

LIVER TRANSPLANT RECIPIENTS' REFLECTIONS ON  
ORGAN DONORS AND ORGAN DONATION:  
A PRELIMINARY ANALYSIS

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ABSTRACT

*This article discusses preliminary findings from phenomenological research into the lived experience of liver transplant recipients in New Zealand, focusing on their views about the organ donor, the donor family, and organ donation more generally. It examines data collected during two phases of research; phase one, comprising seventeen qualitative interviews conducted with transplant recipients across New Zealand, and phase two, which entailed a qualitative survey sent to 180 potential research participants. A brief background to liver transplantation in New Zealand is provided, followed by an outline of the eligibility criteria used to select participants for this research. The perspectives of liver transplant recipients are then explored through the themes of the donated liver as a gift, gratitude, what information recipients have about their donor families, communication with donor families, and conceptions of liver transplantation as a transformative experience. It is anticipated that the phase two data will provide a comprehensive data set for detailed analysis when combined with the material from phase one of the study.*

INTRODUCTION

Requiring a liver transplant is an indicator that the potential transplant recipient is ill to the extent that death will occur in the near future if a donor organ does not become available.

To say organ transplantation raises the dead exaggerates its power. But not by much, because people rescued by transplants are all but dead and wholly out of medical options. They are called back to life by the skills of physicians and surgeons using organs donated by

people wishing to benefit others.  
(Munson 2002: 20)

I received a liver transplant in 2000 for a complex medical situation that developed from a genetic disorder called Wilson's disease. My experience of the transplant journey allowed me to connect with my research participants as an equal. We share a 'language', a 'destination', the transplant experience and a common focal point in the New Zealand Liver Transplant Unit.

#### LIVER TRANSPLANTATION IN NEW ZEALAND

The New Zealand Liver Transplant Unit was established in June 1997, and commenced transplant services in 1998. Prior to this, New Zealanders requiring liver transplants were only able to receive these overseas, most commonly in Australia. In 1986, the first New Zealand liver transplant recipient underwent surgery at Addenbrookes Hospital in Cambridge, the United Kingdom (Gane *et al.* 2002). The first New Zealander to receive a liver transplant in the new Auckland unit was Ms. R.D., in February 1998.<sup>1</sup> After the Liver Transplant Unit had been open for two years, specific local accommodation close to Auckland City Hospital was commissioned for transplant recipients and their caregivers, called Transplant House (Allardyce 2002), which was supported very generously by the New Zealand Lions Club and launched on 19 December 1999 by the New Zealand Prime Minister and the Lions Club International President.<sup>2</sup>

Liver transplantation itself is a young technology. Dr Thomas Starzl performed the first liver transplant on a human, three year old Bennie Solis, on 1 March, 1963 in Denver, in the United States. It was not successful, for a number of reasons:

Bennie's liver was encased in scar tissue left over from operations performed shortly after his birth. His intestine and stomach were stuck to the liver in this mass of bloody scar. To make things worse, Bennie's blood would not clot. Several of the chemical and other factors which are necessary for this process were barely detectable. He bled to death as we worked desperately to stop the hemorrhage. The operation could not be completed. Bennie was only three years old and had not enjoyed a trouble-free day in his life.  
(Starzl 1992: 99)

As effective immuno-suppression medication had not yet been developed, liver transplants were viewed as experimental for many years. With the discovery of Cyclosporine in the late 1970s, and its development as a more effective

anti-rejection therapy than either Imuran-steroid therapy or x-ray therapy, along with its approval by the US Food and Drug Administration in 1983, it became increasingly possible to survive the technical liver transplant surgery and maintain the efficacy of the transplanted organ from another human being. As liver transplant pioneer, Sir Roy Calne writes:

Ciclosporin [*sic*] was a watershed in the development of transplantation. Instead of a treatment limited to a handful of centres worldwide, transplantation became a much valued form of therapy spreading to more than a thousand centres. The kidney was the organ most commonly transplanted, but increasingly good results were obtained with heart, liver, and, eventually, lungs and pancreas.

(Calne 2006: 551)

Since the establishment of the New Zealand Liver Transplant Unit, there have been 437 transplant operations performed to the end of 2010 (ODNZ 2010). Some recipients may require a re-transplant if the first transplant fails. The survival rate at one year is 96% and at five years is 88%. The 10 year survival rate is 85%.<sup>3</sup> New Zealand is most fortunate that these transplantation services are now available. As one recipient stated in their interview with me, 'I knew that I would be dead by Christmas, if I didn't get a transplant' (Male recipient).

#### METHODOLOGY

Following van Manen (1990) I have applied a phenomenological approach to researching the experiences of liver transplant recipients in this study. For van Manen:

Lived experience is the starting point and end point of phenomenological research. The aim of phenomenology is to transform lived experience into a textual experience of its essence – in such a way that the effect of the text is at once a reflexive re-living and a reflective appropriation of something meaningful: a notion by which a reader is powerfully animated in his or her own lived experience.

