you have negative feelings such as blue mood, despair, anxiety, depression?	1	2	3	4	5

Appendix 9: Life Orientation Test Revised (LOTR)

Please tick the box that best represents your answer.

Please be as honest and accurate as you can throughout. Try not to let your response to one statement influence your responses to other statements.

There are no “correct” or “incorrect” answers. Answer according to your own feelings, rather than how you think “most people” would answer.

		Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree
1.	In uncertain times, I usually expect the best.					
2.	It’s easy for me to relax.					
3.	If something can go wrong for me, it will.					
4.	I’m always optimistic about the future.					
5.	I enjoy my friends a lot.					
6.	It’s important for me to keep busy.					
7.	I hardly ever expect things to go my way.					
8.	I don’t get upset too easily.					
9.	I rarely count on good things happening to me.					
10.	Overall, I expect more good things to happen to me than bad.					

Appendix 10: Generalised Self Efficacy Scale (GSES)

Please tick the box that best represents your answer. Please be as honest and accurate as you can throughout. Try not to let your response to one statement influence your responses to other statements.
Answer according to your own feelings, rather than how you think "most people" would answer.

		Not at all true	Hardly true	Moderately true	Exactly true
1.	I can always manage to solve difficult problems if I try hard enough.				
2.	If someone opposes me, I can find the means and ways to get what I want.				
3.	It is easy for me to stick to my aims and accomplish my goals.				
4.	I am confident that I could deal efficiently with unexpected events.				
5.	Thanks to my resourcefulness, I know how to handle unforeseen situations.				
6.	I can solve most problems if I invest the necessary effort.				
7.	I can remain calm when facing difficulties because I can rely on my coping abilities.				
8.	When I am confronted with a problem, I can usually find several solutions.				
9.	If I am in trouble, I can usually think of a solution.				
10.	I can usually handle whatever comes my way.				

Appendix 11: Hospital Anxiety and Depression Scale (HADs)

Please read each item and tick the box that comes closest to how you have been feeling in the past week. Don’t take too long over your replies; your immediate response to each item will probably be more accurate than a long thought out response.

1. I feel tense or ‘wound up’:
   - Most of the time ☐
   - A lot of the time ☐
   - From time to time, occasionally ☐
   - Not at all ☐
2. I still enjoy the things I used to enjoy:
   - Definitely as much ☐
   - Not quite so much ☐
   - Only a little ☐
   - Hardly at all ☐
3. I get a sort of frightened feeling as if something awful is about to happen:
   - Very definitely and quite badly ☐
   - Yes, but not too badly ☐
   - A little, but it doesn’t worry me ☐
   - Not at all ☐
4. I can laugh and see the funny side of things:
   - As much as I always could ☐
   - Not quite so much now ☐
   - Definitely not so much now ☐
   - Not at all ☐
5. Worrying thoughts go through my mind:
   - A great deal of the time ☐
   - A lot of the time ☐
   - From time to time but not too often ☐
   - Only occasionally ☐
6. I feel cheerful:
   - Not at all ☐
   - Not often ☐
   - Sometimes ☐
   - Most of the time ☐
7. I can sit at ease and feel relaxed:
   - Definitely ☐
   - Usually ☐
   - Not often ☐
   - Not at all ☐
8. I feel as if I am slowed down:
   - Nearly all the time ☐
   - Very often ☐
   - Sometimes ☐
   - Not at all ☐
9. I get a sort of frightened feeling like ‘butterflies in the stomach’:
   - Not at all ☐
   - Occasionally ☐
   - Quite often ☐
   - Very often ☐
10. I have lost interest in my appearance:
    - Definitely ☐
    - I don’t take as much care as I should ☐
    - I may not take quite as much care ☐
    - I take just as much care as ever ☐
11. I feel restless as if I have to be on the move:
    - Very much indeed ☐
    - Quite a lot ☐
    - Not very much ☐
    - Not at all ☐
12. I look forward with enjoyment to things:
    - A much as ever I did ☐
    - Rather less than I used to ☐
    - Definitely less than I used to ☐
    - Hardly at all ☐
13. I get sudden feelings of panic:
    - Very often indeed ☐
    - Quite often ☐
    - Not very often ☐
    - Not at all ☐
14. I can enjoy a good book or radio or TV programme:
    - Often ☐
    - Sometimes ☐
    - Not often ☐
    - Very seldom ☐

Appendix 12: Example of story used in Rivermead Behavioural Memory Test (RBMT)

Story Immediate:
I am going to read you a passage of about five or six lines. Listen carefully, and when I have finished, tell me back as much as you can remember. Ready?

Mr Brian / Kelly, / a Security Express employee / was shot dead / on Monday / during a bank raid / in Brighton. / The four raiders / all wore masks / and one carried / a sawn off / shotgun. / Police detectives / were sifting through / eye-witness accounts / last night. / A police spokesman said / "He was a very brave man. / He went for / the armed raider / and put up a hell of a fight".

Now tell me back as much of the story as you can.

Story Delayed:
Do you remember that story I read to you earlier? I would like to know how much of it you can remember now. Tell me as much as you can.

[If the subject cannot remember anything about the story then provide a cue – say "It started off, Mr Brian Kelly, a Security Express employee….. If subject needs cue deduct 1 point from total.]

Appendix 13: Example of Information Sheet sent to GPs (Chapter 3)

NHS
Lothian

Room *****
Edinburgh Royal Infirmary
51 Little France Crescent
Old Dalkeith Road
Edinburgh EH16 4SA

Dear

Attitudes to Living Donor Liver Transplantation in Scotland

You are being invited to take part in the above research project. This study has been developed in order to look into the views of the Scottish population with regards to live liver donations. Before you decide whether or not to take part in this survey and fill out the enclosed questionnaire, it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully.

What is the purpose of this study?

In the UK liver transplants are carried out using livers donated from people who have died. This is an essential operation for many people suffering from severe liver disease but too few livers are donated for transplant. To try and overcome this problem, many countries have introduced a new programme called Living Donor Liver Transplantation (LDLT). Within this type of programme a family member may be able to donate up to 60% of their liver to a loved one with severe liver disease. In 2006, Edinburgh Royal infirmary will be the first transplant unit in the UK to offer LDLT with adults. We are interested in finding out how the Scottish population feel about this new development. A short questionnaire has been designed for this purpose.

Why have I been chosen?

Within this study we hope to obtain the views of various groups of people involved in the area of transplantation. As you are a General Practitioner working in Scotland we are particularly interested in obtaining your views.

Do I have to take part?

It is entirely up to you whether you take part in this study or not. If you do decide to take part you are reminded that your participation is voluntary and therefore you are under no obligation to return the completed questionnaire.

