

**The Lived Experience of Liver Transplant Recipients in
New Zealand**

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Table of Contents

List of Tables	vi
List of Figures.....	vi
Prologue	vii
Attestation of Authorship.....	x
Acknowledgements.....	xi
Ethical Approval	xvi
Abstract.....	xvii
Chapter One: Introduction	1
<i>Introduction.....</i>	<i>1</i>
<i>Significance of the Study</i>	<i>3</i>
<i>Research Focus</i>	<i>4</i>
<i>Research Aims</i>	<i>5</i>
<i>About the Researcher</i>	<i>6</i>
Liver Disease – Pre-transplant: Diagnosis and Denial.....	7
Commencing the Transplant Process: Disempowerment, Acceptance and Conviction	11
Immediately Post-Transplant: Gratitude, Joy and Apprehension	14
<i>Introducing Wellbeing and Quality of Life.....</i>	<i>19</i>
<i>Research Participants</i>	<i>21</i>
<i>Out of Scope</i>	<i>22</i>
<i>Overview of Liver Transplantation in New Zealand.....</i>	<i>23</i>
<i>Brief History of Transplantation Internationally.....</i>	<i>27</i>
<i>What is Covered in the Next Chapters</i>	<i>32</i>
Chapter Two: Key Concepts in the Lived Experiences of Liver Transplant Recipients.....	34
<i>Introduction.....</i>	<i>34</i>
<i>Key Concepts within the Lived Experience of Liver Transplant Recipients</i>	<i>35</i>
<i>My approach to an Overview of the Literature.....</i>	<i>47</i>
Liver Transplantation	47
Wellbeing	50
<i>Ethical Issues in Transplantation.....</i>	<i>61</i>

Chapter Three: Research Design.....	63
<i>Introduction.....</i>	<i>63</i>
<i>Phenomenology.....</i>	<i>64</i>
<i>Methods.....</i>	<i>68</i>
<i>Sampling and Participants.....</i>	<i>68</i>
Chapter Four: Data Collection and Ethical Considerations.....	79
<i>Introduction.....</i>	<i>79</i>
<i>Research Ethics.....</i>	<i>80</i>
<i>Rigour.....</i>	<i>87</i>
<i>Research Methods.....</i>	<i>90</i>
Ongoing Literature Review.....	90
Focus Group.....	90
Qualitative One-on-one Interviews.....	91
The Interview Process.....	92
Survey.....	93
Data Analysis.....	95
<i>Communication with Participants.....</i>	<i>95</i>
Chapter Five: Past Research and Developing a Survey Tool.....	97
<i>Introduction.....</i>	<i>97</i>
<i>Patient Outcomes.....</i>	<i>98</i>
<i>Short Form 36.....</i>	<i>102</i>
<i>Developing My Own Survey Tool.....</i>	<i>105</i>
Chapter Six: Experience of Becoming Unwell.....	114
<i>Introduction.....</i>	<i>114</i>
<i>Literature Review on Becoming Unwell.....</i>	<i>114</i>
<i>Interview Responses on Becoming Unwell.....</i>	<i>122</i>
<i>Survey Responses on Becoming Unwell.....</i>	<i>134</i>
<i>Conclusion.....</i>	<i>137</i>
Chapter Seven: Experience of Waiting for a Liver Transplant.....	139
<i>Introduction.....</i>	<i>139</i>
<i>Literature Review on Waiting for Liver Transplantation.....</i>	<i>144</i>
<i>Interview Responses on Waiting for Liver Transplantation.....</i>	<i>152</i>
<i>Interview Responses on Being Called and Waiting for Theatre.....</i>	<i>167</i>
<i>Survey Responses on Waiting for Liver Transplantation.....</i>	<i>170</i>

<i>Conclusion</i>	179
Chapter Eight: Experience of Waking Post-transplant to Discharge	180
<i>Introduction</i>	180
<i>Nightmares and Delusions</i>	180
<i>Pain</i>	190
<i>Time</i>	193
<i>Post-operative Nursing Care</i>	194
<i>Survey Responses on Time in Intensive Care and the Ward</i>	201
<i>Survey Responses on Nightmares and Delusions</i>	201
<i>Survey Responses on Pain</i>	205
<i>Survey Responses on Time</i>	206
<i>Survey Responses on Returning to the Ward</i>	209
<i>Conclusion</i>	214
Chapter Nine: Accepting the “Gift of Life”	216
<i>Introduction</i>	216
<i>Accepting a Donor Liver</i>	216
<i>Gratitude</i>	219
<i>Shifting Priorities</i>	223
<i>Communication with Donor Families</i>	226
Chapter Ten: Findings and Recommendations	241
<i>Significance of the Research Findings</i>	242
<i>Recommendations from the Research</i>	244
<i>Recommendations for Further Research</i>	246
References	252
Abbreviations	259
Appendices	260
<i>Appendix 1 Ethics Application</i>	261
<i>Appendix 2 Participant Information Sheet</i>	292
<i>Appendix 3 Interview Consent Form</i>	296
<i>Appendix 4 Focus Group Consent Form</i>	297
<i>Appendix 5 Confidentiality Agreement</i>	298
<i>Appendix 6 Ethics Approval</i>	299
<i>Appendix 7 Response to Ethics Committee</i>	301

<i>Appendix 8 KAREN Focus Group</i>	<i>302</i>
<i>Appendix 9 Indicative Questions – Focus Group and Interviews</i>	<i>304</i>
<i>Appendix 10 Development of Indicative Questions</i>	<i>306</i>
<i>Appendix 11 Researcher Safety Protocols.....</i>	<i>308</i>
<i>Appendix 12 Final Ethics Approval.....</i>	<i>310</i>
<i>Appendix 13 Ethics Approval for Survey.....</i>	<i>312</i>
<i>Appendix 14 Survey Consent Form</i>	<i>315</i>
<i>Appendix 15 Research Survey</i>	<i>316</i>
<i>Appendix 16 Example of Monthly Research Updates.....</i>	<i>345</i>
<i>Appendix 17 Summary of Research Files from Bethli’s PC.....</i>	<i>346</i>
<i>Appendix 18 Full Excel Spreadsheet Data on CD Data Disk</i>	
<i>Appendix 19 Full Bibliography on CD Data Disk</i>	

List of Tables

Table 1: Reasons for Liver Transplant in the NZLTU between 1998 and 2005.....	25
Table 2: Liver Transplantation Timeline	29
Table 3: Key Concepts	35
Table 4: Recipient Concepts in Relation to Wellbeing.....	55
Table 5: Ethnicity of Liver Transplant Recipients 1998-2005.....	72
Table 6: The Matrix	74
Table 7: Initial Responses from Mail-out	76
Table 8: Responses Including “Snowballing” Recruitment.....	77
Table 9: Sub-set of Articles with Titles Starting “A” – 336 Search Results.....	100
Table 10: Example of Response to Question 10	108
Table 11: Representative Articles on Patients Waiting for Liver Transplants.....	145
Table 12: Major Themes from These Articles on Waiting for a Liver Transplant	146
Table 13: Interview Participant Responses on Waiting Times for the Transplant	153
Table 14: Question 11 Responses	205
Table 15: Question 12 – Pain	206
Table 16: Question 13 – Time.....	207
Table 17: Survey Participants’ Comments on Gratitude	222
Table 18: Examples of “Other”	223
Table 19: Interview Participants on Communication with Donor	228
Table 20: Survey Participants on Communication with Donor	229
Table 21: Interview Participants on Knowledge of Donor	234
Table 22: Survey Participants on Knowledge of Donor	235
Table 23: Recipient Concepts in Relation to Wellbeing	306
Table 24: Sample Questions.....	307

List of Figures

Figure 1: Laminated ICU Card for Post-operative Communication.....	15
Figure 2: Screen Capture of Literature Search.....	49
Figure 3: Email from Ed Gane July 13, 2008	75

Prologue

Bethli Wainwright died on December 25, 2010. Before she died, Bethli had completed all her research and written several chapters of this thesis. She had outlined or part written a number of others. On December 24, Bethli's supervisors gave an undertaking they would complete her work. She handed to her Chief Supervisor, a memory stick containing all the thesis research files (see Appendix 17, p. 346). Bethli's background as an experienced librarian was reflected in her thesis by her exemplary data management and organisation. Her files included an electronic bibliography of 360 published manuscripts, referenced in the exhaustive literature review that Bethli undertook prior to embarking on her research. Included were her complete interview records and survey analyses.

Working with her files, the models of her completed chapters and the outlines of the other chapters in this thesis, Bethli's supervisors and colleagues have cut and pasted Bethli's words into this thesis. "New" writing has only been undertaken to make sense of transitions. Nothing that Bethli completed has been deleted. Bethli wrote beautifully and we believe that had she completed the thesis herself it would have been both "tighter" and more nuanced.

In the month before her death, Bethli met with her supervisors on several occasions, when it was agreed that the Excel spread sheet of survey results and full bibliography should be included as electronic appendices to this thesis, so that other scholars might further advance her work with full access to her primary data. It was agreed that the final thesis would not contain the final chapters on "Life after discharge from Hospital to Transplant House;" "Life after return to home; Life in the late post-transplant

period,” as to do so would have required significant further data analysis and writing. Bethli agreed that these chapters should be completed and published independently. The survey data for these chapters has been withheld from the electronic appendix.

This thesis represents an invaluable contribution to the current state of knowledge of liver transplantation as seen by the recipient and his or her caregiver. It identifies the most important issues for adult patients with end-stage liver disease, undergoing liver transplantation. There are five distinct phases of liver transplantation process:

- (i) End-stage liver disease when the patient is very ill and unable to experience a “normal” life. He/she is made aware of his or her mortality and the need for liver transplantation. The patient agrees for referral to NZLTU then must wait for this to be scheduled.*
- (ii) Assessment for transplantation, which comprises a week in Auckland, during which the patient attends several outpatient assessments with different members of the liver transplant team, to determine his or her suitability for transplantation. This process culminates in an interview on the Friday afternoon when he or she is offered listing on the deceased donor list for liver transplantation.*
- (iii) Transplant procedure, when the patient is called in the night before, undergoes the operation and is transferred to intensive care, where he/she awakens from general anaesthesia. Particular issues are related to the barriers to communication because of intubation and the side-effects of sedation and analgesia.*
- (iv) Early post-transplant phase. The length of inpatient stay will range from 5 days to several weeks depending on the patient’s status immediately prior to transplantation and immediate post-operative complications, including renal failure, infection and rejection.*
- (v) Late post-transplant phase. This period represents the patient’s recovery from transplantation and return to “normal” life.*

Research of liver transplantation to-date has been dominated by hypothesis-driven scientific research. Although this is important to determine natural history of transplantation and the safety and efficacy of new anti-infectives and immunosuppression agents, such research will never be able to adequately describe the patient's personal experience of transplantation, which few, if any, researchers have shared. This thesis is based on phenomenologic research which gathers subjective experiences of those who have "lived the transplant experience." The fact that the research has been designed and conducted by someone who is herself a liver transplant recipient makes this a unique thesis. By highlighting specific issues that recipients perceive as poorly managed or that impact on the long-term wellbeing of the recipient and caregiver, this phenomenologic research should provide areas of audit and service improvement for nursing and medical staff working in the area of liver transplantation. This thesis will be provided to the NZLTU as a resource for all staff within the unit and will provide a framework for the development of better resources for patients being evaluated for liver transplantation. This thesis will also be shared with other transplant programmes, both locally and internationally, to encourage similar research into organ transplantation. In addition, this thesis will provide the substance for a liver transplant handbook, to be used as an educational resource for future transplant candidates and their families.

Attestation of Authorship

I hereby declare that this submission is my own work and that to the best of my knowledge and belief, it contains no material previously published or written by another person (except where explicitly defined in the acknowledgements), nor material which to a substantial extent has been submitted for the award of any other degree or diploma of a university or other institution of higher learning.