(van Manen 1990: 36)

Van Manen also observed that lived experience can 'never be grasped in its immediate manifestation but only reflectively as past presence' (1990: 36). Adopting this approach allows me to incorporate my own experience into the research, enabling connection with the possible experiences of others regarding the same phenomenon. As van Manen says:

In drawing up personal descriptions of lived experiences, the phenomenologist knows that one's own experiences are also the possible experiences of others.

(van Manen 1990: 54)

Phenomenology is a methodology that explores lived experiences in order to get to the essence of the experience. By taking this approach, I am able to experience the life world of liver transplant recipients, with the additional enhancement of having shared this transplant experience. The benefit of exploring other recipients' life worlds with my own experience in mind, is that in an interview setting we have instant rapport and trust built through a shared language, a common experience and a connection through the medical and surgical staff and resources we all benefited from. We come from all walks of life, but as one recipient noted in the phase two survey, 'we are unique but we all have something in common' (SP#1037). Similarly, another research participant remarked, 'I definitely feel special and I think that only another organ recipient could really know the feeling' (SP#1035). As part of our common language, we recipients talk of the 'gift of life', which is also the terminology we hear at Thanksgiving services and within the hospital environment.<sup>4</sup> In the phase two survey, question 25(e) asked 'Do you see your new liver as a gift?' All respondents replied 'yes'. This is not to deny the conversations recipients may have about terminology and the problems associated with it, such as reflections on sacrifice, obligation and burden, but it is language that is part of transplant recipient vocabulary. When we use this language we communicate a common frame of reference, brought to light by a phenomenological approach to the study of the experience of organ transplantation.

The point is well made by a physician working in this area, who noted:

If we can adopt a phenomenologic perspective, we can try to enter the world of illness as lived by patients rather than confining ourselves to the world of disease as described by physicians.

(Baron 1985: 609)

From my literature review to date, a recipient-focused rather than clinical-focused phenomenological approach to liver transplant recipients' wellbeing and quality of life is relatively rare. As Kavanagh notes:

...Narratives about the lived experiences of patients who have endured the surgery and subsequent treatment regimens of transplant are rare in the literature. On the other hand, even scarcer is the ex-

periential account of a patient who, as a healthcare provider, understands the meanings of transplantation from both perspectives. (Kavanagh 2002: 50)

In the context of kidney transplantation an essay of interest which relates the experience of Carol Ann Rooks, who received a donor kidney as a patient, but within her context of being a nurse is relevant. The work of Chilean philosopher Francisco Varela is another exception. In his account of his own experience of liver transplantation Varela poignantly reflects on the psycho-social, biomedical and immunological complexities of organ transfer, commenting:

As I peer inside me (but which me?) at the other's liver, the medical gesture explodes into a hall of mirrors. These are the points where the transplantation situation can be carried to the sentimental extremes of either having been touched by 'a gift' (from somewhere, from 'life' or 'god'), or else the simplicity of the doctors who remain set at the level of their technical prowess. In between lies the lived phenomenon...  
(Varela 2001: 261)

#### METHOD

As stated above, data for this project has been gathered in two phases. My rationale for this was to ensure that the authentic lived experience of liver transplant recipients in phase one was the foundation for phase two's data collection. Phase one consisted of qualitative, semi-structured interviews of ten percent of the total number of eligible liver transplant recipients for this study. Phase two consisted of a qualitative survey developed from the key concepts identified in the phase one interviews, which I sent to all eligible liver transplant recipients. Supporting these two phases of data collection is an on-going literature review project comprising liver transplant surgeons' memoirs, textbooks on transplantation, organ donation, and ethics, liver transplant recipients' memoirs and biographies, and an extensive collection of research articles sourced through databases such as MedLine. The database topics include (but are not limited to) organ donation, xeno-transplantation, ethics, black markets in transplantation, social wellbeing, quality of life, economic wellbeing, phenomenology, liver transplantation and gender. The data is triangulated through the comparison and contrast of the literature review with both the interview transcripts and my own experience. Now that phase two survey results are available (mid-September 2010), they are a key data component and add to the triangulation.

## ETHICS APPROVAL

Phase one of this research received AUTECH ethics approval on 25 June 2008 (Application Number 08/81). Phase two of the research, the qualitative survey, was approved on 10 June 2010 for dissemination to eligible liver transplant recipients. The phase two qualitative survey was anonymous, and was sent out by the New Zealand Liver Transplant Unit on my behalf, as I do not have access to the database of patients who are eligible for this survey. Within the survey I only asked for high level demographic data, to enable cross-tabulation of findings.