What will happen to me if I decide to take part?
Enclosed is a short questionnaire. We would be grateful if you could read the questions and note your response to each one by ticking the box that best represents your answer. Completed forms should be returned in the stamped addressed envelope provided with this letter. It is anticipated that the questionnaire will take approximately 10 minutes to complete.

What if something goes wrong?
We do not anticipate any problems occurring when you participate in this study. However, if you have any complaints with regards to the study please contact the research assistant, Lesley McGregor, on 0131 *** **** or lesley.mcgregor@****.****.

Will my taking part be kept confidential?
Confidentiality is an important feature of this study and therefore we can assure you that the information you provide will be for the purpose of this research only. Completed questionnaires will be kept anonymous.

What will happen to the results of the research study?
The results of this research study will be published in medical literature. As responses to the questionnaire will be anonymous, it will be impossible for results from individual participants to be identified.

Who has reviewed this study?
This study has been reviewed by Lothian Research Ethics Committee.

Further information
If you wish any further information on the study please contact either of the following persons:

Prof. Peter Hayes	Prof. Ronan O'Carroll
0131 *** ****	01786 *** ****

If you would like to speak to someone entirely independent of the study, you can contact Dr K. Simpson on 0131 *** ****.

I thank you in advance for your time and if you decide to take part, I look forward to receiving your completed questionnaire by the…*(day and date).*

Kind regards,

Lesley McGregor
(Research assistant)

Appendix 14: Example of Information Sheet sent to Patients (Chapter 4)

Department of Psychology
University of Stirling
Stirling
FK9 4LA

Attitudes towards the Living Donor Liver Transplantation programme in Scotland

Dear **Potential participant (patient / recipient)*

You are being invited to take part in the above research study. This study has been developed by Stirling University in order to investigate what people think about the new Living Donor Liver Transplantation (LDLT) programme, now available within the Scottish Liver Transplant Unit (SLTU). We have worked closely with Maureen Cunningham (transplant co-ordinator) and other members of the SLTU team to develop this project. Before you decide whether or not to take part in this study it is important for you to understand why the research is being carried out and what participation will involve. Please take time to read the following information carefully.

What is the purpose of the study?
Since the 1st April 2006 the SLTU have been able to offer certain patients on the liver transplant waiting list the option of living liver donation. Information packs devised by the transplant team to inform patients of this alternative treatment, are being distributed to potentially suitable patients and their families. The purpose of this research project is to find out more about what people think of the information they have received, and how this has influenced their decision regarding living liver donation.

Why have I been chosen?
All patients on the liver transplant waiting list who have received a living donor liver transplant information pack will be asked to participate. The transplant co-ordinators at the SLTU have agreed to inform us whenever a patient currently on the transplant waiting list has been provided with in information pack. A minimum of one month later each patient is sent the letter of invitation that you are now reading.

Do I have to take part?
It is entirely up to you whether you take part in this study or not. We will telephone you within the next few days to ask if you have made a decision regarding your participation. If you decide to take part remember that your participation is voluntary and that you are free to change your mind at any time without giving a reason.

Will my taking part in this study be kept confidential?
We can assure you that the information you provide will be kept confidential. The transplant team will not have access to any of the information you provide and the data will be used only for the purpose of this research.

What will happen to me if I take part?
Participation will involve a brief interview regarding your views on the Living Donor Liver Transplantation programme. It is up to you whether the interview is conducted face-to-face with the research assistant, either within the Edinburgh Royal Infirmary or in your own home, or over the telephone. The interview will last approximately 30 minutes. The research assistant will call you within the next few days to answer any questions you may have. If you are happy to participate in the study, the research assistant will, during this telephone call, arrange with you a convenient date and time for the interview to take place. Where appropriate, your travel expenses will be paid.

What if I am unhappy with the study?
We do not anticipate any problems occurring when you participate in this study. However, if you do have any complaints with regards to the study please contact Lesley McGregor, research assistant on 0131 *** **** or at lesley.mcgregor@stir.ac.uk

What will happen to the results of the research study?
The results of this research study may be published in medical and psychological literature. All information obtained about participants will of course be made anonymous. The results of the study will be fed back to the transplant unit in general terms such as 10% of people said this and 54% of people felt that. It will be impossible for results from individual participants to be identified.

Who is organising and funding the research?
This study is organised by the University of Stirling and is funded by the Chief Scientist Office.

Who has reviewed the study?
Lothian Research Ethics Committee has reviewed this study.

Contact for further information.
If you would like further information regarding this study please feel free to contact Professor Ronan O'Carroll, chief investigator of this study, on 017** *** ***, or at the address at the top of the first page.

If you would prefer to speak to someone entirely independent from the study, you can contact Dr Rory O'Conner on 017** *** ****

I thank you for your time and we look forward to speaking with you in the next few days.

Kind Regards,

Prof. Ronan O'Carroll	Lesley McGregor
(Chief Investigator)	(Research Assistant)

Appendix 15: Interview schedule for patients (Chapter 4)

- How long have you been on the liver transplant waiting list?

- How long had you been on the list when you were given the information pack on LDLT?

- What were your first impressions of the LDLT information pack?
  Was the information clear and understandable?

- What would you say was the best thing about the pack? / the worst thing about the pack?

- How do you feel about the volume of information given within the packs?

- Would you have preferred to have received the information pack earlier in your illness or at a later stage?

- Was receiving the information pack from the transplant unit the first you had heard of LDLT?
  If yes: what were your initial thoughts about LDLT upon receiving the information pack?
  If no: when did you first hear of LDLT?

- What were your initial thoughts on living liver donation?

- Has the information pack affected your views at all?

- We've talked about the written information you've received but has anyone from the liver unit spoken to you about living liver donation?
  Who provided the information?
  Was the information clear and understandable?

- Have you been given the opportunity to ask questions?
  If yes: What questions do you have/have you asked?
  Have responses been given clearly? Have responses been adequate?
  If no: Why do you feel that is the case?
  Do you have any questions concerning living liver donation? What are they?

- Do you feel the staff from the transplant unit are approachable?
  Knowledgeable? Honest?

- Is living donation something that you are considering?
  If yes: What factors are particularly important to your decision making?
  If no: Could you describe to me your reasons for not wishing to pursue living donation further?
    What is it that is puts you off?
    Any concerns about safety, complications, etc?
    Concerned about risk to yourself or relative?

Are you concerned that it is a new procedure?

- Is there anything you would change about the living donor liver transplantation programme available at the SLTU?

- If it were available, would you be interested in watching a DVD or video of other living liver donation recipients and/or donors telling their stories?
  What are your thoughts on that?

- Is there anything else you would like to say, about living liver donation, that you feel I have not touched upon?