Signed:

A handwritten signature in blue ink, appearing to read "Beth S. Wang", is placed over a light blue rectangular background.

Dated: 13 December 2010

Acknowledgements

It has been a privilege to undertake this research project, and I am indebted to many individuals and families, along with organisations within New Zealand, and it is my hope that I have not omitted any from this acknowledgement page. Firstly, I must acknowledge my family who have supported me since birth, and in particular the role of my mother as my principal caregiver from the time I was diagnosed with Wilson's disease at the age of eight, to today, as I approach the end of my life with terminal cancer. Without the support, love, energy, motivation and "being there" of my mother (Robin Wainwright), nothing I have accomplished in my life would have been achieved. This is not to deny the roles played, and support provided by, my late grandmother (Elsa Stokes), my father (Ross Wainwright), my sister (Kylie Burling) and my brother-in-law (Dr. Fraser Burling), along with the delightful relaxation times with my twin nephews, Walter Lennard Burling and Caspian David Burling.

It is hard to know how to group the incredibly important people and organisations to whom I also owe so much – Organ Donation New Zealand, the New Zealand Liver Transplant Unit and my own (anonymous) donor and donor family. Without the sacrificial gift of a donor liver to an unknown New Zealand woman in August 2000, I would not have had this experience or be alive, and in a position to write about the lived experience of liver transplantation in New Zealand. To my donor, and my donor family, I hope this thesis is a small acknowledgement back to you of the importance your gift of life has been to me. To Organ Donation New Zealand, the work you do every day is beyond my comprehension, and I can only thank you sincerely for what it has meant to me, and I hope this thesis is of interest to you. To the New Zealand Liver Transplant Unit, as others say in interviews and surveys, you are like our second family. The

dedication and commitment of staff like Kathy Oliver, Val Honeyman (my wonderful Transplant Coordinator in 2000), and Margaret Johnstone, along with the surgeons and hepatologists, is beyond the call of duty. You hold a place in our hearts and minds that cannot be described. If this thesis provides any insight of use to you for your invaluable work with future New Zealand liver transplant patients and their families, its aim will have been achieved.

I have been privileged and blessed to be supervised by the two best supervisors possible for a research project of this nature and on this topic. Without having heard one of my supervisors talk at a conference in 2007 this thesis would never have been written. I am not an academic, but a New Zealand woman, working full-time, who has had too much experience of what it is like to be a patient in the New Zealand health system. As such, I knew the questions I had, and had some idea of other people's questions around liver transplantation from a non-clinical perspective owing to the website fellow recipient John Russell and I established at the end of 2000 (see www.livers.org.nz). However, I did not have the connections to the academic research environment, or the confidence that what I wanted to find out could be seen as appropriate academic research, until I heard Professor Marilyn Waring speak at the Department of Internal Affairs Local Government Symposium in Wellington in 2007. At this event she said "The expertise lies in the community," and a light-bulb went on in my head. I went to see her at her table as soon as she had finished speaking, as I was so excited by her presentation and her approach that I felt, for the first time, that there would be a way of being able to answer the questions I had in my head about the experiences of New Zealanders who underwent liver transplantation. I was delighted when the internationally recognised and phenomenal Professor Marilyn Waring consented to become my primary supervisor for this research. Since that first conversation Marilyn has been a fantastic guide and

mentor, supervisor, friend, and constant support. A year after the time of my enrolment health issues arose, with a diagnosis of inoperable breast cancer in December 2008, leading on to a further diagnosis of terminal metastatic breast cancer in April 2010. In all this time, Marilyn has worked tirelessly with AUT University to ensure that I have been able to maximise my time to get to the point of completion of this thesis. She has gone the third and fourth mile that I know of, and probably many more that I do not know about. Her personal assistant, Suzanne McIntyre, has also been a constant tower of strength and support, along with providing practical help.

Marilyn's "Pot Luck" group of fellow post-graduate students has been a constant source of inspiration, guidance, fellowship and advice. The ability for Marilyn's students to get together regularly in a social and sharing context is invaluable. It allows us to share new resources, whether these be texts, articles or new software programmes. We reflect on our research and share our insights together, and have the opportunity to "test" presentations to a known audience who can provide critical feedback.

My second supervisor holds a position of the highest esteem and honour within my family, as Dr. Ed Gane is the hepatologist who made the medical decisions that kept me alive pre- and post-transplant in 2000, and has provided the most outstanding post-transplant care since my liver transplant. It is a huge honour to be able to be supervised by such a busy, internationally renowned hepatologist, and I hope the work that I have done over the past few years has been of interest to him, and provided some reciprocal value for the time he has invested in me and this research. I would not have contemplated doing this research if it did not have his support, and the support of Professor Munn, the Clinical Director of the New Zealand Liver Transplant Unit. The support shown to me by Ed's family as well was outstanding, when I know how much

they share him with New Zealanders and must often feel they take second place. His three delightful daughters, and especially Libby, hold a special place in my life, and I know they will all grow up to be just as outstanding as their parents are.

Research of this nature, where you are invited into the most emotionally charged parts of peoples' lives, can be very uplifting, draining, challenging, motivating and disturbing. At times like these, it's important to have a group of people to whom you can debrief. When you have an intense interview, and come home feeling wrung out, it's good to be able to talk through some of your feelings with people who are not intimately connected to your research. I have a wonderful group of "debriefers" who have helped me at practical levels (new PC set-up, going to the movies) and emotional levels (talk, talk, and talk!). This group has also been prepared to read and critique anything and everything I write, give me honest feedback from an "outside" perspective, and help keep me on track. Amanda Cole, Eileen Floro, François Sauvageot and John Cavanagh, I could not have done this without you!

There are other supportive friends and relatives who are there for the good times and the bad, and to name some, but not all, is a danger. However, I'd especially like to acknowledge Anna Wheeler for the practical support towards the thesis and research costs, as well as the "electric blanket" for my back when the cancer pain got too bad, along with Anne Candland for brainstorming ideas for the thesis. My Aunt, Deirdre Collins, is always willing, at the drop of a hat, to come and babysit my thoroughly spoilt cat Snowey each time I go into hospital. Andrew Meisner has always been interested in the latest progress of the research and helping me in hospital stays. Jilly Statham has had a constant and encouraging interest in the thesis and supported me at all times, along with other work colleagues in central and local government, and in

particular my outstanding manager, Regional Commissioner for Social Development, Isabel Evans. Without Isabel's support to undertake part-time post-graduate study while working for her as a Social Development Manager, none of the other support above would have been necessary. Her commitment to, and support of, this research and me has been beyond words. Isabel, I hope there is something in this thesis that is of interest and use to you in your work with New Zealanders.

There would be no research, though, if I did not have participants willing to share their deepest, emotional experiences of liver transplantation in New Zealand. My participants are people I am honoured to know (through interviews) or know of (through surveys), and I will always be extremely grateful to them for their courage, honesty, and commitment to using their experiences to help future New Zealanders undertake the liver transplant journey with a greater understanding of what it meant for us, the first generation of recipients. Many of the people I interviewed have become good friends, and I am deeply appreciative of their support for me and this research project.

Ethical Approval

Approval to undertake this research was granted by the Auckland University of Technology Ethics Committee.

Ethics Application Number: 08/81

Dated: 25 June 2008 (phase one)

10 June 2010 (phase two)

Abstract

This thesis reports on phenomenological research into the lived experience of liver transplant recipients in New Zealand in 17 qualitative interviews, and a qualitative survey of 49 liver transplant recipients across New Zealand. A new survey tool was developed for this work. A brief background to liver transplantation in New Zealand and internationally is provided. The perspectives of liver transplant recipients are then shown in relation to their experiences on becoming unwell, waiting for transplantation, in Intensive Care and the ward, and their way of coping with a donor liver from another human being. The thesis concludes with recommendations for immediate implementation by the New Zealand Liver Transplantation Unit. Appendices include survey responses on an Excel spread sheet and a database of references on liver transplantation to assist further research in this field.

Chapter One: Introduction

I would like to thank you for asking about my experience! The questions you have asked have let me tell you intimate and important details of my life experience that I don't get to tell the doctors that saved me (and the donors). I am so happy for you, doing this survey is an important thing – thank you.

Survey Participant (SP) #6

Introduction

Liver transplantation is part of the wider scientific and medical field of transplantation. Transplantation is a procedure that can be applied to solid organs including lungs, hearts, and livers, as well as skin, corneas, bone marrow and other parts of the human body. Additionally, xeno-transplantation addresses the transplanting of tissues and organs from many different animals (including pigs and baboons) into humans. Successful human-to-human transplantation was a major scientific achievement of the mid and late twentieth century. Dr. Thomas Starzl, the first surgeon to undertake a human-to-human liver transplant, wrote that "...transplantation became a very large miracle, perhaps the least anticipated and potentially the most important one in the history of medicine" (1993, p. 3).

The achievements in transplantation in the twentieth century have been likened to the achievement of landing and walking on the moon.

Roy Calne was not a wilderness explorer but no doubt he could have been. Some years later, David Winter, the director of the American trials with a better anti-rejection drug called cyclosporine, made the point. People like Calne, he said, had been the ones to walk on the moon (Starzl, 1993, p. 190). Dave Winter was like a mother hen throughout this time and until cyclosporine finished its long journey through the FDA at the end of 1983. The liver trials offered even more persuasive testimony for cyclosporine than those with the kidney, and

soon the evidence from Bahnson's and Shumway's heart trials would follow. From time to time, I see Winter. He still calls us "moonwalkers," a complimentary term which he first applied to Roy Calne. Being a modest man, it never dawned on him that he was one also (Starzl, 1993, pp. 245-246).

Transplantation has relied on the surgical techniques being perfected on many laboratory animals and experimental surgery on humans. It is indebted to the courage, innovation and inspiration of surgeons including Dr. Thomas Starzl, Professor Henri Bismuth, Dr. Rudi Pichalmyer, and Sir Roy Calne, as well as pioneers in fields *initially* unrelated to transplantation, including what we now know as immunosuppression.

Current liver transplantation surgery is known as Orthotopic Liver Transplantation (OLT or OLTX), as orthotopic implies that the donor liver is replaced in the position/location that the recipient's own liver previously inhabited. This technique was pioneered initially in dogs, then in humans. Experimentation had shown that transplanting a donor liver into another part of the abdomen and leaving the original liver in place was unsuccessful in patients with chronic liver disease. However, this technique has since been successfully developed as treatment for some rare inherited enzyme deficiencies and acute liver failure. The surgical technique was perfected for whole liver transplant operations in the early 1960s. However it was not until the need for suppressing the recipient's immune system was clearly identified, and then non-fatal methods of immune-suppression implemented, that the long-term viability of livers (and the lives of recipients) was achieved.

With the development of liver transplantation, a new medical intervention has been made available to clinically assessed, selected New Zealanders with some form of acute, liver failure or primary liver cancer. Before the establishment of a liver transplant unit

in New Zealand, New Zealanders who required a liver transplant were forced, by circumstances, to undergo this overseas, most commonly in Australia. The contract to provide liver transplantation services was won by Auckland Hospital in June 1997 (Allardyce, 2002)¹. Liver transplantation for New Zealanders in New Zealand commenced in early 1998. In New Zealand "...liver transplantation is now regarded as preferred management for acute and chronic liver failure and for small hepatocellular carcinoma" (Gane et al., 2002, p. 11). The numbers of transplants have increased steadily from only 13 to more than 40 each year. A total of 450 New Zealanders have undergone liver transplantation at the New Zealand Liver Transplant Unit (NZLTU) since 1998.

Significance of the Study

Requiring a liver transplant is an indicator that the potential transplant candidate is ill to the extent that death will occur in the near future if a donor organ is not available. As the reasons for transplant vary, the timeframes vary too. Someone in acute liver failure may have hours or days to live, someone with liver cancer may have months or even years to live if the tumours are controlled and managed.