## RESEARCH PARTICIPANTS

I determined six eligibility criteria, based on test interview data as well as on my preliminary literature review. These were:

1. Recipients must be adult, not pediatric patients. My test interview of a pediatric recipient showed that there would be significantly different challenges faced by children than by adults; particularly noted was a lack of compliance with medication. "The increased risk of non-adherence to liver transplant recipients in the adolescent age group has prompted some providers to suggest the implementation of a "teen transplant clinic" (Berquist, R.K., Berquist, W.E. *et al.* 2006:309).
2. Recipients must have received a liver from a deceased donor. Living donors in liver transplantation tend to be family members of the recipient, which brings in a very different dynamic to that of accepting an organ from a stranger. Living donor liver transplantation has been available through the New Zealand Liver Transplant Unit since 2002. The policy in New Zealand with deceased organ donation is to ensure anonymity of both donor family and recipients. In the opinion of Organ Donation New Zealand Clinical Director Dr. Stephen Streat FRACP (personal communication, 4 May 2010), without the anonymity of both donor families and recipients being protected, potential risks within this 'relationship' can range from the mild (e.g. guilt) to moderate (e.g. pathologic grief) to extremely serious (e.g. stalking), and that the behavior is not predictable, nor reversible once contact has been made.
3. Recipients should have received their (first) liver transplant between 1998, when the New Zealand Liver Transplant Unit commenced its services through Auckland Hospital, and 2005. Prior to 1998, New Zealanders

who required liver transplants went overseas for treatment or died without transplant. The experience of going to Brisbane, Australia for a liver transplant has been well documented by Margaret Chalmers in her book *Extra time: A story of a liver transplant* (1995), which illustrates the challenges of being removed from a New Zealand environment and the need to raise funds to pay for the costs not covered by the Government's partial funding of the transplant.

By using 2005 as a cut-off date for eligibility to participate in this research, recipients have distance from the transplant. This allows time to reflect on the experience once past the initial mix of euphoria and depression, documented in the literature and known to me from my own experience. All eligible recipients would therefore have a minimum of two and a half years between the date of the interview and the date of the transplant.<sup>5</sup>

4. Recipients must be alive. By this I mean that although the impression of the caregiver(s) about the liver transplant process and the recipient is valid, if the recipient is not alive to share their world view, the caregiver world view is not a proxy for it.
5. Recipients must be able to communicate using one of New Zealand's official languages. As this research is self-funded, I could not afford the expense of professional translators for many languages. For that reason, the New Zealand Liver Transplant Unit excluded approximately five per cent of the recipients who were otherwise eligible to be considered for interview.
6. Recipients participating in the interviews must be currently resident in New Zealand. This criterion is not relevant when it comes to the qualitative survey which can be sent to eligible New Zealand liver transplant recipients living overseas.

Once the New Zealand Liver Transplant Unit applied these criteria against their database of liver transplant recipients (in 2008), 182 liver transplant recipients were shown to be eligible for the research, including myself.

The New Zealand Liver Transplant Unit made available their annual reports for the period of my research, which was informative primarily as to the reason for transplantation. There was limited ethnic and age data available. To ensure diverse ethnicities were represented in phase one interviews, the ethnic data available (see Table 1) was used, along with discussions with both supervisors,

one of whom had access to the New Zealand Liver Transplant Unit's database (as the chief Hepatologist).

Table 1. *Ethnicity of liver transplant recipients 1998–2005*

	European	Maori	Pacific Peoples	Asian	ME,LA,A <sup>6</sup>	Other
1998	8	2	1	1	1	
1999	No data available to researcher					
2000	≈ 73%	≈ 2%	≈ 11%	≈ 9%		≈ 2%
2001	≈ 58%	≈ 17%	≈ 14%	≈ 8%		
2002	≈ 74%	≈ 11%	≈ 8%	≈ 7%		
2003	70%	≈ 12%	≈ 11%	≈ 4%		
2004	≈ 62%	≈ 14%	≈ 9%	≈ 6%		
2005	≈ 69%	≈ 9%	≈ 6%	≈ 9%		

In six of the annual reports bar graphs for the ethnic breakdown of liver transplant recipients were provided, without corresponding data tables, hence the approximate percentages.

Candidates for interview were initially selected by my supervisor Dr. Ed Gane. Based on the established eligibility criteria, he posted 20 packs containing an Information Sheet and a Consent Form with a self-addressed, stamped envelope, to the selected recipients. This generated seven responses. One further participant was recruited during a conversation at a Liver Clinic. In order to achieve a ten percent sample of the total number eligible for this research, snowballing was employed as a further participant identification technique. I was able to achieve a representative sample for interview through these approaches.

As an eligible recipient, I did complete the interview questions myself, which allowed me to check the appropriateness of the questions, approximate the time that would be required for interviews, and get an indication of my own response as a patient. I have not included my transcript in this research; however, I do draw on my own experience. Additionally, 17 other liver transplant recipients were interviewed which provided 30 hours 25 minutes of data. The shortest interview was 44 minutes and the longest was 2 hours 54 minutes, with a median interview time of 1 hour 47 minutes.



Nine men and eight women were interviewed; five in the South Island, five in the North Island (outside of Auckland) and seven in Auckland. There were eleven New Zealand European recipients interviewed, four Maori recipients, one Pasifika recipient and one Asian recipient. The three longest interviews were with Maori and Pasifika recipients, of whom two were female, while the New Zealand Europeans are represented in the eight shortest interviews; five of these recipients were male.

#### DATA ANALYSIS

I used NVivo 8 to code my interview transcripts, which have all been transcribed verbatim into Microsoft Word. I also used Microsoft Word to capture exported 'nodes' from NVivo 8, and Microsoft Excel.