Potential donor?
Do you know of any family member or friend who has read the LDLT information booklet and perhaps considered being your donor? This may have only been for a second before deciding against it but I would be interested in hearing their views about the living liver donation programme set up at the SLTU.
May I have your permission to approach them to ask them for their participation in this study?
Do you have their contact details?

Appendix 16: Interview schedule for potential donors (Chapter 4)

- How long has your relative been on the liver transplant waiting list?

- How long ago did your relative receive a liver transplant?

- I believe your relative was provided with an information pack specifically about living donor liver transplantation, that is the option of a healthy family member donating part of their liver to a loved one on the waiting list. Did you receive a pack yourself or did you read the pack your relative received?

- Did you discuss the option of LDLT with your relative?
  If Yes: What was the outcome of this discussion?
  If No: Why was that?

- What were your first impressions of the LDLT information pack?
  Was the information clear/understandable?
  What would you say was the best thing / worst thing about the pack?
  How do you feel about the volume of information given within the packs?
  Would you have preferred to have seen the pack at an earlier or later stage?

- Was reading the information pack from the transplant unit the first you had heard of LDLT?
  If yes: What were your initial thoughts about LDLT?
  If no: When did you first hear of LDLT?
  What were your initial thoughts when you first heard that LDLT existed?
  What affect has the information pack had on your views?

- We've talked about the written information provided by the transplant unit but did anyone ever speak to you about the option of living liver donation for your relative?
  If yes: Tell me about that.
  Who spoke to you?
  Was the information clear/understandable?
  If no: Why do you think that was?

- Were you / have you been given the opportunity to ask questions?
  If yes: What questions did you have, if any?
  If no: Why do you feel that was?
  Do you have any questions regarding LDLT?
  Do you feel the staff are approachable?

- Have you at any point considered becoming your relative's living liver donor?
  If yes: What happened? What were/are the main issues you were/are thinking about when you were considering LDLT?
  Did you speak to anyone at the transplant unit about it?
  What was their response?
  Have you requested a formal assessment by the transplant team?
  If no: Could you tell me your reasons for not pursuing living donation?
  What concerns do you have? - safety? complications? risk to you or relative? Are you concerned that it's a new procedure in Scotland?

- Given what you know of the living liver donation programme that is now available at the Scottish liver transplant unit, is there anything you would change about the LDLT programme?

- If it were available would you have been interested in watching a DVD or video of other living donation donors and patients telling their stories?

  What are your thoughts on that?

- Is there anything else you would like to tell me about LDLT programme? Any other comments?

Appendix 17: Example of Consent Form (Chapter 4)

UNIVERSITY OF STIRLING

NHS Lothian

CONSENT FORM

Attitudes towards the Living Donor Liver Transplant programme in Scotland

Please tick box

1. I confirm that I have read and understand the information sheet for the above study and have had the opportunity to ask questions. ☐

2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving reason, and without my medical care or legal rights being affected. ☐

3. I understand that there are no risks involved in the participation of this study and that I will not directly benefit from participation. ☐

4. I agree to take part in the above study. ☐

Name of Participant (in block capitals)	Date	Signature
Research Assistant	Date	Signature
Researcher	Date	Signature

Appendix 18: Example of Information Sheet sent to Medical Staff (Chapter 5)

Department of Psychology
University of Stirling
Stirling, FK9 4LA

Living Donor Liver Transplantation: a qualitative study with medical staff at the Scottish Liver Transplant Unit.

Dear

You are being invited to take part in the above research study. This study has been developed by Stirling University in order to investigate what medical professionals involved in the area of liver transplant think about the option of Living Donor Liver Transplantation (LDLT). Before you decide whether or not to take part in this study it is important for you to understand why the research is being carried out and what participation will involve. Please take time to read the following information carefully.

What is the purpose of the study?
Since the 1st April 2006 the SLTU have been able to offer certain patients on the liver transplant waiting list the option of living donor liver transplantation. However, since this time only one LDLT procedure has been conducted at the SLTU. We are interested in finding out why this is. A previous study investigated the views of patients with liver disease and their families, with regards to the introduction of LDLT. We now wish to ascertain the views of the medical professionals involved in the area of liver transplantation in order to establish a wider understanding of the reasons behind the slow uptake of LDLT in Scotland.

Why have I been chosen?
As a professional involved in the area of liver transplantation at the SLTU, we are interested in your personal opinions with regards the introduction and progress of LDLT in Scotland.

What will happen to me if I take part?
Participation will involve a brief interview regarding your views regarding Living Donor Liver Transplantation. The interview will be conducted within the Edinburgh Royal Infirmary, either at the Clinical Research Facility or in another appropriate room within the liver unit. The interview will last approximately 20-30 minutes. You are asked to email the research assistant on lesley.mcgregor@******. to inform her of your decision to take part or not, and to put to her any questions you may have regarding the study. If you are happy to participate in the study, the research assistant will arrange with you a convenient date and time for the interview to take place. Where appropriate, your travel expenses will be paid.

Do I have to take part?

It is entirely up to you whether you take part in this study or not. If the research assistant has not had a response from you within 5 days, the RA will email you to confirm your wish to participate or not. If you do decide to take part you are reminded that your participation is voluntary and therefore you are free to change your mind at any time without giving reason.

Will my taking part in this study be kept confidential?

We can assure you that the information you provide will be kept confidential. The data will be used only for the purpose of this research. The interview will be recorded with a digital voice recorder but the audio recording will be deleted following transcription of the interview. At the point of transcription, the data will be anonymised through the use of a personal identification (ID) number. Only the researcher will know which names and ID numbers correspond. Only group data will be reported in future presentations and publications of the results.

What if I am unhappy with the study?

We do not anticipate any problems occurring when you participate in this study. However, if you do have any complaints with regards to the study please contact the research assistant, Lesley McGregor, on 0131 *** **** or at lesley.mcgregor@****** Alternatively, please contact the chief investigator, Professor Ronan O'Carroll, on 01786 *** **** or at ronan.ocarroll@*******

What will happen to the results of the research study?

The results of this research study may be published in medical and psychological literature. All information obtained about participants will of course be made anonymous. The results of the study will be reported in general terms such as 10% of people said this and 60% of people felt that. It will be impossible for results from individual participants to be identified.

Who is organising and funding the research?

This study is organised by the University of Stirling and is funded by the Chief Scientist Office.

Who has reviewed the study?

Lothian Research Ethics Committee has reviewed this study.

Contact for further information.

If you would like further information regarding this study please feel free to contact Professor Ronan O'Carroll, chief investigator of this research project, on 01786 *** ****, or at ronan.ocarroll@****.***.

I thank you for your time and we look forward to speaking with you in the next few days.