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, p. 20)

The development of liver transplant surgery, from highly experimental in the 1960s to becoming a preferred management option for acute and chronic liver failure in the late

¹ Tenders were received from Australian and New Zealand hospitals.

1990s, has necessitated constant research, experimentation, and innovation. This is reflected in the literature.

What is noticeable about the literature on liver transplantation is the predominance, naturally, of clinically focused research articles. These may range from innovative medical practices to enhanced surgical techniques to trials of new drug therapies. The literature that includes an interest in quality of life or health-related quality of life still comes from the clinical paradigm. Research by recipients, or inclusive of a recipient's "voice" or perspective, is rare across transplantation, especially in the area of liver transplantation, and is most commonly found in memoir or biographical writings.

A recent study specifically on liver transplant recipients with Hepatitis C noted that "A major limitation to fully understanding psychological wellbeing after liver transplantation is the almost exclusive use of quantitative methods of enquiry. The methodological rigidity of this approach has been criticised for excluding phenomena that are difficult to define or measure" (Dudley, Chaplin, Clifford, & Mutimer, 2007, p. 1300). They noted the exceptions were qualitative studies that included patient descriptions of their own experiences. The authors went on to comment on the weakness of the health-related quality of life approach, stating that "...factors measured often are not weighted to reflect their relative significance for the individual" (p. 1305).

Research Focus

The focus of my research is what is the lived experience of liver transplant recipients in New Zealand. As a liver transplant recipient myself, and as someone already connected to the community of fellow liver transplant recipients, particularly through the communication I receive via my website www.livers.org.nz, I have been aware, since

my transplant in 2000, of the information and knowledge often wanted or needed by either fellow recipients or New Zealanders potentially awaiting transplant. Broadly this information or knowledge “gap” is around the non-clinical quality of life of recipients. An example is a phone conversation I had early in 2008. The sister of a potential recipient contacted me via my website, gave her phone number, to ask if someone could talk to her about what having a liver transplant might mean for her brother. He was nervous of accepting the idea of a liver transplant, as, according to his sister, he didn’t want to end up living the rest of his life sitting in front of the television, when he was an active outdoors man.

Within renal transplantation Kavanagh wrote that “Narratives about the lived experience of patients who have endured the surgery and subsequent treatment regimens of transplant are rare in the literature” (2002, p. 50). My literature review indicated that a recipient-driven approach to researching and reporting on the lived experience of liver transplantation had not yet been undertaken nationally or internationally.

Research Aims

My research had multiple aims. These included:

1. to provide information on our lived experiences of liver transplantation to ourselves, that is the group of New Zealanders transplanted to date;
2. to provide information to future liver transplant recipients – not generalisable but indicative of the first eight years;
3. to pass on a depth of knowledge around the individual realities of liver transplantation to policy-makers in the Ministries of Health and Social Development;

4. to influence operational processes within agencies that connect to, or support, liver transplant recipients in New Zealand;
5. to provide additional knowledge and value to the NZLTU;
6. to add to the body of knowledge, which may benefit future researchers and health professionals.

About the Researcher

On Thursday 21 November 1974, aged eight, I was diagnosed with hepatic Wilson's disease, a genetic disorder. Presentation of Wilson's disease can be hepatic and/or neurological, often determined by the age at which one is diagnosed. I inherited genes from both parents (ATP7B on chromosome 13) that caused my liver to lack the enzyme that metabolised copper. My disease, including extensive liver cirrhosis from an early age, directly led to my need for, and receipt of, a lifesaving liver transplant 26 years later on Tuesday 15 August 2000. My experience of liver transplantation, and the people I have met within the liver transplantation "environment", is my *raison d'être* for this research.

My personal experience of liver disease including issues of denial and compliance, as well as my second liver failure and subsequent experiences waiting for a liver transplant, qualify me as a patient/recipient expert in this area. I believe this thesis topic is extremely important to a group of New Zealanders who have liver disease or live

with, or know someone with liver disease, who may potentially face a liver transplant in their future.²

A liver transplant was something I had never thought about in connection with myself. It is a major change to start thinking about giving up on your own organ (sense of loss), and trying to accept that you can only stay alive through the future death of a potential donor and the gift of donation that that donor's family have made. Can I still work? Can I travel? What is the life expectancy? And many other questions as time goes by.

As a transparent, reflexive researcher, I need to summarise some of my life pre-transplant, during the transplant process and post-transplant, experiences which led to this study.

Liver Disease – Pre-transplant: Diagnosis and Denial

Wilson's disease is fatal without treatment. Those of us born with this disorder lack the ability to metabolise copper, as our livers lack this enzyme. Juvenile presentation is typically hepatic, and with age presentation can be increasingly neurological.

Prior to my diagnosis at 8 years old, I had been sick on a regular basis for about three years. A particularly severe jaundice and vomiting attack with associated illness saw me hospitalised in Hawera (1974) and almost immediately transferred to the Taranaki Base Hospital under the care of Paediatrician Dr Leo Buchanan.

² Personal communication NZLTU May 2011 advised that an estimated 200,000 New Zealanders have chronic liver disease and 250-300 die each year from this. Between 30-50 are transplanted very year.

Wilson's disease was one of many potential illnesses that I was tested for, owing to the experience my Paediatrician had had in the United Kingdom. This was tested through specific blood and urine tests, and also through checking for Kayser-Fleischer rings (copper deposits) in my eyes. Once the diagnosis had been made, appropriate treatment was implemented to both address the current health situation and then get me on to a maintenance regime using Penicillamine to draw the copper out of my body.

At the age of 10, I was still taken to the specialist by my mother. Any tests that were necessary as an outpatient were also done accompanied by my mother. From this stage onwards, I wanted (and expected) her to be my spokesperson. When specialists asked how I was, I'd look over to her to answer for me. This approach lasted into my 20s. This was not to say that I was not compliant with my drug therapy – I took the medication, I did the regular urine tests and went to the lab for blood tests.

I never saw a social life as being something relevant to me or to my future. Physically I was not well enough to participate in sporting activities, so my recreational pursuits were solitary. Reading was my favourite activity. Study and achieving at school, and later university, was also very important, as it was an area where I felt I could try to excel on a "level playing field".

Working was something I wanted to excel at; I was always very aware that I only had my own income-earning abilities to depend on, and wanted to do everything that it was possible to do to maximise my ability to keep a job and minimise any fear or threat of redundancy or firing.

My most uplifting experience was travelling to Germany in 1988 and backpacking alone through Europe for six months. This was the first time I had been away from home, overseas alone, and speaking in a foreign language. It was a validating experience as I met people who had no idea of my health issues. It is the place where I tested and proved myself as an individual and was accepted for being me.

As I approached my 30s, I started to take some responsibility for “owning” my disease and associated maintenance such as solo visits to the specialist. I was not aware enough of general health, and I was resistant to the concept of being “sick” or “ill”, so I wasn’t always in a position to actually take appropriate care of myself. I had bronchitis that turned to double pneumonia in Wellington, which I didn’t recognise, as I thought you had to vomit to be sick, so not breathing didn’t seem to be a symptom for illness in my experience. I finally called a doctor to my flat in Hataitai, Wellington, after I had been home sick nearly a week, who rushed me to Wellington hospital as apparently I was getting a blue tinge. I returned to Auckland in early 1996, and my health slowly deteriorated without my noticing.

In late 1999 I was offered a job with a nation-wide collection of law firms, in a head office role, which I accepted. I worked long hours every day, worked most Saturdays, and put all my symptoms (extreme tiredness, overweight, fluid leaking out of my legs ruining pantyhose on a daily basis) down to poor lifestyle. I was not making time for exercise, or necessarily eating as well as I could. I had to take a taxi to go the short distance from the office to the Auckland District Law Society library on a regular basis, as it was impossible for me to get up the hill.

I had an on-going ear infection at this time, which I had been struggling to get under control for over four months with the assistance of my General Practitioner.

Sunday 20 March 2000 I went to the Emergency Doctor, as I wasn't feeling that great, and the leaking fluid out of my legs was most embarrassing as well as being very uncomfortable. My blood test results came and I had asterisks (bad) everywhere, and it was a very good thing I was seeing the new Liver Specialist the next day. Then I went straight to bed. I woke up, probably around 2 a.m., as I was freezing cold, and having real difficulty breathing. I went by ambulance to North Shore Hospital.

As soon as the North Shore Hospital Gastroenterologist arrived, I was transferred to the NZLTU at Auckland Hospital, arriving there Thursday afternoon, 24 March 2000. Ward 7B became my new home.

For nearly twenty-six years my experience of Wilson's disease was of managing it through medication that chelated and removed the excess copper from my body. In March 2000, after urgent admittance to Auckland Hospital, the NZLTU advised me that my liver had failed for the second time. In their expert opinion, I desperately required a liver transplant, for both acute and chronic liver problems, associated with a rampant blood infection, and porto-pulmonary hypertension.

Facing liver transplantation was not something I had anticipated. I was unaware of this procedure, nor was I aware it was available in New Zealand. My family were facing the concept of a liver transplant. What is this procedure? What would life be like for me if I did have a transplant and it was successful? How long had this been done in

New Zealand? Was it dangerous? How many drugs would I need to be on after a transplant? Their questions were endless; I couldn't comprehend it myself, as I struggled to breathe.

Commencing the Transplant Process: Disempowerment, Acceptance and Conviction

I had an acute infection and liver failure, with the liver team advising my family and me that I had a 10% chance of surviving Thursday night.

Unfortunately the next few weeks were not positive. It took a few days for the infection (*Staphylococcus Aureus*) in my ear and blood to be isolated and treated, and then the work on the acute liver failure started. I was very unwell at this time, and the talk was of a triple transplant (lung, heart, liver), which had not been done in the Southern Hemisphere.

I was not worried about what was going on, as I was too tired to be worried. I concentrated on breathing, which was a challenge. The firm that I worked for and my mother organised for Power of Attorney over me and Power of Attorney over my property to be drawn up, and a new Will was written at my bedside. Once I had signed these documents, I could not actively participate in my external life any more. I was enrolled with Work and Income on a benefit, my bills were out of my hands, family and friends fed my cat.

Owing to the complications that I presented with, after the acute infection had been controlled, I knew on April 10 2000 that I could not be listed for a liver transplant as the heart and lung issues precluded this. The prognosis was a maximum of two years to live

without a transplant, and no one felt my heart would survive an operation. By late May 2000 the multi-organ transplant idea was deemed to be too high a risk. At this time I was sometimes at home, sometimes in hospital. My diet was NO added salt (not easy), and I had high protein drinks (Ensure) to try and keep my body together (it was breaking down). I had day/night reversal, so my best hours were around 1 a.m. Home help was supplied, so I had someone each weekday to wash and feed me and clean the house. A key hung outside the door so that the District Nurses and the Medlab Phlebotomists could let themselves in. (It is disconcerting to be woken up with someone strange standing in your room, putting a needle in your arm).

On Monday 24 July 2000 the liver unit commenced a week-long formal assessment of me as a potential liver transplant recipient. Unfortunately this brought up a technical hitch, as further tests demonstrated that the surgeons potentially had no way of attaching a donor liver to me (via the donor portal vein), as my portal vein and my superior mesenteric vein were not viable. The surgeons noted that the only hope was being able to access the splenic vein (already re-routed to a kidney when the spleen was removed in January 1987). However, irrespective of the many issues and hurdles, the liver unit listed me for transplant on Friday 28 July 2000. I told them that if they could get me through the transplant operation, I would give them the best recovery they would ever see.

I was kept fully aware that the technical chances of this succeeding were not high, and that the chances of my heart surviving the operation also were not high. A possibility that the surgeons explained thoroughly was of opening me up, seeing that it was not possible to transplant the donor liver, and closing me up again. They said this would decrease my life expectancy owing to the strain it would place on my weakened system.