#### PRELIMINARY FINDINGS

This research highlights similarities and differences within a group of people who have a shared experience at one level and a unique experience at another level. Recipients come to the transplant experience from a variety of backgrounds and with different medical conditions. They may present with comorbidities, as I did. They may be people with chronic liver conditions such as Wilson's disease or Hepatitis B, or acute illnesses, or both. They are different ages, from a variety of socio-economic backgrounds, a range of ethnicities and they have differing family and social support mechanisms. Some may have been working up until the time of the transplant, others may be in-patients, or in the Intensive Care unit. Some may have days or weeks to live and know it; others may have months or longer to live under excellent medical management.

#### *Accepting the gift*

What liver transplant patients have in common is the experience of facing a transplant (with or without consciously facing death), the medical team that become like an extended family, the surgical team that perform this complex surgery, and meeting others in the ward, in Transplant House, and in liver clinics, where experiences are shared and friendships forged. One of the most significant factors about facing a transplant, unlike other major surgery, is the mental acceptance of the organ, a donor liver, from another human being. We all have different coping mechanisms, and this is demonstrated in recipients' attitudes towards the thought of a donor liver, their donor, and their donor family prior to their transplant.

From my personal experience, I struggled for a number of weeks thinking about the need for a donor liver. A donor liver meant that somewhere, someone else was going to die, and their liver would give me life. I had to mentally tell myself that I was not causing this person's death, nor was I wishing for someone to die. Someone was going to die anyway, and a family, somewhere, would make a decision in a time of stress and grief, that would save my life; a gift of life to a stranger. Others have also struggled with accepting the concept of the gift of a donor liver, as shown in the two quotes below:

And they said: 'OK, you're on the list.' God. And I sort of made myself think: 'This is really the best thing,' but I had always felt ambivalent about having someone else's liver. I never could quite feel it was the right thing to do. But I then realised it was between my life and death. They said: 'It will probably take six months, on average, to get one.'... about nearly three weeks after they'd given me the [pager], put me on the list, I was sitting right here one night [sofa] and I said to [spouse]: 'I can't do it, I cannot go through with it. I simply can't have someone else's liver. It's not right.' And [spouse] said: 'Well you think, sleep on it, don't be rash. Just sleep on it.'

(North Island recipient)

I had to do a lot of self-talk, and I still do, I still do a lot of self-talk.

(North Island recipient)

Some may also struggle with thinking about accepting an organ from a gender other than their own. Others may not even think about the gender.

...in the assessment...they'd asked me how I'd feel if it was a male donor...I was really surprised because I just had this sort of total revulsion kind of, ewww, I don't want a male. Not that I hate men or anything, but it just seemed really foreign, the idea that part of a man, I'd sort of assumed it would be a woman for some unknown reason.

(Female recipient)

Others may be so ill that thinking beyond their own pain and situation may be difficult or impossible. They may not think about the donor and donor family until after the transplant surgery has occurred, or they may be so acutely ill they do not know they have had a transplant until after their surgery. The recipient in the first quote was in Intensive Care.

...my mother-in-law came in and she said: '[Name], they've found a

liver, they found one.' And I said: 'When is it gonna happen, I can't stand this any more, it's just driving me mad.' And she said to me: 'They have to test it to see if everything's fine.' I said: 'Is it here? Is it here?' And she said: 'I think it's here, I'm not sure...' and I'd be rocking. I'd rock on the bed, and I'd count to 60, and I'd say: 'That's another, 'nother minute gone.' And my sister would say: '[Name], you know, you've got a little while to go yet.' And I'd say: 'Oh, OK.' And I'd count another 60 and I'd be going backwards and forwards, backwards and forwards, then I'd [go] *flat down* on the bed, and I'd say: 'I can't, I can't cope any more, I can't do this any more, how much longer do I have to wait?'...all you want to do is for them to take the pain away...inside me it was, it was eternity, it was never gonna happen, so when the nurses came in and took me away, to prepare me for the surgery, it was a relief, and I just cried, I just absolutely cried, and everyone standing in the room bursting into tears, going: 'It's going to happen, it's going to happen.'

(North Island recipient)

The recipient in the second quote was airlifted to Auckland from the South Island.

I had gone into a coma....my liver functions were very, very, very, very, very high. Still got the records because they were really, really high... [*airlifted in*] the Child Flight plane. Quite quickly...I was alive in the morning. I woke up in the morning feeling not too bad, but as the morning ventured on I realized I probably shouldn't go to work. I can remember it all. Think I'd better ring up. And rung my Mum and took the keys down for someone to open up the office. And then I said to Mum: 'I don't think I should be driving.' 'Cause I was like, I was going into hypoglycemia as I understand it, wobbling everywhere. By the time I got to the doctor I was actually swelling, and staggering everywhere. Couldn't even sign anything, and vomiting apparently...I do remember swelling. I was trying to hold my pants together.

(South Island recipient)

Some recipients, prior to transplant, may not focus on the gift of a donor organ from a deceased fellow human, but may concentrate on the medical assistance available and provided to them.