Kind Regards,

Lesley McGregor
(Research Assistant)

Appendix 19: Example of Consent Form (Chapter 5)

UNIVERSITY OF STIRLING

NHS Lothian

CONSENT FORM

Living Donor Liver Transplantation: a qualitative study with medical staff at the Scottish Liver Transplant Unit

Please tick box

1. I confirm that I have read and understand the information sheet for the above study and have had the opportunity to ask questions. ☐
2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving reason, and without my medical care or legal rights being affected. ☐
3. I understand that there are no risks involved in the participation of this study and that I will not directly benefit from participation. ☐
4. I agree to have my interview audio recorded. ☐
5. I agree to take part in the above study. ☐

Name of Participant (in block capitals)	Date	Signature
Research Assistant	Date	Signature
Chief Investigator	Date	Signature

Appendix 20: Interview schedule for medical staff (Chapter 5)

- When you heard that the SLTU had put in a bid to become the first NHS hospital in the UK to offer LDLT, how did you feel about it?
  Prompts: Excited, proud, apprehensive? Did you agree?
  Ethical and moral considerations?

- How do you feel about it now?
- What were your expectations for the new LDLT programme at the SLTU?
  Prompt: Within the first 6 months and within the first year?

- Why, in your personal opinion, was the first LDLT not performed until 21 months after it became available?

- Why, in your personal opinion, has no other LDLT procedure been conducted at the LDLT?

- What do you believe are the key concerns for patients on the transplant waiting list, faced with the option of LDLT?

- How do you feel about those concerns?

- What do you believe are the key concerns for family members, in their role as potential donors?
  How do you feel about those concerns?

- How do you feel about the risk to the donor?
  Prompt: Long term and short term?
  What level of risk to the donor do you feel is acceptable?

- Previous research has suggested that some patients see living liver donation as a “last option”. How do you feel about that?

- How do you feel about LDLT becoming available in other parts of the UK?

- How do you see the future of LDLT in Scotland?

- How do you see the future of LDLT within the rest of the UK?

- In your personal opinion which is better, a deceased or a living donation?
  Prompt: Why?

- Other transplant centres in other countries have performed a number of LDLT procedures. For example, Toronto in Canada, are thought to conduct approximately 70 LDLT transplants a year. Why do you think there is such a big difference between these transplant units and the unit here in Scotland?

Appendix 21: Flow chart of potential LDLT donors

	April 2006 to April 2009
Potential donors given clinic appointments	**22 donors**
If the potential donor has a compatible blood group to the recipient then a clinic appointment is arranged to conduct stage 1 of the assessment.	5 recipients received cadaveric transplant 1 recipient died 2 declined before attending stage 1
Stage One	**14 donors**
Clinic review by consultant transplant surgeon and coordinator including: BMI checked (≤30) Confirm donor/recipient relationship Confirm recipient and family views Discuss risks and benefits of living donation Medical investigations	1 refused to go further 5 turned down due to medical complications/contraindications 1 recipient died 1 recipient received cadaveric transplant 1 in progress
Donor Advocate Team	**5 donors**
All 4 members of the DAT meet with the potential donor to independently assess their suitability to donate.	1 declined by DAT 1 recipient died 1 recipient received a cadaveric donation 1 medical contraindications appeared
Stage Two	**1 donor**
Further medical investigations	
Stage Three	**1 donor**
If the donor still wishes to continue they are prepared for the donation operation	

Appendix 22: Example of Invitation sent to Potential Living Donor Liver Transplantation (LDLT) Recipients (Chapter 6)

NHS
Lothian

Room *****
Edinburgh Royal Infirmary
51 Little France Crescent
Old Dalkeith Road
Edinburgh EH16 4SA

Dear

The Assessment of Wellbeing Through the Living Donor Liver Transplant Experience

You are being invited to take part in the above research study. This study has been developed in order to investigate the impact of Living Donor Liver Transplantation (LDLT) upon the lives of both recipients and donors. Before you decide whether or not to take part in this study it is important for you to understand why the research is being carried out and what participation will involve. Please take time to read the following information carefully. If after reading this letter you feel that certain areas have not been made clear please feel free to contact us for more information. We are only too happy to answer any questions you may have whilst you consider your decision. Contact details are given at the end of this letter.

What is the purpose of the study?

In the UK liver transplants are carried out using livers donated from people who have died. However, not enough people wish to donate their organs when they die. As a result, adults who require a liver transplant often face a long wait before a suitable organ is found. In an attempt to overcome this problem, the Scottish Liver Transplant Unit (SLTU) has recently introduced an alternative to organ donations from people who have died. This new procedure is called Living Donor Liver Transplantation (LDLT).

LDLT allows a healthy family member to donate up to 60% of their liver to a relative with serious liver disease. Both the part of the liver donated and the part that remains in the donor will each re-grow to its original size in about one year.

LDLT with adults is a relatively new procedure. Consequently, more research needs to be done in order to learn about the long-term physical and psychological effects of the procedure upon both the donor and the recipient. The purpose of this study is to evaluate donors and recipients pre and post transplant, to see how LDLT has affected their lives. Only through such research can donors and recipients be given the most appropriate advice and support.

Why have I been chosen?
Within this study we hope to recruit all donors and recipients involved in the LDLT programme at the SLTU. The transplant co-ordinators have agreed to inform the research assistant whenever a relative of a person currently on the transplant waiting list contacts them about becoming a donor. At this point both the potential donor and recipient are sent the letter of invitation that you are now reading.

Do I have to take part?
It is entirely up to you whether you take part in this study or not. The research assistant will telephone you within the next 7 days to ask if you have made a decision regarding your participation. If you do decide to take part you are reminded that your participation is voluntary and therefore you are free to change your mind at any time without giving reason.