On Monday evening, 14 August 2000, at about 6:40 p.m., my Liver Transplant Coordinator (Val) phoned me. I had a Liver Clinic appointment the next day, so I thought it was about this appointment. She said: “we think we’ve got you a liver!” I arrived in Ward 7B, excited, nervous, apprehensive, thinking of simultaneously planning my funeral service, and wondering/hoping that I would get a new liver and wake up from the operation.

I waved as I was wheeled through to theatre, then it was the process of transferring me to the narrow operating table. In front of me (from my position on the table) I could see the sunrise over the harbour from the windows. I lay down, said to the anaesthetist if they felt or saw my thumb moving it meant I was still awake and to knock me out, and then I heard someone talking to another person while they were ultra-sounding my new liver! My eyes were not open, but my brain “waking up” to the knowledge that there was a new liver (not my old one, with me sewn up again), was the most intense, beyond-belief feeling possible to have. It was literally a new life, a feeling of incredible, overwhelming joy.

Facing imminent death, and hoping to become eligible for a procedure that appeared serious and life-changing, while seeing the reaction of friends and family to the situation, was stressful. I had so many new concepts to face, while struggling to breathe and live. Mostly I wanted to meet others who had “been there, done that”; who had survived this experience.

Immediately Post-Transplant: Gratitude, Joy and Apprehension

The time in the Department of Critical Care Medicine (DCCM) was surreal. I was fixated on knowing what time it was, I think because I was so aware of the times I needed to have the Iloprost³ nebulised, but being intubated I was unable to clearly explain this as I was not able to talk. I also had not finished packing my bag for hospital, so had neglected to bring a watch with me. There was a huge sense of fear and of disempowerment over not knowing the time and whether the Iloprost doses (that I literally believed my life depended on) were being administered at the right time. I recall that DCCM staff amended the Iloprost regime without the liver unit's approval and sign-off, and this got changed back. I felt very out-of-control not knowing the time.

I was able to communicate using a pre-printed, laminated board my sister and I had planned and set up for me based on my knowledge from the splenectomy of how frustrating Intensive Care is when you cannot communicate (see Figure 1, p. 15). This had key words, phrases and questions on it, as well as contact names and phone numbers, and being laminated, I could tap it and it would make a noise, attracting the nurse's attention. I was also able to scribble (very badly) with a pencil on some paper the nurse supplied. I kept this, and there are feeble scrawls saying over and over again how happy and grateful I was to be alive.

I had to be reoperated, owing to internal bleeding, which was of concern owing to the state of my general health, and the risk an operation posed. The nurses were resistant to phoning my family to let them know this as it was the middle of the night, but I knew

³ Iloprost is a drug used to improve microcirculation and liver function after liver transplantation (Klinzing, Stumme, Albin, Habrecht, Settmacher & Marx, 2008).

Figure 1: Laminated ICU Card for Post-operative Communication

Side 1

AJB6047 Bethli Wainwright

<input type="checkbox"/> Yes	<input type="checkbox"/> No
<input type="checkbox"/> Please	<input type="checkbox"/> Thank you
<input type="checkbox"/> More	<input type="checkbox"/> Less
<input type="checkbox"/> Lovely	<input type="checkbox"/> Horrible
<input type="checkbox"/> Just right	<input type="checkbox"/> Perfect thank you
<input type="checkbox"/> Maybe	<input type="checkbox"/> I don't know

Please call:	Cellphone	Home	Work
<input type="checkbox"/> My Mother Robin	025 265 5260	828 3775 (& fax)	529 9348 (& a-phone)
<input type="checkbox"/> My Father Ross	021 115 7701 (Carol)	576 7659	638 6193
<input type="checkbox"/> My boyfriend Ivor	025 299 3809	416 8405	373 7599 ext 7644
<input type="checkbox"/> My sister Kylie	021 595 432	827 0070 (& a-phone)	379 1205
<input type="checkbox"/> My brother-in-law Fraser (doctor)	021 647 101	827 0070 (& a-phone)	486 1491 pager 1726 (N/S hospital)
<input type="checkbox"/> Dr Gane	025 283 1811		
<input type="checkbox"/> Professor Munn			

Side 2

<input type="checkbox"/> What day is it?	<input type="checkbox"/> Am I allowed to sit up / get up?
<input type="checkbox"/> What is the time?	<input type="checkbox"/> Could you pass me my teddy please?
<input type="checkbox"/> How did the operation go?	<input type="checkbox"/> How is Ptohi? (my cat?)
<input type="checkbox"/> Was everything successful?	<input type="checkbox"/> Who is feeding Ptohi?
<input type="checkbox"/> Please explain further...	<input type="checkbox"/> Is there any mail / e-mail?
<input type="checkbox"/> When will Prof Munn / Dr Gane be here?	<input type="checkbox"/> Please fluff up my pillows.
<input type="checkbox"/> Are there any doctors around?	<input type="checkbox"/> Please straighten / smooth my blankets.
<input type="checkbox"/> Hello Nurse / Doctor. What is your name?	<input type="checkbox"/> Please remove a blanket / pillow.
<input type="checkbox"/> How long will I be in Intensive Care?	<input type="checkbox"/> Please gently rub my back.
<input type="checkbox"/> I have a pain ... (point to it)	<input type="checkbox"/> Please put my glasses on / off.
<input type="checkbox"/> Could I have some pain relief?	<input type="checkbox"/> Could you please clean my teeth?
<input type="checkbox"/> Could I have some ice?	<input type="checkbox"/> Could I have a tissue please?
<input type="checkbox"/> I am too hot.	<input type="checkbox"/> Please dim the lights.
<input type="checkbox"/> I am too cold.	<input type="checkbox"/> Could I have the lights on / off / out of my eyes?
<input type="checkbox"/> I feel nauseated.	<input type="checkbox"/> Please hold my hand (especially for needles!)
<input type="checkbox"/> I need a toilet / bed pan.	<input type="checkbox"/> Could I have some Vitamin A cream for my lips?
<input type="checkbox"/> Please don't bump the bed.	<input type="checkbox"/> Please wipe my face with a wet / dry cloth (hot / cold).

that my mother would want to know, and if she was not phoned, and I died, she would be very upset. Finally the nurse agreed to phone her; this was a stressful communication event using tapping and poor pencil scrawls when I was also feeling apprehensive about this extra surgery. Once I was back in the ward, it was scary and exciting. Moving to the ward was a big step forward. Every tube that was removed was a step forward. The drug cocktail was weird. No one explained how bad I would taste and smell to myself, as I got used to all these new drugs. After a couple of weeks it was OK, but for the first week I thought I wouldn't be able to put up with my own smell and taste. Owing to the complications in my transplant, I was advised by the liver unit that I would be in hospital for a longer period of time than most transplant patients, and that even though I lived in Auckland, I might have to transition through Domain Lodge or Transplant House, the accommodation near the hospital. I was happy to do whatever the liver unit wanted, although I hoped to be able to go directly home to my own home. Some of the nursing staff gave me anxious moments, as they came in and talked about my going home, when I was still not able to get myself and my oxygen tank down to the showers. This was because they were working on "normal" transplant time frames. It did cause me to feel very insecure at times, as I knew I didn't feel at all like I could possibly go home.

After three weeks I was off the oxygen, all the tubes were out, and I was allowed home. Being a passenger and wearing a seatbelt in a car were difficult owing to the position of the scar, but a "tummy" pillow was of great assistance. For the first six months I was not allowed to go to any places where a large number of people might gather, such as supermarkets, churches or cinemas. I was also not allowed any fast-foods. At this stage I had to have constant caregivers, and I was still on nebulised Iloprost. Friends and family took annual leave to look after me week about. I was driven to Physiotherapy at

Waitakere Hospital, the District Nurses came every day, and the mobile library dropped off books every so often.

Personal achievements were the small things: the first time I could slightly bend down, pick up a potato from the kitchen cupboard, peel it, cut it and put it in a pot all by myself. The first time I could lift my hands above my head and try and wash my own hair. The first time I tried to step out of the bath (off the bath seat) by myself. After 12 weeks I was deemed well enough to be able to live by myself again, without overnight caregiver support. Prior to the transplant, but after my initial hospitalisation, I had had a special medical alarm installed in the house that could be activated from a button on a band on my wrist. For the nebulised Iloprost at 9 p.m., 2 a.m. and 7 a.m., the Medical Alarm people (based in Tauranga) would ring me on the loudspeaker phone, make sure I got up OK and got into the lounge to nebulise the drug. If there were any problems, they would call an ambulance and the hospital straight away. After 12 weeks I was also permitted to drive to Waitakere Hospital for physiotherapy by myself, but no further than that.

It was at this time that my perception of my quality of life deteriorated. The initial excitement of having the new liver had subsided, the caregivers were no longer present, but were picking up their own lives again, I was still unable to work, leave the house (except for physiotherapy), or do very much. I wanted to do something, participate in something, have some kind of social interaction, but this was actually the loneliest part of the entire transplantation process.

During the transplant time I had a lot of questions, most of which I did not voice, about what my future might be like. There was really excellent information about the

transplant process, the drug regime, the interactions of the drugs, the food safety issues, physiotherapy, exercise, diet and nutrition. There was no information, and no one I could really ask, about other things:

- Do you disclose the transplant to a potential employer?
- How many people get jobs again? Is it hard? Is there a prejudice?
- Can you buy property? (When I ended up in hospital in March 2000, my home was on the market, and I was hoping to purchase a home in Royal Heights).
- Can you travel? Can you get travel insurance?

Subsequent to my successful liver transplant (August 2000), I discovered that there is a connectivity between recipients, developed within the hospital environment, that may linger on into “post-transplant” life. This is informal, and tends to involve a “checking” with other recipients as to the “normality” of symptoms and feelings (non-clinical) within the collective experience of recipients. Although this “checking” may have commenced within the hospital-based support group, it continues by email and phone contact. Inga Clendinnen, an Australian liver transplant recipient, documents this in her memoirs.

We are not really friends. We know too little of each other’s lives beyond the hospital to be friends. What we are is comrades. We are like Roman veterans meeting back in the city between stints on the frontiers, serving in different camps, with the deprivations various, the natives differently troublesome, but sharing a knowledge incommunicable to all those others – family, lovers, friends – who know nothing of life on the frontier. The great dividers of class, occupation, faith, ethnicity, sex, age, have no authority here. The senior veterans command a touch more deference, that is all. (2000, p. 281).

My research addressed this liver transplant recipient environment formally, through a supervised, ethically approved and structured research approach.

Clendinnen introduced her memoirs with the explanation that her story was "...not the story of a medical crisis. If it were, it would be for medicos to write...to feel the mind disintegrate and to fear the disintegration of the self, is to suffer an existential crisis, not a medical one" (2000, p. 1). She further stated that "What distinguishes the healthy from the ill – which is a more significant division in any society than class or gender or possibly even homelessness – is that the healthy consider feeling well to be the normal state of things" (p. 10).

The comment by van Manen that "In drawing up personal descriptions of lived experiences, the phenomenologist knows that one's own experiences are also the possible experiences of others" (1990, p. 54) provides validity for my inclusion of my experience of liver transplantation within this research.

Introducing Wellbeing and Quality of Life

As a transplant recipient, and as a student reading in the area of wellbeing, I viewed wellbeing as being a very subjective, personal experiential concept that can change with time and within different contexts. Robertson wrote that "An individual's quality of life is described by Leyendecker et al. (1993) as the individual's subjective perception of their physical, social and psychological state following their illness or treatment" (Robertson, 1999, p. 498).

There is much discussion in the literature on how quality of life can be defined, assessed and measured, and the relationship between wellbeing and quality of life. The first research in New Zealand that considered the quality of life of liver transplant recipients was undertaken by Beilby in 2001. I was part of the researcher's participant group.