And that struck me. *My body was closing down.* And only through

the medical intervention I've still got it. But some of the things that happened in the closing down process to me is like ageing quickly.  
(Male recipient)

The depiction of transplant operations in the media, especially in documentaries and medical television dramas, also exercises an influence on what patients expect to see prior to transplant.

I did think about the donor family...it wasn't the first thing that sprung to my mind, it was more about what was actually happening...it was really wet and rainy and awful – horrible weather. And I remember looking out the window looking for a helicopter. I had this vision in my mind that it was going to come from somewhere like Australia or somewhere, just like you see on TV films, the helicopter arriving with the box, the chilly bin. I don't remember anything necessarily about what I thought about the donor family at that time.  
(Female recipient)

Some recipients express a very matter-of-fact attitude towards the donor organ and the transplant surgery, often demonstrating an acceptance of death as the only alternative.

...they said: 'Oh, we've found a liver for you, do you agree to have one?' And I said: 'It's a bit Hobson's Choice...' we said yes, and signed for it. And they said: 'Right-oh, we'll take you down to the pre-op.' The orderlies wheeled me out of there and into the lift. And at the same time a courier got in the lift and they had a big chilly bin with them. And the orderly said: 'What have you got there?' And he says: 'Oh, somebody's going to have a new liver.' And I was lying there. And he says: 'It's just come from Australia.' So, it had just arrived, you know. So I went down in the lift with my new liver sitting alongside me.  
(Male recipient)

### *Gratitude*

Gratitude is an area more fully explored in the phase two survey, after showing through clearly in interviews as a major concept or theme for recipients. Forsberg *et al.* undertook phenomenological research from a nursing perspective in Sweden into the lived experience of liver transplant recipients in order to improve nursing practices. In their research, 'Honour the donor' emerged

as a consistent theme. This was made up of three parts: (1) being indebted to someone unknown; (2) treasuring the gift; and (3) being grateful (Forsberg, A., Bäckman, L. *et al.* 2000: 330). My interviews have also shown that we, as recipients, do demonstrate an appreciation for the 'gift of life'. However, there are some differences from the research of Forsberg *et al.* that should be noted. We also demonstrate immense gratitude to the health system in New Zealand, the medical and surgical teams, our families, our caregivers and often our employers. Although we may express gratitude and some of us may be overwhelmed by being given life again through organ donation and transplantation, interviews highlighted how recipients wanted to repay specific organisations or donate to specific causes, for example, if they won Lotto. The next two quotes illustrate the impetus to contribute financially in the event of a Lotto win.

I know the flights were dear. So, and they paid for us all that time up there in the Unit. Yeah. So, I'm grateful enough. I mean if I ever won Lotto or anything I'd gladly pay the money back to them. And more probably because I wouldn't have been here otherwise. I've had ten, just nearly ten years.

(South Island recipient)

...it'd be nice to be able to give something back to the Liver Unit, if I won a couple of million in Lotto, I'd probably give them a donation or something or to the Transplant House – donate some money to the Transplant House or something like that. Even though I never got to stay in it.

(North Island recipient)

In the next quote, the recipient demonstrates the breadth of gratitude felt, after a number of years, which still brings emotions to the fore.

I felt very grateful to doctors, nurses, family, donor family – that I had the transplant. It was a very profound sense of gratitude to the extent that I didn't know how to thank (long pause – emotional) – it took me months. It wasn't until I got home – I had to find the right sort of card to send to the donor family. So that had to be a sort of special card. Didn't know how to thank the hospital. I didn't know how to thank anybody. I didn't know how to thank the [*employer*]... one of the things that I will be thanking them for is the support. Through the superannuation scheme. You know the gratitude was just so pronounced, you didn't know how to thank them. And I've never heard from my Donor family. I accept that. That's OK.

(Male recipient)

Some of us also experience gratitude for our own livers, that these damaged livers managed to keep us alive given their state. One recipient kept their liver for a number of years after their transplant.

...they did save mine. I only buried it in October [2009] actually. I buried it finally. They did keep it. It was nice and plump and...mine was the normal shape, normal size, but it, um, and you could see little bits where it hadn't died. But I buried it...I planted it in our backyard...I just felt that it was time for me to let go.  
(Female recipient)

### *Liver transplantation as a transformative experience*

In a number of interviews the liver transplant experience appeared to be one that caused recipients to re-think and reprioritise what is important to them. Early indications from phase two survey responses show this to be a major theme or concept for a number of recipients as well. Experiencing organ donation through the gift of a liver may also awaken or change our experience of spirituality or thinking spiritually, about the Divine.

I sort of feel like, even though I've been gifted, I think it, I was physically gifted but I think I was *spiritually* gifted as well. It just didn't stop at an organ. Actually, I think it's much more than that. Much, much more. I think it's great.  
(Female recipient)

The quote, below, is from someone who works in a faith-based role, and shows how the transplant experience caused a re-thinking of beliefs.

...from a faith perspective...I've followed much more through on the scientific side of things. In the sense that I *now* talk of an expansive God...people say they experience God through nature, through the Bible, through the person of Jesus. And I say, through science and technology and travel. That whole area where...our generation has benefited more than...any previous generation. And so that I'm much more into contextual theology as you call it, and the living in the environment that we live in now, and the resources that are available to us. And that takes me to the whole area of genetics, etc, because I'm interested in the prospect of genetic organs being, for transplant being available etc...Because I've faced some of those questions that people tend to shy away from. I'm not scared of death.