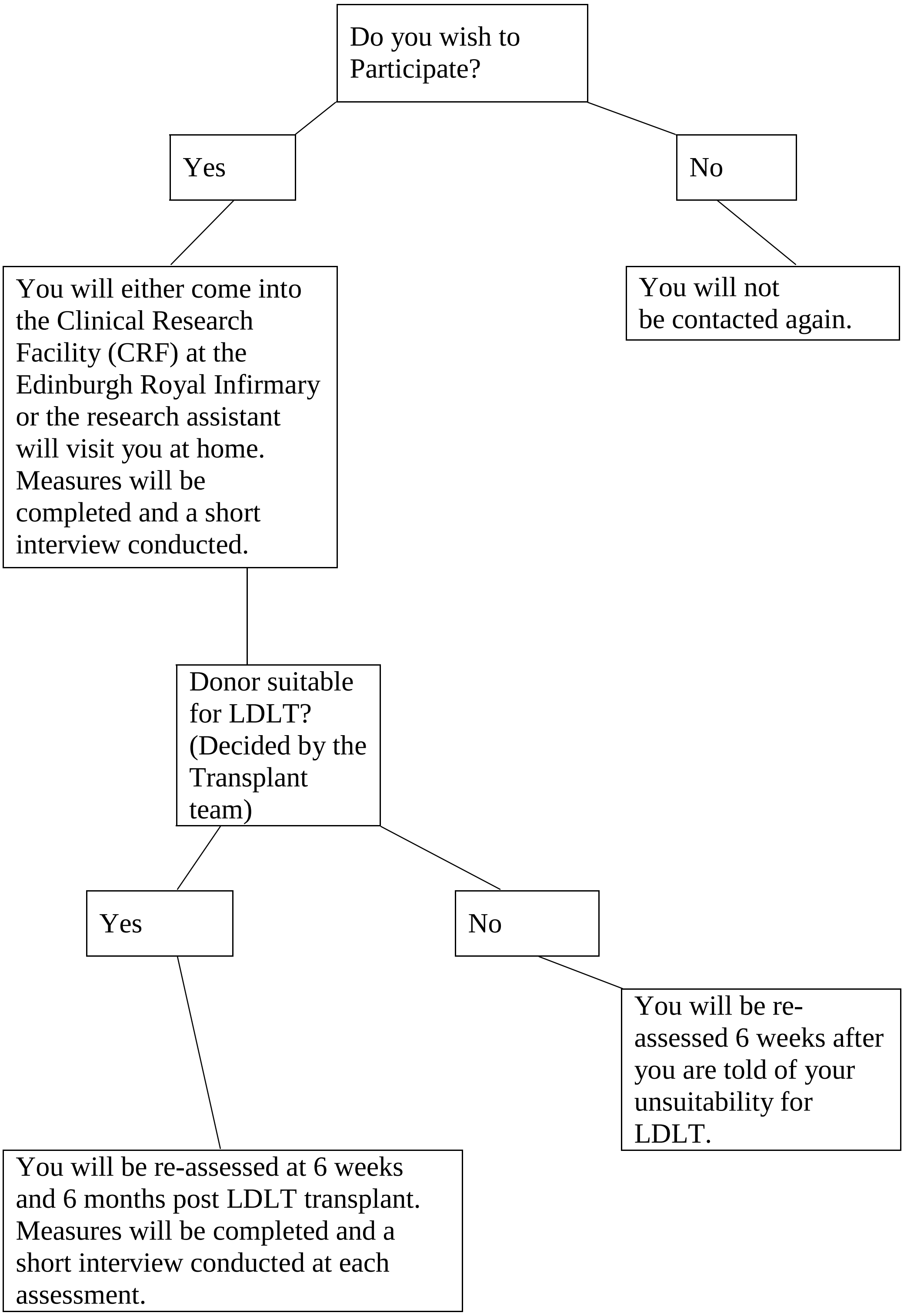
What will happen to me if I take part?
Participation will involve being assessed by the research assistant on a maximum of three separate occasions. If you agree to take part, your first assessment will be carried out within the next few weeks whilst your relative is being tested for donor suitability. The test for suitability is carried out by the transplant team and is NOT in any way influenced by your participation in this research project. If your relative is deemed suitable and goes ahead with LDLT, you will be reassessed by the research assistant 6 weeks and 6 months after the transplant operation. If your relative is deemed unsuitable for LDLT, you will be reassessed 6 weeks after the decision of unsuitability is made.

The research assistant will call you within the next 7 days to ask if you are happy to participate in the study. If you do decide to take part, the research assistant will, during this call, arrange with you a convenient date and time for your first assessment to take place. All assessments will either be conducted at the Clinical Research Facility within the Edinburgh Royal Infirmary or within your own home and will last approximately 2 hours. Travel expenses will be paid. Prior to your first assessment the research assistant will send you a consent form which you will be asked to read, sign and hand to the research assistant when you meet.

Each assessment will follow a similar format. To begin with you will be asked to complete simple, brief measures of: 1) memory, attention and concentration, 2) quality of life, 3) anxiety and depression, 4) disability, 5) beliefs about illness and 6) family relationships. This will take approximately 40 minutes to complete. Short breaks can be taken when required. After completion of the measures, the research assistant will interview you about your views and beliefs regarding LDLT. The questions asked will differ depending on whether it is your first, second or third assessment. Each interview will be recorded and will last no longer than 1 hour.

Shortly before your second and, if appropriate, third assessments are due, the research assistant will call you to schedule another appointment. The process will follow a similar format to the first assessment.

The following diagram illustrates the above information regarding participation.



What if I am unhappy with the study?

We do not anticipate any problems occurring when you participate in this study. However, if you have any complaints with regards to the study please contact Lesley McGregor, research assistant on 0131 *** **** or at lesley.mcgregor@*******

Will my taking part in this study be kept confidential?
Confidentiality is an important feature of this study and therefore we can assure you that the information you provide will be for the purpose of this research study only. The transplant team will not have access to any of the information you provide during the assessments.

What will happen to the results of the research study?
The results of this research study will be published in medical and psychological literature. All information obtained about participants will of course be made anonymous. It will be impossible for results from individual participants to be identified.

Who is organising and funding the research?
This study is funded by the Chief Scientist Office.

Who has reviewed the study?
Lothian Research Ethics Committee has reviewed this study.

Contact for further information.
If you would like further information regarding this study please feel free to contact:

Professor Ronan O'Carroll	Or	Professor Peter Hayes
01786 *** ****		0131 *** ****

If you would prefer to speak to someone entirely independent from the study, you can contact Dr K. Simpson on 0131*** ****

I thank you for your time and we look forward to speaking with you in the next few days.

Kind Regards,

Prof P.C. Hayes	Lesley McGregor
(Principal Investigator)	(Research Assistant)

Appendix 23: Additional Consent Form used for Case Study (Chapter 6)

NHS
Lothian

CONSENT FORM

Case Study: Psychological Functioning in Living Donor Liver Transplantation

Please tick box

1. I confirm that I have had discussed the future reporting of my data and have had the opportunity to ask questions. I understand that material may be published in medical scientific journal, theses and presented at scientific conferences. ☐
2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving reason, and without my medical care or legal rights being affected. ☐
3. I understand that there are no risks involved in the participation of this study and that I will not directly benefit from participation. ☐
4. I understand that a pseudonym will be used instead of my real name within the final report of this case study in an effort to try and retain anonymity. ☐
5. I understand that additional medical information may be retrieved from my medical records if it is deemed relevant to the case study report, but will be treated confidentially. ☐

Name of Participant (in block capitals)	Date	Signature
Research Assistant	Date	Signature
Researcher	Date	Signature

Appendix 24: Example of interview schedule for Living Donor Liver Transplantation (LDLT) donor (pre operation)

Decision-making process

When did you first hear about Living Donor Liver Transplantation?