Although this research is useful, at the time I felt unable to explain to the researcher exactly how I felt about the experience of transplantation, as I was constrained by the data collection tool, the MOS 36-item Short-Form Health Survey (SF-36). In addition, I was interviewed only a few months after my transplant, when I was alternating between feelings of euphoria and depression, as I attempted to balance my feelings of appreciation for a new life, my fear of re-attaching to “life” and its responsibilities, my feelings of “abandonment” as my family and friends picked up their lives again, and of still being socially isolated owing to my health status at the time of interview. Mood dysrhythmia is a real side effect of the high doses of steroids administered in the early post-transplant period.

Nordenfelt (1991 a, b) has suggested that health is a resource for, but not a condition of, quality of life (cited in Sarvimäki, 2006, p. 5). Many definitions of wellbeing separate the concept into individual parts, such as physical, mental or psychological, social and spiritual (Sarvimäki, 2006). Heidegger took an alternative viewpoint, looking at wellbeing or “being well,” as “Dasein,” or existence/being. He focused on the concept of “Being-in-the-World.”

Taking Heideggerian phenomenology as the philosophical underpinning to this research, my focus is on the lived experience of New Zealanders facing and surviving a liver transplant. This follows Sarvimäki’s idea that:

...researching wellbeing inspired by this philosophy might be better carried out as a strategy focusing upon human beings caught up in their life course in everydayness, in their doings and not-doings, projects and anxieties (Sarvimäki, 2006, p. 9).

Research Participants

All recipient participants in this research have some commonality. Eligible recipients were all (out-) patients of the NZLTU, based in Auckland City Hospital. They were recipients of a liver from an unknown deceased donor. Focus group participants, and recipient participants invited for an interview, were based in New Zealand. As the NZLTU commenced liver transplantation services in 1998, I took 1998 as my starting year for the research. The rationale for recipient participant eligibility is fully covered in the section on my sampling strategy in Chapter Three.

The recipient participants⁴ were recruited from New Zealanders who underwent their first liver transplant in New Zealand between 1998 and 2005. The selection of 2005 as the last year of eligibility was to ensure that there had been at least four years between the time of the transplant, and the time that the research commenced with each participant.

Cohen (1982) warned of the immediate post-operative euphoria resulting from the release of anxiety and stress and enhancing patients' perception of their wellbeing. An additional euphoric side effect of the high dose steroids administered in the first three months after transplantation is also a factor. Leyendecker et al. (1993) found that, retrospectively, patients stated they were very insecure and anxious and so attributed the excellent ratings obtained in their assessment during the first year post-transplant, and the patients' initial euphoric mood, to psychological defence mechanisms.

⁴ Focus group members, interview participants and survey participants.

Each recipient participant was a minimum of four years post-transplant at 1 January 2009. I believed this might provide an adequate distance for reflection back on the experience. Participants were recipients of a deceased (unknown) donor liver.

Out of Scope

All recipient participants had to be aged twenty or older at 1 January 2009. Primarily this was because experiencing a liver transplant when a child or a teenager may potentially raise issues that might not be faced by older recipients; it could cause the research to become more complex. I tested this hypothesis with a New Zealand adult (in their twenties) who received a deceased donor liver in Australia at the age of five. This adult read the information sheet,⁵ signed the consent form⁶ and was very supportive of this research project. During the interview it became very apparent to me that receiving a liver at a young age raises very different issues to those issues that adult recipients of livers may face. As the majority of New Zealanders receiving a liver transplant are adult (over the age of twenty) at the time of transplant, my research is only focusing on this group of liver transplant recipients. This does not, however, deny the importance of researching the lived experience of paediatric liver transplantation. This will be discussed later in the thesis (Chapter Ten) when I suggest areas for further research.

My research explicitly omits any attempt to place the lived experiences of liver transplant recipients into any quantitative framework that assesses wellbeing in the context of New Zealand normative data. I am not repeating the Beilby research, as illustrated in the quote below.

⁵ Attached to this proposal as Appendix 2, p. 292.

⁶ Attached to this proposal as Appendix 3, p 296.

Consistent with the literature, New Zealand transplant recipients reported better physical and psychological functioning than pre-transplant patients. The positive changes in psychological functioning appeared to be particularly pronounced for the liver patients. Although physical functioning improved following transplantation, it was found to be worse than that of New Zealand normative data (Beilby, 2003, p. 5).

To be assessed and approved for liver transplantation is only a part of the overall picture. Living donor liver transplantation is available, but is not part of this thesis. In addition, there is a critical aspect around organ donors and brain-death. Lock states:

All along, the brain-death debate has hinged on several critical questions: What is a person? What is the relationship of person to body? Does the person cease to exist when the physical body dies? And perhaps the most fundamental, most obdurate question of all: What exactly *is* death—physical, personal, and social (Lock 2002. p, 37).

There is a considerable body of research in this field, exploring donation and brain-death through sociological and anthropological lenses. This area is excluded from my research.

Overview of Liver Transplantation in New Zealand

The NZLTU opened in June 1997, commencing transplant services in 1998. Two years later, with major support from the New Zealand Lions Clubs, it commissioned its associated local accommodation, “Transplant House” (Allardyce 2002, p. 2).

Since the establishment of the NZLTU, there have been 440 transplant operations on 425 recipients. Some recipients may require a re-transplant if the first graft fails. The survival rate at one year is 96% and at five years is 88%. The 10 year survival rate is

85%.⁷ New Zealand, and New Zealanders, are most fortunate that these transplantation services are now available to us. As one recipient stated:

I knew that I would be dead by Christmas, if I didn't get a transplant.

IP#5

Table 1 (page 25) shows the many reasons for a liver transplant in the NZLTU between 1998 and 2005, the time period of my study. Although this table shows 249 reasons for liver transplantation, this includes recipients of live liver donations,⁸ paediatric recipients⁹ and deceased recipients as well as living adult recipients of deceased donor livers. The total number of eligible recipients for this research project is 182.¹⁰

⁷ These statistics were provided to the researcher verbally by the Hepatologist at the NZLTU on Friday 28 May 2010 in the presence of the primary supervisor.

⁸ The NZLTU was contracted from 2002 to perform initially five live liver donation liver transplants annually, and is now contracted for an unlimited number.

⁹ The NZLTU was contracted from 2002 to perform up to 45 paediatric liver transplants through Starship Children's Hospital, Auckland. The first paediatric transplant was in 2002.

¹⁰ The process of elimination to get to this number is covered later. It was an exercise undertaken with the hepatologist at the NZLTU.

Table 1: Reasons for Liver Transplant in the NZLTU between 1998 and 2005

(NOTE: number of transplants does not equal number of patients as some patients received multiple transplants)

Condition	1998		1999		2000		2001		2002		2003		2004		2005	
	#	%	#	%	#	%	#	%	#	%	#	%	#	%	#	%
Alcoholic liver disease w/out viral hepatitis (ALD)		0.0%	1	3.7%	5	15.2%	3	8.1%	2	5.3%	5	13.2%	2	5.6%		
Alpha-1 antitrypsin deficiency		0.0%		0.0%		0.0%		0.0%	2	5.3%	1	2.6%	1	2.8%	1	3.6%
Amanita poisoning		0.0%		0.0%		0.0%		0.0%		0.0%		0.0%		0.0%	1	3.6%
Amyloidosis		0.0%		0.0%	1	3.0%		0.0%		0.0%		0.0%		0.0%		
Autoimmune hepatitis (AIH)		0.0%		0.0%	1	3.0%		0.0%	2	5.3%		0.0%		0.0%	1	3.6%
Biliary atresia		0.0%	3	11.1%		0.0%		0.0%		0.0%	4	10.5%	3	8.3%	5	17.9
Budd-chiari syndrome		0.0%	2	7.4%		0.0%	1	2.7%	1	2.6%		0.0%	1	2.8%	1	3.6%
Cryptogenic		0.0%		0.0%	2	6.1%	4	10.8%	4	10.5%	3	7.9%	1	2.8%		
Drug		0.0%		0.0%		0.0%	1	2.7%		0.0%		0.0%		0.0%		
Haemochromotosis	2	16.7%		0.0%		0.0%	1	2.7%		0.0%		0.0%		0.0%	1	3.6%
Hepatic artery thrombosis (HAT)		0.0%		0.0%		0.0%	1	2.7%		0.0%		0.0%		0.0%	1	3.6%
Hepatitis B virus related (HBV)	4	33.3%	10	37.0%	11	33.3%	9	24.3%	6	15.8%	9	23.7%	7	19.4%	3	10.7%

Condition	1998		1999		2000		2001		2002		2003		2004		2005	
	#	%	#	%	#	%	#	%	#	%	#	%	#	%	#	%
Hepatitis C virus related <i>with or w/out alcohol</i> (HCV)	2	16.7%	2	7.4%	3	9.1%	9	24.3%	12	31.6%	11	28.9%	14	38.9%	5	17.9%
Non A/B hepatitis	1	8.3%		0.0%	3	9.1%		0.0%	1	2.6%	2	5.3%		0.0%	2	7.1%
Non alcoholic steatohepatitis		0.0%		0.0%		0.0%		0.0%	1	2.6%		0.0%	1	2.8%	2	7.1%
Other causes (acute)		0.0%	4	14.8%		0.0%		0.0%		0.0%	1	2.6%		0.0%		
Other causes (chronic)		0.0%	5	18.5%		0.0%		0.0%		0.0%		0.0%	4	11.1%		
Primary Biliary cirrhosis (PBC)		0.0%		0.0%	2	6.1%	4	10.8%	1	2.6%	1	2.6%		0.0%	2	7.1%
Primary non-function		0.0%		0.0%		0.0%		0.0%	1	2.6%		0.0%		0.0%		
Primary sclerosing cholangitis (PSC)	3	25.0%		0.0%	3	9.1%	2	5.4%	2	5.3%	1	2.6%	2	5.6%	1	3.6%
Rejection (post Tx)		0.0%		0.0%		0.0%	1	2.7%	3	7.9%		0.0%		0.0%		
Sarcoidosis		0.0%		0.0%		0.0%		0.0%		0.0%		0.0%		0.0%	1	3.6%
Systemic sclerosis (SSc)		0.0%		0.0%	1	3.0%		0.0%		0.0%		0.0%		0.0%		
Wilson's disease		0.0%		0.0%	1	3.0%		0.0%		0.0%		0.0%		0.0%	1	3.6%
TOTAL	12	100.0%	27	100.0%	33	100.0%	37	100.0%	38	100.0%	38	100.0%	36	100.0%	28	100.0%

Brief History of Transplantation Internationally

The first technically successful attempt at human-to-human liver transplantation was for the child Bennie Solis, born with biliary atresia, who was transplanted on 1 March 1963, by Dr. Thomas Starzl in the United States. Bennie received a liver from another child, who had died during open heart surgery. At this stage, in 1963, Dr. Thomas Starzl and his team "...had performed nearly two hundred liver transplantations in dogs..." (Starzl, 1993, p. 99) and had achieved what they viewed as an effective immunosuppression regime to minimise liver rejection through Imuran-steroid therapy. Bennie did not survive the operation. Dr. Starzl described the operation in his autobiography.

However, nothing we had done in advance could have prepared us for the enormity of the task. Several hours were required just to make the incision and enter the abdomen. Every piece of tissue that was cut contained the small veins under high pressure that had resulted from obstruction of the portal vein by the diseased liver. Inside the abdomen, 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, 1993, p. 99).

The Starzl team did not undertake any liver transplants for a further three years, working instead on renal transplantation, which had achieved more initial success. In 1968 in Europe a woman with a primary cancer in her liver was referred to Sir Roy Calne at Addenbrooke's Hospital, and together with Dr. Francis Moore, the cancerous liver was removed from the woman, who received a donor liver from a child. She survived for two and half months, before developing "...a fatal pneumonia, due to the

immunosuppressive drugs given to prevent rejection” (Calne, 1998, p. 97). This was the first liver transplant in the United Kingdom and in Europe.