I've been given an ex[tra], I've been given a bonus in life...I don't expect an after-life, which is traditional Christian teaching, and I'm satisfied if this is the only life I have. If any thing else happens, it's because of the grace of God...

(Male recipient)

There is also that element of surreality, as if we are part of science-fiction, not science-fact.

...someone else saved my life, you know, their liver saved my life ...I kind of think of it as second-hand sometimes. But not in a bad, but, just, I don't know...I never felt like I was going to give it back...in the beginning it's, well for me it was really *surreal*. You know, it was like: 'Gosh, I've got some organ that used to belong to someone else and, now it's inside me, and it's working better than the one I had was.' But, kind of...on a daily basis you become more accepting, because it's there and it's working.

(Female recipient)

One recipient likened the experience of being told that they needed a liver transplant to the feeling of being '...stuck into an episode of *Twilight Zone*.' Few of the people I interviewed had any long-term expectation of requiring a liver transplant. Some, who became very ill, very quickly, had little time to think about what a liver transplant was, and what it meant.

...he said to me: 'Your liver's really knackered. It's not going to last.' So at that moment the only thought that came to my mind, was – I was dying! So my whole life had flashed in front of me, in front of my face, so I was...trying to grapple, that moment, with the idea that I'm going to die, because I figured: 'Well, once you lose your liver, then you're going.' And then what was even more scary was the fact that [Dr.] Ed Gane had talked about a liver transplant, and I'd never heard of a liver transplant before. I didn't know what to expect! I think I remember asking one of the doctors what a liver transplant was, and he sort of quickly explained to me what it was. Basically, you'd be accepting a liver from another person, and you go through the operation. It was one of the junior doctors at the time, and would have been about a simple, quick, two minute explanation, and I just lay back and pretended I knew what he was saying, but I certainly didn't tell anybody that I was afraid...

(Male recipient)

After our liver transplants, a number of us experience a significant shift in our priorities. I do not as yet have enough data analysed to see whether there is a strong trend for this to be most felt by female recipients, but early indications are that liver transplantation may have a catalysing effect on female recipients, who may make more changes in their lives post-transplant than male recipients. It should also be remembered that some changes may be imposed on recipients, for example, changes in diet, lifestyle choices. One female recipient commented on changing priorities, below:

My priorities have changed a lot...when I realised that I would have been dead without the transplant...I've just let things slide that would have really upset me in the past, that now I c[an], I sort of feel it's just better to let them go and be happy, and just be a bit more relaxed about it all. And that life doesn't have to be a huge struggle, trying to do this and trying to do that. That maybe it's alright just to smell the flowers...

(Female recipient)

Little irritations may become less important; personally rush hour traffic in Auckland does not bother me now, as I appreciate being well enough to drive in it. Another female recipient comments on focusing on big dreams not small issues:

...it's given me a completely different outlook on life, in terms of – don't stress the small stuff. Don't sweat the small stuff, or whatever the saying is. And it gives you that kind of perspective to look at life differently, and do what you, if you want to do something, do it, really, if it's possible.

(Female recipient)

Some display a broadening of horizons in terms of awareness of, and empathy for, people in situations of need whether local, national or international.

...how you view the world and the gratitude, to me, becomes, it's universal really. I've become more interested in, well, I notice more than I ever did before, like all the poor people in Haiti and I think about the little things that I can do. And I've just got more tolerance and more patience. I'm more understanding. I have a lot more empathy. I'm a lot more interested. Whereas before, I might have been just ambling through life, probably in a self-centered way, I suppose. But now, it's not like that at all. And I gravitate towards people that



may have issues.  
(Female recipient)

Many I interviewed remember their liver transplant anniversary, and for some research participants it is seen as a second birthday. Others articulate it as a second chance at life, and liken it to birth.

...it's almost like you're being reborn, you know, it's almost like you're starting your whole life over again. That's basically what it feels like, and it's so *weird*.  
(Female recipient)

However, one male recipient likened his experience to a 'blip' in life:

...so that's why I say to people, if you're told you need a major operation and it's going to make you better—take it. But keep your mind active, keep your mind on the fact that you're going to be, you know, it's just a little blip while you're in, back to what you were doing before!  
(Male recipient)

Another saw the transplant journey as an 'adventure':

I was on an adventure, is the way that I've always felt about it...Certainly, to me, the whole thing's been an adventure, and I've always felt very positively about it. Never worried about the outcome.  
(Male recipient)

Feeling that you don't deserve a transplant has been commented on by male and female recipients. For some, there can be an added cultural dimension, as shown below:

I haven't gotten over that feeling of guilt...do I deserve this?...do I actually deserve to live, because somebody else had died, or to receive somebody else's liver. But at the same time, also because I'd grown up in a culture where stories are told about evil spirits, and people coming back after death, and ghosts all over the place...I was also really really scared, that these things might happen...I was really afraid of the transplant, thinking that the person whose liver I've received would come back and try to reclaim.  
(Male recipient)

*Communicating with donor families*

After our liver transplants, the New Zealand Liver Transplant Unit, and in particular our donor co-ordinators, advise us that we can communicate with our donor families through them. We are requested not to identify ourselves in our communication. We cannot sign our full names or provide our addresses, or write anything specific that would enable our donor family to easily determine who we are and where we live. For example, I cannot inform my donor family that I am doing this research. Many of us take advantage of this opportunity to thank our donor families, although it is extremely difficult to know what to say and how to write it.