What was your first reaction?
What was situation with recipient?

At what point did you get in touch with the co-coordinators/the transplant unit about becoming a donor?

What was their reaction?

Did you discuss your decision with your relative before approaching the co-ordinators?

If yes: Who brought it up first?
How did they feel about it?
If no: What was the reason for that?
When you did discuss it, how was the subject brought up?
How did they react?

How would you describe your relationship with your relative?

Close? Get on? Always been this way?

If the transplant unit agree that you are suitable for donation, you would be one of the first living liver donors in the UK. How do you feel about that?

Scared, proud, nervous
Why?

Reasons for donating

What do you know about your relative's liver disease?

How long with condition?
Cause?
Symptoms?

Why do you want to become their liver donor?

Do you feel under any pressure or influence?

What do you think are the advantages of being a liver donor?

What positive impact do you think it will have on your life?

What do you think are the disadvantages?

What negative impact do you think it will have on your life?

Views of others

How do you think other people feel about you possibly becoming a liver donor?

What do family and friends think? What was their reaction to the news?
What about your GP and the medical staff at the hospital?

(Do you have a job at the moment?)   How does your work feel about you possibly becoming a donor?

If told: what was their reaction?
If not told: How do you think they will react to the news?
Happy to give time off?

Has anyone else thought about donating to your relative?

If yes: What happened?
If no: Why do you think that is?

Satisfaction with hospital staff/processes

Have you met with the Donor Advocate Team yet?

If yes: What were your first impressions?
As expected?
If no: How do you feel about meeting the team?
What are your expectations of the meeting?

How do you feel about the service you have been given by the staff at the transplant unit so far?

Supportive / encouraging?
Enough information about living donation, risks etc?

Do you think the service could be improved in any way?

What about your relative? How do you feel they have been treated by the transplant team?

Since diagnosed
Since you came forward as their potential donor

What if scenarios

It's possible that your relative's body will reject your donated liver. They may require another transplant. How do you feel about that?

Worried or untroubled?
Why?

It's also possible that your relative will not survive the operation. How do you feel about that?

Worried or untroubled?
Explain to me why this is.

It may be decided that you are not suitable for donation. How would you feel about that?

Disappointed or relieved?
Explain to me why this is.

Body Image

I'd like to now touch upon the area of body image. With all the tests you be going through and the operation itself, your body is about to be given a lot of attention. I therefore want to know more about what you think about and how you feel about your body.

Describe to me how you feel about your body.
Tell me what you like about your body and why?
Tell me what you don't like about your body and why?

Do you think you look after your body? In what way?
What about exercise, watching what you eat, smoking, alcohol intake, etc?
Has this always been the case?

Do you think how you feel about your body will change following liver donation?
In what way?
Could you explain that to me?

Some people that I've talked to mention being worried about the scar that they will have following the donation operation. How do you feel about having a scar?
Tell me more about that?

How do you feel about having part of your body removed?
What are your thoughts?

Anxieties/concerns
What concerns, if any, do you have?
For yourself - Surgery, risk of death and complications
Scar - What are your thoughts about the scar?
Pain
Your health with only part of a liver
Your employment
Your relative – Surgery,
Scar - What are your thoughts about the scar?
Pain
Rejection
Their health with only part of a liver
Their employment

How do you cope with these concerns?
Do you have someone to talk to?

Expectations
How would you describe your quality of life at this present time?
In what way is it good/fine/bad?

What do you imagine life will be like for you at 6 weeks post transplant?
Back to normal? – Working, Socialising
Pain?

What about at 6 months?

Back to normal? – Working, Socialising
Pain?

What do you think life will be like for your relative 6 weeks after the operation?

Back to how they were before illness?
Pain?

What about 6 months after the operation?

Back to how they were before illness?
Pain?

How do you think donating will affect your relationship with your relative?

Any change? Why?

What about your relationships with other family members? - How do you think they will be affected?

Any change? Why?

Extra

How do you feel about Living Donor Liver Transplantation in general?

Good idea, bad idea? Why?

Would you consider donation to a complete stranger? An anonymous donation?

If the situation were reversed, would you accept a liver donation from your family or friends? Do you think donors should be paid for the liver they give away?

Is there anything else that you'd like to mention that you feel hasn't been covered by the questions I've asked?

Appendix 25: Information Sheet and Consent Form for Message Framing Study (Chapter 7)

Participant Information Sheet and Consent Form

Why should I take part?
We are interested in the attitudes of the general public towards living organ donation. Living donation is when a healthy family member donates an organ or part of an organ to a loved one on the transplant waiting list. We need to collect data from the student population to allow us to compare the results with other study groups.

What will participation involve?
You will be asked to read a short vignette, describing a situation whereby living organ donation is proposed as an option for a patient awaiting a transplant. This will be followed by a few questions relating to the vignette and then more general questions about you and organ donation. All questions will be answered on a likert type scale.

How long will participation take?
We estimate that participation will take approximately 20 minutes. Completion of this study will result in you receiving 0.5 credits.

Will my participation be confidential?
The data you provide by completing this study will be treated will full confidentiality. When the results are written up for publication, data from individual participants will not be identifiable.

As an informed participant of this experiment, I understand that:

1. My participation is voluntary and I may cease to take part in this experiment at any time, without penalty.

2. I am aware of what my participation involves.

3. There are no risks involved in the participation of this study, and that I will not benefit directly from participation.

4. I am aware that any questions I have about the study will be answered upon emailing lm57@******

I have read and understood the above, and give consent to participate:

Participant's signature:___________________________________ Date:__________

Researcher's signature:___________________________________ Date:__________

Appendix 26: Example of Invitation Letter sent to Potential Living Donor Kidney Transplant (LDKT) Donors

NHS
Lothian

Room *****
Edinburgh Royal Infirmary
51 Little France Crescent
Old Dalkeith Road
Edinburgh EH16 4SA

Dear

The Assessment of Wellbeing Through the Living Donor Kidney Transplant Experience

You are being invited to take part in the above research study. This study has been developed in order to investigate the impact of Living Donor Kidney Transplantation (LDKT) upon the lives of both recipients and donors. Before you decide whether or not to take part in this study it is important for you to understand why the research is being carried out and what participation will involve. Please take time to read the following information carefully. If after reading this letter you feel that certain areas have not been made clear please feel free to contact us for more information. We are only too happy to answer any questions you may have whilst you consider your decision. Contact details are given at the end of this letter.