As effective immunosuppression 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, provided the patient survived the technical liver transplant surgery, it became increasingly possible to maintain the efficacy of the graft. The two barriers¹¹ to successful transplantation were:

1. The challenge of complex surgery leading to bleeding and perioperative death (as in Starzl’s first transplant) and
2. Prevention of acute rejection which occurs one to three weeks after recovery from surgery.

Cyclosporine has reduced the second barrier above, but not the first.

As another liver transplant pioneer, Sir Roy Calne, wrote:

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, p. S51).

The timeline of liver transplantation internationally is summarised in Table 2, p. 29.

¹¹ Personal communication with the NZLTU May 2011.

Table 2: Liver Transplantation Timeline

Rest of the world	New Zealand
AUSTRIA: Kidney transplant experiments with animals, Vienna Medical School.	1902
FRANCE: Xeno-transplantation experiments of animal kidneys into humans.	1909
ENGLAND: Sir Peter Medawar and Dr Thomas Gibson experiment with skin grafts and develop knowledge of immune reaction	1940s
UNITED STATES: First documented kidney transplant – 17 June, Patient Ruth Tucker transplanted by Dr R. H. Lawler, Little Company of Mary Hospital, Chicago. Survived five years.	1950
FRANCE: January – two separate kidney transplants in Paris using two kidneys from executed (guillotined) prisoner. Recipient #1 died day 17. Recipient #2 died after day 19. FRANCE: Late January – living donor kidney transplant. Recipient died around day 32.	1951
UNITED STATES: Identical twin kidney transplant – December 23, Patient (Richard) received kidney from identical twin. No immunosuppression regime required. Surgery lead by Dr. Joseph Murray at Peter Bent Brigham Hospital, Boston. Survived eight years.	1954
UNITED STATES: First kidney transplant using immune-suppression (total body irradiation). Initially successful, female recipient died from lack of blood clotting factor leading to haemorrhaging.	1958
UNITED STATES: First successful fraternal twin kidney transplant – January. Surgery led by Dr. Joseph Murray at Peter Bent Brigham Hospital, Boston. Recipient received total body irradiation treatment prior to transplant and survived 20 years, dying of heart failure.	1959
UNITED STATES: First human liver transplant – 1 March, child, Bennie Solisborn, died on operating table from uncontrolled bleeding. UNITED STATES: First human lung transplant. Surgery led by Dr. James Hardy. Recipient died on day	1963

Rest of the world		New Zealand
18. No immune-suppression used.		
UNITED STATES: Xeno-transplantation of chimpanzee heart into human by Dr. James Hardy, University of Mississippi. Unsuccessful.	1964	
	1965	First kidney transplant.
SOUTH AFRICA – December 3. Successful orthotopic heart transplant (with immunosuppression) by Dr. Christian Barnard, Groote Schuur Hospital, Cape Town. Recipient died on day 18. UNITED STATES – later in December. Second human heart transplant by Dr Adrian Kantrowitz, New York. Recipient survived 6.5 hours.	1967	
UNITED STATES: Southeast Organ Procurement Foundation, SEOPF (USA) formed as a membership-based scientific organization for professionals working/researching in the area of transplantation. ENGLAND: First liver transplant in Europe, Transplant by surgeon Sir Roy Calne within the Cambridge-King's College Hospital programme.	1968	
SWITZERLAND: Discovery of Cyclosporin (from soil samples), Sandoz Ltd (Basel, Switzerland) – March. Immune-suppression properties not known.	1970	
FRANCE / UNITED STATES: The International Pancreas and Islet Transplantation Registry founded at a meeting in Lyon, France. It is based at the University of Minnesota and it maintains a database of all reported Pancreas transplants in the world.	1980	
UNITED STATES: Cyclosporin (immune-suppression medication) drug use approved to prevent rejection of transplanted organs by the US Food and Drug Administration.	1983	
UNITED STATES: National Organ Transplant Act, Author: Congressman Al Gore, Tennessee. UNITED STATES: United Network for Organ Sharing (UNOS), incorporated as a non-profit organisation. WHO: Human Organ and Tissue Transplantation WHA 57.18. World Health Organisation, fifty-seventh	1984	

Rest of the world		New Zealand
<p>World Health Assembly (May 2004).</p> <p>UNITED STATES: October 14 – Baby Faye received a heart from a baboon (xeno-transplantation) at Loma Linda University, California. Survived one month.</p>		
<p>UNITED STATES: Federal contract to UNOS for OPTN, the Organ Procurement and Transplantation Network</p>	1986	
	1987	<p>First heart transplant.</p> <p>Donor Co-ordination services established, now known as Organ Donation New Zealand.</p>
<p>UNITED KINGDOM: Human Organ Transplants Act 1989.</p> <p>UNITED STATES: First successful living-donor liver transplant, November 27. University of Chicago Medical Centre transplanted part of the liver from mother Teresa Smith into 21-month old daughter Alyssa, who had Biliary Atresia (still alive in 2006).</p>	1989	
<p>UNITED STATES: First living donor lung transplant (uncommon procedure).</p>	1990	
<p>UNITED KINGDOM: UK Transplant Support Service Authority established.</p>	1991	
<p>UNITED STATES: June and July – xeno-transplantation of baboon livers into human recipients in Pittsburgh, Pennsylvania. Unsuccessful.</p>	1992	
<p>UNITED KINGDOM: NHS Organ Donor Register established. (Opt-in system.)</p>	1994	
	1998	<p>NZLTU opened, and first New Zealanders received liver transplants in New Zealand.</p>
<p>UNITED KINGDOM: July – UK Transplant Support Service Authority reviewed and became UK Transplant,</p>	2000	<p>Bethli Wainwright received liver transplant – August,</p>

Rest of the world	New Zealand
with mandate to increase rates of organ donation.	NZLTU.
UNITED KINGDOM: 15 November – Human Tissue Act (Royal Assent.)	2004
UNITED KINGDOM: October – UK Transplant merged with the National Blood Service and Bio Products Laboratory. New organization known as NHS Blood and Transplant.	2005
	2008 Human Tissue Act 2008 passed (ethical and appropriate collection and use of human tissue). Pig tissue transplants approved – 21 October. Trial approved for eight people with Type 1 Diabetes

What is Covered in the Next Chapters

Chapter Two introduces the key concepts of this research based on the lived experience of transplant recipients, and describes how the initial set of these concepts was developed for the purposes of the fieldwork for this thesis. It includes an overview of the literature on wellbeing, and ethical issues that face transplant recipients and which they must live with.

Chapter Three introduces the reader to phenomenology, the methodology chosen for this research. Key works by Heidegger and van Manen are reviewed. The methods and sampling frameworks used in the field work are described, and there is a discussion of triangulation and its effect in assisting rigour in qualitative research.

Chapter Four is concerned with data collection and the ethical issues raised in the thesis fieldwork, and describes the actual fieldwork experiences of using the methods chosen. The chapter also reports a number of my reflections from my fieldwork which were reported to supervisors at the time.

Chapter Five reviews survey research of liver transplant recipients undertaken in the past. A critique of this is followed by a description of the process I used to develop my own survey tool.

Each of the following three chapters begins the report of findings from the literature review, the key informant interviews and the survey. Chapter Six focuses on becoming unwell. Chapter Seven moves to the next stage in the recipient process: getting on the transplantation list, and the wait for the call before the transplantation operation. Chapter Eight leads us through the experience of waking post-transplant and in the recovery wards before discharge to Transplant house or to home in Auckland.

Chapter Nine covers the experience of life post-transplant, with a focus on gratitude and reciprocity, and the desire recipients have to help.

Chapter Ten contains recommendations for immediate implementation in the NZLTU. It concludes with recommendations for further research arising from this thesis, a discussion of the thesis and the contribution it makes.

Chapter Two: Key Concepts in the Lived Experiences of Liver Transplant Recipients

Before the transplant I worried that it would be a burden on my family; that is financially, physically, and mentally. I took all the chances I could to enjoy myself, e.g. travelling, dancing parties, meeting relatives and friends. I worried about the expenses of G.P. consultations, medicines, transportation from home to hospital and clinics and some unexpected expenses. Fortunately, with the help of the social worker, I got support from WINZ. As long as I was relieved from my worries, I was willing to undergo the transplant.

SP#9

Introduction

In this chapter I discuss the key concepts within the lived experience of liver transplant recipients that were developed from the pilot interviews. I outline the ethical process that ensures the anonymity of donor family and recipient. I then provide an overview of the recipient-focused literature, as opposed to the clinical-focused approach, noting examples of personal experience of recipients, their families and nursing staff. I note some of the ethical issues involved and give evidence of my own experience of them. The chapter concludes with a brief literature review of social and economic wellbeing in the context of liver transplantation.

Key Concepts within the Lived Experience of Liver Transplant Recipients

Key concepts were developed initially from pilot interviews, based on the initial key informant interview draft outlines. I asked two of my focus group to be respondents, and I also trialled and recorded a pilot interview with myself. I transcribed these, and developed the following early thematic matrix of concepts (Table 3, below).

Table 3: Key Concepts

(NOTE: “P” refers to one of the three Pilot Participants.)

Major Concept	Sub Concept	Symbols Indicating Concept
What is “being unwell” (P1)	Acne/itch/rash (P1) Relativity – comparing yourself to the dying, you are well (P1) Tiredness (P1) Huge effort (pre-Tx) (P1) Letting things slide (pre Tx) (P1) Not having normal lifestyle, but not questioning the changes (P1) Sick for so long without realisation (P1) Achievements when sick astounding looking back (P1) Being tired (pre-Tx) (P2)	Everything slowed down (P1)
Being informed (P1)	Post-transplant information re crowds, diet etc (P1)	Stationery changed (P1)
Unreality/Surreal (P1)		
Life while waiting	Shifted house while waiting for Tx (P2) Mates helping shift (P2) Work let me rest (P2) Giving up work (P2) I struggled on (P2)	

Major Concept	Sub Concept	Symbols Indicating Concept
Acceptance/Denial (P1)	Disbelief (P1) Deal with it (P1) Stress (from denial) (P1) Acceptance of poor quality of life (post-Tx) as reality (P1) Facing reality – dead without transplant (P1) Wouldn't acknowledge I was ill (P2)	Going to theatre still not believing having transplant (P1)
No real big deal – in good hands – little bit of shock (P2)	Sister's brother-in-law was number 13 (some familiarity) (P2)	
Communication with other Tx patients	Talked to brother-in-law (number 13) (P2) Daughter-in-law works with number 1 (P2)	
Scared (P1)	Coping (P1) Fear of never getting to live in own home again (being "normal") (P1) Tac tremors upsetting (P1) Scared of driving post-Tx (P1)	Tac tremors stop you writing cheques (P1) Couldn't write, couldn't draw, couldn't paint (Tac tremors) (P1)
Intensive Care	12mm pipe down throat the worst thing – wanting to tear it out – hands tied down (P2) Communication without voice – points to ring– wants wife (P2) Visit DCCM once well (P2)	
Black humour	"You had crap yet?" (P2)	
My mess, my responsibility	Vomiting – I'll clean it up (P2)	
Pain – post-transplant	Feel as if you've been run over by 24 trains and a couple of big buses (P2)	
Time	You kept wanting to know the time (Nurses comment to recipient) (P2)	