...there were a few occasions where I'd began to write a letter, and you're writing, and you're saying that's not appropriate, that sounds silly, how could you put those words in? And then you put it away and come back, and I hadn't written the letter.

(Male recipient)

...it was nearly two years before I wrote a letter. Because I really didn't know what to say, and even then I didn't know what to say. I know that some family has lost somebody, and I'm living because of it.

(Male recipient)

For others, it can be difficult writing to the donor family if, in the first few months or years after transplant, their health is not optimal.

It took me three years to write to the Donor. Actually, because I still, I had to feel very (pause – sigh) very *naturally* grateful, and all the time I was feeling sick, I couldn't quite feel as grateful as I knew I wanted to and needed to. And I didn't want to write anything artificial. So it wasn't until I started to feel well that I sent it. And could write it and choose it and spend a lot of time, actually, writing it.

(Female recipient)

There can be an added complication if the recipient required a re-transplant, as for a rare few, the first donor liver may not work effectively.

...it was a problem...there was a bit of a mix up somehow that apparently after I had my first one, they must have contacted the donor family and told them that I was well and good and everything. And then when I had to write the letter, it was real awkward. But all I

could put in it was to say that I was very grateful, that it kept me alive in the interim, until I had the next one. I was lucky enough to, again, like, to mmm. So that wasn't easy...we had all sorts of problems here, [spouse] and I. We sat down here and we started and screwed it up and put it in the rubbish bin. I wouldn't know how many times.  
(Male recipient)

The anniversary of our transplant, which is the anniversary of the donor's death, is a key time when we reflect on our donor and donor family and may communicate with them.

I probably still think about them, especially around the anniversary. Like when I think: 'Oh, it's another year', six years, since I had my transpla[nt], and then I think: 'Oh, God, it's six years for them since they lost the person they lost.' I don't, I suppose I've kind of come to terms, like when I was saying about feeling guilty about not *doing* enough with it...But yeah, I still think about him. And them, his family. But maybe not as often as I did in the beginning.  
(Female recipient)

I try to send a note to the family either on the anniversary or at Christmas. Sometimes I might miss, like 2007, I think I missed because we were in the process of looking for a house and planning our trip to America and things like that. But I think I either sent a card at Christmas or I sent quite a long letter, the following anniversary, saying that we'd been to America and where we'd been and what we'd done and that we'd moved down here...we'd bought a house and stuff like that. 'Cause you've still sort of got to be careful that you don't, I mean I sign my name as '[Name]', on my letters, which seems okay...but if they track me down then they track me down. I'd be quite open to meeting up with them.  
(Female recipient)

### *Information recipients have about their donor families*

Munson has speculated that if transplant recipients 'seldom write thank-you letters [*it is*] because they feel unequal to the task of expressing so much gratitude' (Munson 2002: 21). It certainly appears to be true, from my own experience and from the experiences of those I interviewed, that writing to the donor families is a very difficult endeavor. However, 64.7% of those I interviewed have written to the donor family. Rarer, for us, is to hear from the donor family.

Only 11.76% have heard from ‘our’ families. Table 2 illustrates the communication between recipients and donor families for the 17 liver transplant recipients interviewed.

Table 2. Donor – Recipient communication

Interviewees	Male		Female		Total	
	as % of Male	as % of Male	as % of Female	as % of Female	as % of Total	as % of Total
Not written to donor family	2	22.22%	1	12.50%	3	17.65%
Unknown if they wrote to donor family (but doubtful from interview context)	2	22.22%	1	12.50%	3	17.65%
Written to donor family	5	55.56%	6	75.00%	11	64.70%
<b>Sub-total</b>	<b>9</b>	<b>100%</b>	<b>8</b>	<b>100%</b>	<b>17</b>	<b>100%</b>
Have not heard from donor family	6	66.67%	4	50.00%	10	58.82%
Unknown if they have heard from donor family (but doubtful from interview context)	2	22.22%	3	37.50%	5	29.42%
Heard from donor family	1	11.11%	1	12.50%	2	11.76%
<b>Sub-total</b>	<b>9</b>	<b>100%</b>	<b>8</b>	<b>100%</b>	<b>17</b>	<b>100%</b>
Replied to donor family	0 <sup>a</sup>	0%	0	0%	0	0%

(<sup>a</sup> Wants to reply, feels guilty for not replying)

The level of information we have about our donors, and whether we have heard from them or not, can impact on how close or distant we keep the thought of the donor and donor family in our lives. Having no information can depersonalise the transplant process.

