

Considering adult living donor liver transplantation: a qualitative study of patients and their potential donors.

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## **Abstract**

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 pursued this treatment option. A qualitative interview study was devised to elicit the views of patients and their families with regards to LDLT. Interviews were conducted with 21 patients and 20 potential donors.

The main reason why recipients did not pursue LDLT was their perception of risk to their donor. The anticipated feelings of guilt if the donor was harmed, resulted in LDLT being rejected. However, despite this many recipients 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 However, consideration of the effects of donating upon their own immediate family often superseded their wish to donate.

Whilst donors need to be given time to consider the implications of LDLT upon their own lives, it is essential that recipients understand that LDLT cannot be a last option, in order to allow them to reconsider their options realistically.

In April 2006, the Scottish Liver Transplant Unit at Edinburgh Royal Infirmary became the first NHS transplant unit in the UK to offer adult patients the option of living donor liver transplantation (LDLT). Traditionally, liver transplants are performed using a liver donated by someone who has died. This procedure typically leads to successful outcomes for patients (O'Carroll, Couston, Cossar, Masterton, & Hayes, 2003); (Bathgate et al., 1999). However, a major problem with this procedure is the scarcity of livers being donated following death (Barber, Falvey, Hamilton, Collett, & Rudge, 2006; British Medical Association, 2007). Due to the shortage of livers, patients have no choice but to wait on the transplant list until a suitable liver is found. Unlike patients awaiting a kidney transplant, an alternative form of treatment (i.e. dialysis) is not available and their condition consequently deteriorates. Many patients either have to be removed from the list due to significant deterioration in their health, and therefore perhaps miss an opportunity for a new liver, or die before 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 suitable state of health, LDLT has been introduced.

LDLT allows a healthy family member to donate part of their liver to a relative on the transplant waiting list. This procedure is made possible through the liver's unique ability to regenerate following resection. The procedure was first developed for use in children (parents donating to children) but has since been adapted for adult patients. Adult-to adult transplant is a more complicated procedure as normally the right lobe of the donor liver is required which constitutes approximately 60% of the donor's entire liver mass (Renz & Roberts, 2000). Anatomically, this results in a more complicated procedure compared to

when the smaller left lobe is donated (the left lobe is normally used when a child is to receive the liver segment). In a recent systematic review of the literature surrounding studies involving LDLT 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 1-100% (with a median rate of 16.1%) and included biliary leaks, wound infections and pneumonia (Middleton et al , 2006).

As a result of the risk to the otherwise healthy donor, the introduction of LDLT in the UK has been contentious (Neuberger & Price, 2003). Advances in transplant procedures, such as the acceptance of livers for transplant from non-heart beating donors, and the ability to split a donated liver to benefit two patients, have been 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 terms of survival rates, LDLT produces similar results to transplants using a whole liver from a deceased donation, but the additional benefit is in reducing time spent on the transplant waiting list and consequently waiting list mortality (Brown, 2008).

In Scotland, the shortage of livers is a particular problem when we consider that the cirrhosis mortality rates are among the highest in Western Europe (Leon & McCambridge, 2006). 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 submitted a funding bid to allow them to provide the first living donor liver transplant programme in the UK. This was granted and in April

2006, the programme commenced. At that time approximately one patient per month was dying on the Scottish cadaveric liver transplant waiting list (McGregor, Hayes, & O'Carroll, 2008). 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. We considered it important from a clinical as well as a psychological perspective to establish why the decision to pursue the option of LDLT had not yet been made.

## **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. 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 article.

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, 11<sup>th</sup> January 2007).

## Participants

### Patients

A total of 32 patients were invited to participate in this study and 21 were interviewed (7 did not wish to take part, 2 died, and we were 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, 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, the average time previously spent on the list was 127 days (SD = 47.01, range = 44 – 202). The liver diseases that had resulted in the need for a liver transplant varied but included Primary Sclerosing Cholangitis (N=6) and Primary

Biliary Cirrhosis (N=5). Others included alcoholic liver disease, hepatitis C, and non-alcoholic fatty liver disease.

### *Donors*

A total of 21 family members were invited to participate and 20 accepted. The nature of the relationship with the patient varied but included daughters (N = 5) and wives (N = 3). Other relationships included brothers, sisters, sons and husbands. This 'donor' group included 13 females and 7 males, with an average age of 43.22 years (SD = 10.48, range = 21-60).

### Data collection

We developed two interview schedules, one for donors and one for patients. The topics covered in both interview schedules are listed in Box 1. The interview was not structured around one particular theoretical model but rather explored general areas derived from the literature and through discussions between authors. 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 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 loved one 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 over the 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 decided to take part in a telephone interview. A consent form was sent to the participants once the date and time for the interview was arranged. 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.

#### Data analysis

We used thematic analysis to analyse the interview transcripts. Thematic analysis allowed the researcher to identify, analyse and report themes within the interview transcripts (Braun & Clarke, 2006). Each transcript was read and re-read with interesting points noted in the form of codes. These codes were then analysed further and combined into possible themes. For the purpose of this article 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.

## **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*.

Patient Themes:

*1. Risk to donor*

The main reason why patients were not actively pursuing living donor liver transplantation was their perception of risk to their potential donor (See Box 2). 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 (See Box 2).

## *2. Potential Guilt*

This feeling of responsibility for their donor's suffering is linked to another common theme found within the transcripts of the patients, potential guilt (See Box 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.

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 cadaveric donations, someone has had to die and a family has had to lose a loved one before the patient can receive a life saving transplant. However, with cadaveric transplantation, feelings of personal responsibility towards the donor can be reduced in that the donor was 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 3).

### *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). 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 cadaveric 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.

Donor Themes:

*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 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 cadaveric 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.

### *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 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. 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.

### *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's life, 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 7). 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 cadaveric 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'.

## **Discussion**

The implementation of a Living Donor Liver Transplant 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 cadaveric transplant for the recipient, or quite simply, the recipient 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 (Lee et al., 2005; Karliova et al., 2002) 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 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.

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Box 1: Interview topics

Box 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

Box 2: Patient quotes - Risk to Donor

Box 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)

Box 3: Patient quotes – potential guilt

Box 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)

Box 4: Patient quotes – Last option?

Box 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)



Box 5: Donor quotes – Automatic response

Box 5: Automatic response

(\*Tx = recipient transplanted, WL = recipient 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)

Box 6: Donor quotes – Need to save life

Box 6: Need to save life

(\*Tx = recipient transplanted, WL = recipient 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)

Box 7: Donor quotes – Concern for personal situation

Box 7: Concern for personal situation

(\*Tx = recipient transplanted, WL = recipient 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)