Major Concept	Sub Concept	Symbols Indicating Concept
	<p>Want to know when getting out of DCCM (P2)</p> <p>Nurses give distance to milestones (e.g. losing tube in throat) in hours – need to be able to measure distance to milestone (P2)</p>	
Encephalopathy	<p>Brain confused (P1)</p> <p>Day/Night reversal (P1)</p> <p>Not able to cope with too much information (P1)</p>	
Being prepared (P1)	<p>Not packing a bag (P1) (tired? denial?)</p> <p>Worried about pets (P1)</p> <p>Not understanding the impact of Tac tremors (P1)</p> <p>Not wanting information overload (P1)</p> <p>liver unit does good job at informing enough (P1)</p>	Having small operation first made transplant less scary (P1) [dress rehearsal]
Others not informing you when jaundiced/sick until afterwards (P1)	<p>Wife said you're yellow, you're tired (P2)</p> <p>Wife was surprised as went into theatre green and came out pinky-red (P2)</p>	
Gender of donor (P1) Male donor (P2)	Wife saw death notice in the paper (P2)	
Guilt about donor (P1)	Waiting for another's death (P1)	
Thanking donor	<p>Write to them on the anniversary each year (P2)</p> <p>Donor family's choice whether to respond (P2)</p> <p>Happy to meet donor family in a neutral place – personal opinion (P2)</p> <p>How do you help someone or say thank you to someone who has</p>	No response from donor family (P2)

Major Concept	Sub Concept	Symbols Indicating Concept
	given you life? (P2) Can't say thank you (P2)	
Driver's Licence re donor status	Should be your choice not your family's choice (P2)	Friends didn't know livers were transplanted in NZ (P2)
Out-of-town vs Auckland	He was from Dunedin, people from out of town – big problem, we're lucky we live here (P2) Only 20 mins into hospital if anything goes wrong (P2)	
Thanksgiving Service		
Self-imposed expectations on what donor/donor family would expect you to do – guilt at not measuring up (P1)		
Respect the gift (P1)	Thinking about donor – especially around the anniversary (P1)	Think of liver as second-hand, but not in a bad way (P1) Over time the liver/gift becomes less exceptional – it's yours, you won't give it back (P1) Surreal at the beginning – having some other person's liver (P1)
Information about the Donor (P1)	Curiosity about donor (3 livers the night of that transplant – expected to see media coverage of huge car accident) (P1)	
Facing death (P1)	Coping strategies (P1) Accepting death (P1) Others have died because no transplant (P2)	Too tired to live anymore – death an escape/relief (P1)
Expectations	I knew it was going to be good	

Major Concept	Sub Concept	Symbols Indicating Concept
	<p>(while being wheeled into theatre) (P2)</p> <p>Saw image of Pacific Island tropical paradise – knew from that it would be good (P2) (Link to his work)</p>	
Financial stress (P1)	<p>Freehold house (P1)</p> <p>No retirement scheme as irresponsible person, not because don't think will live that long, plus well-off parents (P1)</p> <p>No financial problems – wife worked full-time (P2)</p>	
Asking for help/Accepting assistance (P1)	<p>Post-transplant more willing to ask for, and accept help (P1)</p> <p>Had a ton of support (wife, mates, children) (P2)</p> <p>Not over-dependent on others, but would ask for help if needed (P2)</p>	<p>Not looking for NGO/Govt services support (P1)</p> <p>Not looking for support (P2)</p>
Work and Income Benefits (P1)	Knowing what to ask for (P1)	
Medical staff (P1)	<p>Wanting to strangle a nurse or two (P1)</p> <p>Doctors and most nurses incredible (P1)</p> <p>Came to admire the nurses (P1)</p> <p>Critical care nurses fantastic – there all the time (P2)</p> <p>In the ward – vomited – said to nurse I'll clean it up (P2)</p> <p>Whole team were number 1, they were good (P2)</p> <p>Hated physio at the time, thankful now (P2)</p> <p>They're so good – nurses, doctors, registrars (P2)</p> <p>She was good, [Name] (P2)</p>	<p>Nurse not listening to patient (P1)</p> <p>Make it easy for patient (esp re pain) vs make it easy for nurse (P1)</p>

Major Concept	Sub Concept	Symbols Indicating Concept
	[Name] re adoption (P2) Amazing surgeons (P2)	
Hospital environment	Old hospital pretty grotty (P1) Fear of hospital environment when immune-suppressed (P1)	Messages from medical staff do not match the environment – scares the patient. Added stress. (Paint peeling, water coming through the windows). (P1)
Risk management/business continuity planning	I presume they're training someone up? Because they're not going to be there forever (P2)	
Patient vs Doctor expectation of clinic visits	Last time he didn't even take BP, not impressed, that's what patient came in for, not just to talk (P2)	
Dr Gane	Dr Gane was amazing (P1) They're very good (P2)	
Post-transplant complications	Being readmitted would never stop (P1) Getting to know fellow patients in same situation – mostly women (P1) Antibiotics constantly – change month about (P2) Back to hospital 15 times since transplant (P2)	
Post-transplant support	3 or 4 visits from local nurse (P2)	
Others overly protective	Everyone said take it easy when I pottered around (P2)	
Staying positive (P1 p15)	Small improvements (P1) Small achievements (P1) Being obstinate about doing things yourself (P1) Thousands of others worse off than you (P2)	Others thought it a big deal (P2)

Major Concept	Sub Concept	Symbols Indicating Concept
Attitude	<p>Don't worry, just fix it (P2)</p> <p>Things were clearer (P2)</p> <p>Really happy to be alive (P2)</p> <p>Stubborn – determined to do things post-Tx (P2)</p> <p>Don't worry about going back into hospital for infections etc post-transplant (P2)</p> <p>Do what has to be done, others worse off (P2)</p> <p>Stubborn or determined? (P2)</p> <p>Second chance (P2)</p> <p>People might refuse a liver, but you've got to take that chance (P2)</p> <p>Even though the odd person might die, still take that chance (P2)</p>	<p>Senses better (P2)</p> <p>If you sit on the fence you get splinters in your bum (P2)</p>
Hospital as safe place (P1)	<p>Becoming institutionalised (P1)</p> <p>Not worrying about food and bills (P1)</p> <p>Not wanting to leave hospital (P1)</p> <p>Familiarity – with staff and processes, old hand (P1)</p>	
Going home (P1)	<p>Scared of going home (P1)</p> <p>Being in the house alone – frightening (P1)</p> <p>Well enough to self-care (P1)</p> <p>Once a reality – not scared (P1)</p> <p>Not nervous about going home (P2)</p>	<p>Feeling the bedroom had been newly painted and was brighter (reality – no change) (P2)</p>
Caregivers	<p>Neighbours getting sick of feeding cats (P1)</p> <p>Parents gave up their lives for that time (P1)</p> <p>Hard on caregivers (P1)</p>	

Major Concept	Sub Concept	Symbols Indicating Concept
	<p>Tough on son (P1)</p> <p>Parents facing daughter's death – daughter never wanted parents to die first – reality of daughter's death upset mother (P1)</p> <p>Wife and children worry more than recipient (P2)</p> <p>Wife suffered more than he did (P2)</p> <p>Caregiver and siblings worried more than I did (P2)</p> <p>Wife mowed lawns and did odd jobs (P2)</p> <p>First few weeks caregivers have to keep eye on you 24/7 then back to normal (P2)</p> <p>Caregivers want to go to Clinic appointments (P2)</p> <p>Harder on wife and children – patient gets help, but caregivers give it (P2)</p>	
Big things post-transplant	<p>Getting back to driving and going home (P1)</p> <p>Liver had CMV – got it twice (P2)</p>	
GP Care	GP overly cautious (P1)	
Taking advice post-Tx	<p>Shouldn't go to Pacific Island because of risk of disease but do it anyway (P2)</p> <p>Get sick, go back into hospital upon return (P2)</p>	<p>Risk taking</p> <p>Maybe it's stupid – but I do it (P2)</p> <p>Not a fanatic on bottled water in the Pacific Islands (P2)</p>
Lifestyle stays the same	<p>Go deer stalking and drag heavy deer out of bush (P2)</p> <p>Go fishing (P2)</p> <p>Hasn't hindered me a bit (P2)</p> <p>Travelled to the Pacific Islands three times post-transplant (P2)</p>	

Major Concept	Sub Concept	Symbols Indicating Concept
Lifestyle changes for recipient (P1 p21)	<p>Own toothpaste, own towels, everything through dishwasher (P1)</p> <p>Washing hands frequently (P1)</p> <p>Being easier on son (P1)</p> <p>Feel retired in a way (P1)</p> <p>Used to love painting but post-transplant has not painted – thinks because of cleanliness, not liking germs, not getting dirty – never used to care about that. (P1)</p> <p>Feels less creative (P1)</p> <p>Become more accepting (P1)</p>	
Waiting	<p>Post-transplant – first year another year of waiting (P1)</p> <p>First year a milestone (P1)</p> <p>Fatality rates at year 1 (P1)</p>	
Employment	<p>Haven't gone back to work (P1)</p> <p>Guilt about not making really good use of liver (P1)</p> <p>Really lovely life (P1)</p> <p>Some days too tired to do anything, harder if employed to get the rest you need (P1)</p> <p>Fear about being well enough to work (P1)</p> <p>Scared of being sick (P1)</p> <p>Thought it was quite bad for people not to work – re-thinking this (P1)</p> <p>Transplant in May, back at work in December (P2)</p> <p>Employer advised in August no job waiting (P2)</p> <p>No employer support (P2)</p> <p>Got new job through own networks (P2)</p>	Change from really ambitious to really laid back (P1)

Major Concept	Sub Concept	Symbols Indicating Concept
	<p>When retrenched set up on business (P2)</p> <p>Disclosed Liver Tx (P2)</p> <p>No issues – boss had just had a knee replacement (P2)</p> <p>Letter from hospital saying could work (P2)</p> <p>Letter helpful (P2)</p>	
<p>Changing priorities (P1 p22)</p>	<p>Let things slide and be happy (P1)</p> <p>Tension – not enough to enjoy life, have to achieve something because of gift of life (P1)</p> <p>Painting was a therapy – deal with unhappiness and “stuff”, but not unhappy now – can’t paint. (P1)</p> <p>You think more about life, what it’s about (P2)</p> <p>You certainly realise what life’s all about, having that second chance (P2)</p>	
<p>Does the donor personality come through (P1 p23)</p>	<p>Real change in recipient (P1)</p>	
<p>Acceptance</p>	<p>Everything’s all right the way it is – don’t have to climb the ladder of ambition/success (P1)</p> <p>Happy with what you’ve got (P1)</p>	
<p>Travel</p>	<p>Medical insurance a problem to get (P1)</p> <p>Worry about something going wrong (P1)</p> <p>More you travel the less you worry about it (P1)</p> <p>Lose the possibility to live in the USA again as costs of medication and care prohibitive (P1)</p> <p>Letter from Ed Gane saying OK</p>	

Major Concept	Sub Concept	Symbols Indicating Concept
	<p>to travel to Oz (P2)</p> <p>Letter from Ed Gane for Perth liver unit in case he had trouble (P2)</p> <p>Insurance from State (house and contents with them, gave insurance for Oz – didn't cover liver (P2)</p>	
Driving	<p>Stopping pre-transplant (P2)</p> <p>Drive the welfare bus at the New Lynn RSA post-Tx (P2)</p> <p>Drive to go deer stalking, drive to Taupo, Hamilton, Tauranga (P2)</p> <p>Drive more safely post-transplant? (P2)</p>	
New Zealand Health System (P1 p24)		
Post-transplant longevity	<p>Grandkids – maybe not live long enough (post-Tx) to see them (P1)</p> <p>May not have to worry about getting old and retiring (P1)</p> <p>Feel lucky to be alive (P1)</p> <p>Specialists seem to be planning for the long term (P1)</p>	
Prejudice	<p>Medic Alert causes curiosity when applying for job (P1)</p> <p>Would probably not disclose Liver Tx for part-time job, but would probably have to for full-time job (P1)</p>	How can you go deerstalking with another person's liver in you, when I find it hard with my own? (Farmer) (P2)
Support Group	<p>Night-time meeting very helpful as travel insurance covered – representative from Mike Henry (P2)</p>	
Medication	<p>Taking a few pills is nothing to me (P2)</p>	