...going back to thinking about the donor family, I guess because they haven't responded to me, and I still, I don't *know* who they are. I don't even know if they were a male or female. And I guess, that kind of makes it a bit more distant. If I had a picture in my mind of whether

it was a male or a female, I might get more of an idea of what, maybe what they were in. I'm very, this is going to sound really awful, but I guess I'm really detached, because I don't have an idea at all.

(Female recipient)

Table 3 shows how much factual information the 17 recipients interviewed have of their donors. However, there is a lot more 'gut feeling' about the donors and conjecture as well. Based on how long it took the donor liver to reach Auckland Hospital, some surmise as to whether the deceased donor was in the South Island. Others, as stated previously, have strong feelings as to the gender of the donor. Some are concerned about the age of the donor, e.g., did they get an 'old' liver? This may not be purely because they might feel the liver does not have a long future, it can also be connected to cultural valuing of Elders and guilt about benefiting from a group of people held in high esteem.

Table 3. *Amount of information recipients know about the donor*

Gender	Age Range	Reason for death	Other
Male	30s	–	–
Male	50s	–	–
Male	Middle-aged	–	–
–	–	–	Australian
–	–	–	From Central Otago
–	–	–	Cause of death known
Male	20s	Motor accident	–
Female	Young	Accident	Sporty
9 know nothing at all about their donor			

Some recipients see one aspect of attending the Thanksgiving Service as an opportunity to possibly listen to their donor family talk. Each year, at the Thanksgiving Service, a donor family representative is invited to share their tragedy and decision to donate life to others.

'Cause you go to the Thanksgiving and you sit there and wonder: 'Am I sitting next to them?' And you wait for the person to do their talk and think: 'Is this going to be my family?'

(Female recipient)

Whenever I go to the gathering, every year, I'm always looking. I'm always looking, you know...  
(Female recipient)

Other recipients, however, see the potential connection between donor families and recipients at the Thanksgiving Services as a risk area, knowing that the official position is for donor families not to meet their specific recipients.

[*Thanksgiving*] Well, one year, there was a woman there whose daughter had been killed in an accident at [*location*], and she said that the boy that got the liver wrote to her, the mother, and thanked her very much; that he'd gone back playing soccer and he'd got his first goals since the transplant. Well, my way of thinking, if that boy wa[s], that wrote the letter, who was the recipient, was in the hall, he would have known who the donor's mother was, by her speaking at that thing.  
(Male, Auckland)

This has not stopped some recipients (not those I interviewed), in tracing their donor family. One recipient I interviewed knew of another recipient in the same town who now has regular contact with the donor family.

...he found out about, and he and his donor family – they keep in touch. They keep in touch...he was telling me every second year he goes over there and lives with them for a week, and then the following year they come out here and they live with him for a week, and I thought: 'That's brilliant'.  
(Male recipient)

One of the areas I have explored in the phase two qualitative survey is what information liver transplant recipients would like to have about their donor, and what information they currently have.

## CONCLUSION

The 17 interviews from phase one have already proved illuminating, and have allowed me to develop questions for the phase two survey that should provide a greater depth of information in relation to the views of liver transplant recipients about organ donation, their donor and donor family. Already from the phase two survey I know that 75.5% of survey participants have written to their donor families, and that 22.4% of survey participants have received a letter or

card from their donor family. Additionally 26.5% of survey participants are not happy with the amount of information they have about their donor. There are many other aspects relating to the donor, donor family, organ donation, 'gift of life' terminology, and transformative impacts of transplantation that are covered in the detailed survey which will be made available through the doctoral thesis. It is possible that some of the findings from both phases may be able to influence operational policy within the organ donation and transplantation fields. One area may be that of offering recipients the opportunity to have consistent limited information about their donor if they wish it. Another area may be that of 'harnessing' the gratitude recipients feel, in promoting organ donation or other related activities, as 69.3% of survey participants feel a need to reciprocate in some way for their second chance at life.

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#### NOTES

- 1 *New Zealand Herald* article from Tuesday April 13, 1999, sighted in a liver transplant recipient's scrapbook, which includes a photo of the first recipient and detailed information about her. Original newspaper not sighted. No page reference available.
- 2 A scanned copy of the programme is available at [http://www.livers.org.nz/car-givers/accom\\_launch.htm](http://www.livers.org.nz/car-givers/accom_launch.htm) (retrieved 25 October 2010).
- 3 These statistics were provided to the researcher verbally by the Hepatologist at the New Zealand Liver Transplant Unit on Friday 28 May 2010 in the presence of her primary supervisor.

- 4 Thanksgiving Services are annual and biennial memorial services organised by Organ Donation New Zealand. These services are designed to acknowledge families who donate organs and tissues following the death of a family member. Regular services are held at Auckland and Wellington cathedrals and are attended by families of donors, recipients and their families, as well as health professionals involved in organ donation and transplantation (Editor's note).
- 5 Nearly 11 months of 2009 were on health leave from AUT, therefore there was only one interview undertaken, late in 2009. The remaining interviews were completed between January and April 2010.
- 6 Middle Eastern, Latin American, African.

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