What is the purpose of the study?
For many people with kidney failure a kidney transplant is the best treatment option. Unfortunately, the number of kidneys available from deceased donors is not adequate. Living Donor Kidney Transplantation is a surgical procedure that allows a healthy relative or close friend to donate one of their kidneys to the person in need of a kidney transplant. The purpose of this study is to evaluate kidney donors and recipients pre and post transplant, to see how LDKT has affected their lives. Only through such research can donors and recipients continue to be given the most appropriate advice and support.

Why have I been chosen?
Within this study we hope to recruit all donors and recipients involved in the LDKT programme at the Edinburgh Renal Transplant Unit. The transplant co-ordinators have agreed to inform the research assistant whenever a relative or friend of a person currently on the transplant waiting list contacts them about becoming a donor. At this point both the potential donor and recipient are sent the letter of invitation that you are now reading.

Do I have to take part?

It is entirely up to you whether you take part in this study or not. The research assistant will telephone you within the next 7 days to ask if you have made a decision regarding your participation. If you do decide to take part you are reminded that your participation is voluntary and therefore you are free to change your mind at any time without giving reason.

What will happen to me if I take part?

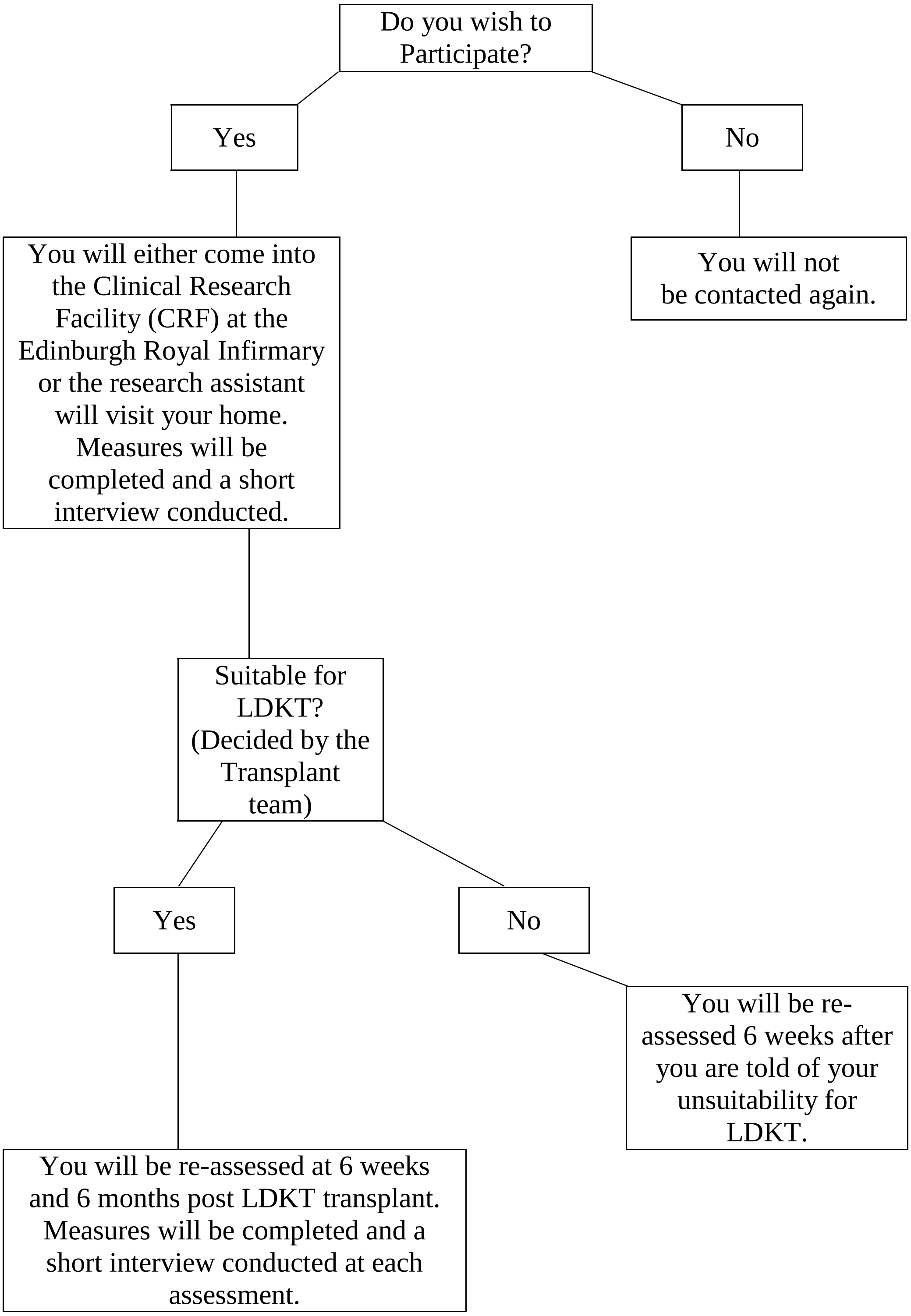
Participation will involve being assessed by the research assistant on a maximum of three separate occasions. If you agree to take part, your first assessment will be carried out within the next few weeks whilst you are being tested for donor suitability. The test for suitability is carried out by the transplant team and is **NOT** in any way influenced by your participation in this research project. If you are deemed suitable and go ahead with LDKT, you will be reassessed by the research assistant **6 weeks** and **6 months** after the transplant operation. If you are deemed unsuitable for LDKT, you will be reassessed **6 weeks** after the decision of unsuitability is made.

The research assistant will call you within the next 7 days to ask if you are happy to participate in the study. If you do decide to take part, the research assistant will, during this call, arrange with you a convenient date and time for your first assessment to take place. All assessments will either be conducted at the Clinical Research Facility within the Edinburgh Royal Infirmary or within your own home and will last approximately 2 hours. Travel expenses will be paid. Prior to your first assessment the research assistant will send you a consent form which you will be asked to read, sign and hand to the research assistant when you meet.

Each assessment will follow a similar format. To begin with you will be asked to complete simple, brief measures of: 1) memory, attention and concentration, 2) quality of life, 3) anxiety and depression, 4) disability, 5) beliefs about illness and 6) family relationships. This will take approximately 40 minutes to complete. Short breaks can be taken when required. After completion of the measures, the research assistant will interview you about your views and beliefs regarding LDKT. The questions asked will differ depending on whether it is your first, second or third assessment. Each interview will be recorded and will last no longer than 1 hour.

Shortly before your second and, if appropriate, third assessments are due, the research assistant will call you to schedule another appointment. The process will follow a similar format to the first assessment.

The following diagram illustrates the above information regarding participation.



What if I am unhappy with the study?
We do not anticipate any problems occurring when you participate in this study. However, if you have any complaints with regards to the study please contact Lesley McGregor, research assistant on 0131 242 1626 or at lesley.mcgregor@******.

Will my taking part in this study be kept confidential?
Confidentiality is an important feature of this study and therefore we can assure you that the information you provide will be for the purpose of this research study only. The transplant team will **not** have access to any of the information you provide during the assessments.

What will happen to the results of the research study?
The results of this research study will be published in medical and psychological literature. All information obtained about participants will of course be made anonymous. It will be impossible for results from individual participants to be identified.

Who is organising and funding the research?
This study is funded by the University of Stirling.

Who has reviewed the study?
Lothian Research Ethics Committee has reviewed this study.

Contact for further information.
If you would like further information regarding this study please feel free to contact:

Professor Ronan O'Carroll 01786 *** ***	Or	Dr Jen Lumsdaine 0131 *** ***

If you would prefer to speak to someone entirely independent from the study, you can contact Prof. Peter Hayes on 0131 *** ***.

I thank you for your time and we look forward to speaking with you in the next few days.

Kind Regards,

Ms Lesley M. McGregor
Research Assistant

Appendix 27: Example of Consent Form (Chapter 8)

NHS
Lothian

CONSENT FORM

The assessment of wellbeing through the living donor kidney transplant experience

Please tick box

1. I confirm that I have read and understand the information sheet for the above study and have had the opportunity to ask questions. ☐
2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving reason, and without my medical care or legal rights being affected. ☐
3. I understand that there are no risks involved in the participation of this study and that I will not directly benefit from participation. ☐
4. I agree to take part in the above study. ☐

Name of Patient (in block capitals)	Date	Signature
Research Assistant	Date	Signature
Researcher	Date	Signature

Appendix 28: Correlation Matrix for Living Donor Kidney Transplant (LDKT) Donors (Chapter 8)

		1	2	3	4	5	6	7	8
1. RLOC	CC	1.000	.414*	.817**	-.113	.318	-.126	-.255	-.422*
	Sig		.039	.000	.333	.099	.303	.146	.036
	N	20	19	19	17	18	19	19	19
2. LOTR	CC	.414*	1.000	.435*	-.174	-.012	.118	-.403*	-.115
	Sig	.039		.031	.259	.482	.320	.049	.325
	N	19	19	19	16	17	18	18	18
3. GSES	CC	.817**	.435*	1.000	-.055	.130	.157	-.228	-.203
	Sig	.000	.031		.419	.310	.267	.181	.210
	N	19	19	19	16	17	18	18	18
4. SF36 Physical functioning (Recovery score)	CC	-.113	-.174	-.055	1.000	-.377	-.432*	.508*	.247
	Sig	.333	.259	.419		.068	.042	.019	.170
	N	17	16	16	17	17	17	17	17
5. FLP Physical (Recovery score)	CC	.318	-.012	.130	-.377	1.000	.302	.000	-.034
	Sig	.099	.482	.310	.068		.112	.500	.446
	N	18	17	17	17	18	18	18	18
6. FLP Psychological (Recovery score)	CC	-.126	.118	.157	-.432*	.302	1.000	-.525*	-.017
	Sig	.303	.320	.267	.042	.112		.010	.473
	N	19	18	18	17	18	19	19	19
7. WHOQOL-BREF Physical (Recovery score)	CC	-.255	-.403*	-.228	.508*	.000	-.525*	1.000	.649**
	Sig	.146	.049	.181	.019	.500	.010		.001
	N	19	18	18	17	18	19	19	19
8. WHOQOL-BREF Psychological (Recovery score)	CC	-.422*	-.115	-.203	.247	-.034	-.017	.649**	1.000
	Sig	.036	.325	-.228	.170	.446	.473	.001	
	N	19	18	.181	17	18	19	19	19

* Correlation is significant at the 0.05 level (one tailed),
** Correlation is significant at the 0.01 level (1 tailed)

CC = Correlation Coefficient, Recovery score = Score at time 1 minus score at time 3; RLOC = Recovery Locus of Control, LOTR = Life Orientation Test Revised; GSES = Generalised Self Efficacy Scale; SF36 = Short Form 36; FLP = Functional Limitations Scale; WHOQOL-BREF = World Health Organisation Quality of Life Scale - Bref

Appendix 29: Correlation Matrix for Living Donor Kidney Transplant (LDKT) Recipients (Chapter 8)

		1	2	3	4	5	6	7	8
1. RLOC	CC	1.000	-.020	.278	-.031	.180	.534**	-.317	-.093
	Sig		.465	.105	.450	.218	.006	.081	.344
	N	22	22	22	19	21	21	21	21
2. LOTR	CC	-.020	1.000	.190	.472*	-.539**	-.118	.348	.458*
	Sig	.465		.198	.021	.006	.306	.061	.018
	N	22	22	22	19	21	21	21	21
3. GSES	CC	.278	.190	1.000	.089	-.091	-.047	-.035	.104
	Sig	.105	.198		.358	.348	.420	.440	.327
	N	22	22	22	19	21	21	21	21
4. SF36 Physical functioning (Recovery score)	CC	-.031	.472*	.089	1.000	-.399*	-.199	.583**	.428*
	Sig	.450	.021	.358		.045	.207	.004	.034
	N	19	19	19	19	19	19	19	19
5. FLP Physical (Recovery score)	CC	.180	-.539**	-.091	-.399*	1.000	.625**	-.608**	-.646**
	Sig	.218	.006	.348	.045		.001	.002	.001
	N	21	21	21	19	21	21	21	21
6. FLP Psychological (Recovery score)	CC	.534**	-.118	-.047	-.199	.625**	1.000	-.508**	-.558**
	Sig	.006	.306	.420	.207	.001		.009	.004
	N	21	21	21	19	21	21	21	21
7. WHOQOL-BREF Physical (Recovery score)	CC	-.317	.348	-.035	.583**	-.608**	-.508**	1.000	.675**
	Sig	.081	.061	.440	.004	.002	.009		.000
	N	21	21	21	19	21	21	21	21
8. WHOQOL-BREF Psychological (Recovery score)	CC	-.093	.458*	.104	.428*	-.646**	-.558**	.675**	1.000
	Sig	.344	.018	.327	.034	.001	.004	.000	
	N	21	21	21	19	21	21	21	21

Correlation is significant at the 0.05 level (one tailed),
** Correlation is significant at the 0.01 level (1 tailed)

CC = Correlation Coefficient, Recovery score = Score at time 1 minus score at time 3; RLOC = Recovery Locus of Control, LOTR = Life Orientation Test Revised; GSES = Generalised Self Efficacy Scale; SF36 = Short Form 36; FLP = Functional Limitations Scale; WHOQOL-BREF = World Health Organisation Quality of Life Scale - Bref