Major Concept	Sub Concept	Symbols Indicating Concept
Ensure drinks	In the end I refused to take them (P2)	
Solidarity with other patients	<p>Saw a women in chemist getting Ensure, talked to her, she ignored him (P2)</p> <p>Others I talked to – see them in the hospital – they’re like long lost friends. (P2)</p> <p>Bumped into one bloke at hospital front door, gave me a big hug as if I’ve known him all my life (P2)</p>	
Alcohol	Have a glass of wine now and then – know I shouldn’t – days I have it, I feel good (P2)	Friends don’t pressurise to drink, provide non-alcoholic drinks (P2)
Talking to other patients	One guy wanted to refuse it, tell him the alternative is a wooden overcoat – at last minute he changed his mind (P2)	
Can I help?	<p>I’ve said to [Name] and others – if I can help in any way, I’ll help! (P2)</p> <p>Talking at Med School to 120 doctors (P2)</p>	
Fatalistic/Realistic?	<p>Every time you get in a motor car there’s a chance of an accident (P2)</p> <p>Every time you walk down a set of steps (P2)</p>	
Experience provides Expertise	Until you go through the experience you don’t know (P2)	
Coping strategies	When you first asked me a few questions, I had to sort of put my brain into gear. Whether it’s your body’s way of (pause) throwing it out and, you know, not wanting to remember. (P2)	

Major Concept	Sub Concept	Symbols Indicating Concept
Looking at own liver	Kept own liver on the bed cabinet for a whole day (P2)	
Do what can to support students learning in order to save patients' lives	Let students work on old liver to learn from it (P2)	
Technical knowledge	I want to know how they join the veins, [be]cause you can't push [th]em together and put a hose clip around there (P2)	

This early framework helped provide a draft outline of questions for key informant interviews. It assisted with trialling the use of technology, length of interviews, questions and sequential prompts and the like that would be used.

My approach to an Overview of the Literature

Liver Transplantation

As mentioned in Chapter One, a recipient-focused, as against clinical-focused, phenomenological approach to liver transplant recipients' wellbeing and quality of life appears rare. Chilean philosopher Francisco Varela wrote of his own experience of liver transplantation, and reflected:

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, p. 261)

The development of liver transplant surgery from highly experimental in the 1960s to becoming a preferred management option for acute and chronic liver failure in the late 1990s has necessitated constant research, experimentation and innovation. This is reflected in the literature. A search of the medical database MEDLINE in the *SU Subjects All* field, for the words “liver transplantation” retrieves **31,949** articles.¹² An example of an article retrieved by this search is below.

Biais, M., Nouette-Gaulain, K., Cottenceau, V., Revel, P., & Sztark, F. (2008). Uncalibrated pulse contour-derived stroke volume variation predicts fluid responsiveness in mechanically ventilated patients undergoing liver transplantation. *British Journal Of Anaesthesia*, 101(6), 761-768.

Narrowing the search by adding a second subject search, of *SU Subjects All* of “(quality of life) or QOL” retrieved **466** articles. Further narrowing the search through subtracting (NOT) articles that included the words “living donors” in the *SU Subjects All* field reduced the articles retrieved to **422**. A final narrowing of the search through subtracting (NOT) articles that included the words “children or adolescent or (young adults) or paediatric or childhood” in the *TI Title* field reduced the total number of articles retrieved to **372**. The screen shot from this search is displayed as Figure 2 over the page.

Of the original 31,949 articles narrowed to 372 articles, only five appeared to potentially have direct relevance to my research, and 159 articles would be worth reading for enhancing my knowledge of the wider context. Of the **five** that appeared to

¹² Searches completed 27 November 2008 by the researcher.

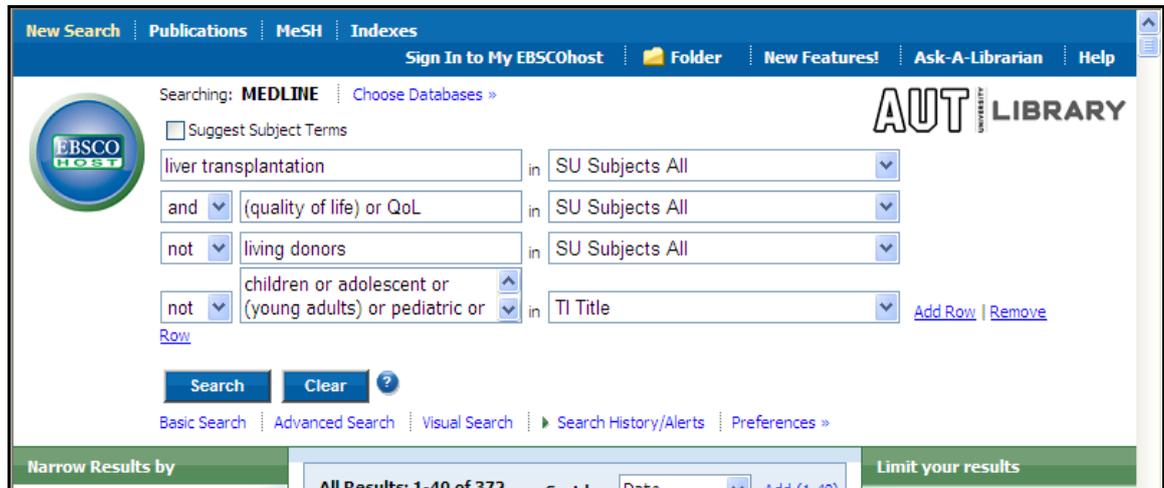
have direct relevance, two were available in full text online, and three were obtainable through inter-library loans.¹³

The articles ranged from 1988 to 2005. What is noticeable about the literature on liver transplantation is the predominance, naturally, of clinically focused research articles. These may range from innovative medical practices to enhanced surgical techniques to trials of new drug therapies.

¹³ These articles were:

- Bucuvalas, J. C., & Alonso, E. (2005). Outcome after liver transplantation: More than just survival rates. *Liver Transplantation, 11*(1), 7-9.
- Foley, T., Davis, C., & Conway, P. (1989, February). Liver transplant recipients-self-report of symptom frequency, symptom distress, quality of life. *Transplantation Proceedings, 21*(1 Pt 2), 2417-2418.
- Johnson, C., & Hathaway, D. (1996, September). The lived experience of end-stage liver failure and liver transplantation. *Journal of Transplant Coordination: Official Publication of the North American Transplant Coordinators Organization (NATCO), 6*(3), 130-133.
- Robertson, G. (1999, August). Individuals' perception of their quality of life following a liver transplant: an exploratory study. *Journal of Advanced Nursing, 30*(2) 497-505.
- Tymstra, T., Heyink, J., Roorda, J., Bijleveld, C., Gips, C., & Slooff, M. (1988). Research into quality of life: A qualitative approach in the evaluation of a liver transplant programme. *Health Policy (Amsterdam, Netherlands), 10*(3), 231-240.

Figure 2: Screen Capture of Literature Search



Wellbeing

An individual's state of wellbeing is part of a wider community and societal structure. When approaching individuals within an informal "community", such as the "community" of liver transplant recipients, I anticipated that the concepts of wellbeing that arose would reflect individual situations, family dynamics and also broader public health concepts that lead to the recipient's self-assessed feeling of wellbeing. I thought it useful to begin by looking at the concept of "wellbeing" most often articulated by government agencies in New Zealand and elsewhere.

New Zealand is a member of the World Health Organization (WHO). WHO defined health in their Constitution as "Health is a state of complete physical, mental and social wellbeing and not merely the absence of disease or infirmity" (WHO, *n.d.*).

In New Zealand the Ministry of Social Development produces an annual social wellbeing report card, the Social Report. This has indicators to measure the wellbeing of

New Zealanders over time in areas including paid work, economic standard of living, leisure and recreation, health, safety and social connectedness. Additionally, the biennial Quality of Life report covers 11 domains of wellbeing for 12 local authorities.

The domains are:

- People;
- Economic Standard of Living;
- Housing;
- Built Environment;
- Safety;
- Civil and Political Rights
- Knowledge and Skills;
- Economic Development;
- Health;
- Natural Environment;
- Social Connectedness;

(Jamieson, 2007).

The public health focus on wellbeing is broad, and explored some concepts that are not directly part of the healthcare system (that is, not directly funded from Vote Health), along with some specific health concepts. All these areas have a very significant role to play in determining the health of New Zealanders during the course of their lifetime.

Key public health concepts include:

- Defining “health” as “...including physical, mental, emotional, family / whānau, community and spiritual wellbeing” (Public Health Advisory Committee, 2004, p. 8).
- Using taxation to try to alter behaviour such as increasing taxes on tobacco and alcohol.
- Encouraging labour market participation (families who have family members engaged in paid work).

- Reducing poverty or alternatively working towards adequate household income levels for all families including a focus on reducing indebtedness.
- Enhancing educational performance of New Zealanders from childhood.
- Having dry, warm, secure, non-crowded and affordable housing from birth.
- New Zealanders having affordable access to primary healthcare.

The public health approach, when applied to the wellbeing of liver transplant recipients, raised an immediate question in relation to the possible impact of the socio-economic status of the recipient on their long-term wellbeing outcomes. If one accepts the probability that each New Zealand Liver Transplant recipient:

- Received the same quality of transplant (organ, operation, post-operative care);
- Received the same advice from the NZLTU in relation to:
 - Compliance requirements for immunosuppression medication;
 - Diet and food safety recommendations;
 - Alcohol avoidance;
 - Physical activity recommendations;
 - Travel advisories;
- Had the immunosuppression medication funded by the New Zealand government;
- Had regular blood tests at no personal charge;

the impact of the individual's socio-economic status and geographic decile rating on self-assessed longer term wellbeing outcomes should be included.

King (2003) noted that poor health can also lead to low income. For example, Smith (1999, cited in Judge and Paterson 2001), using US data from the Health and

Retirement Survey, found that reductions in household wealth and income often follow the onset of ill health.

Within health literature, other concepts arise. These include concepts explored in the “Impact-on-Family Scale”, a 24-item questionnaire looking at:

- Financial burden (4 questions);
- Familial/Social Impact (9 questions);
- Personal Strain (6 questions);
- Mastery (5 questions) (refers to coping strategies)

(Kolk et al., 2000, p. 324-325).

Herzlich (1973) demonstrated in a French study that “health was seen as residing in the individual, in terms of temperament and constitution, whereas illness was seen to be externally caused” (Easthope & White, 2006: 43). Research showed that for young Australians “social relationships are implicated in health outcomes” (Easthope & White, 2006, p. 48).

A European study looking at the socio-economic determinants of health-related quality of life for children and young people in Europe developed a questionnaire that addressed 10 quality of life dimensions. These were:

- Physical wellbeing;
- Moods and emotions;
- Parent relations and home life;
- Autonomy;
- Bullying (social acceptance);
- Psychological wellbeing;
- Peers and social support;
- Self-perception;
- School environment;
- Financial resources

(von Rueden et al., 2006, p. 131-132).

As my research focused on adult liver transplant recipients, the school environment dimension was irrelevant, however the other categories have applicability, including that of social acceptance (although possibly not bullying specifically).

In addition to liver transplant recipients exploring their understanding of their own wellbeing, and their view of health concepts of wellbeing, there are recipient “stories” or personally written recipient experiences on my New Zealand Liver Transplant Recipients website (www.livers.org.nz) which I looked at to glean concepts referred to by a variety of recipients in New Zealand.

I roughly grouped the concepts available in “our stories” within www.livers.org.nz by the quality of life dimensions used in the European study of the socio-economic determinants of health-rated quality of life for children and young people. This started to show a possible trend towards psychological wellbeing issues (including moods and emotions) more than economic wellbeing issues dominating recipients’ wellbeing. In the majority, recipients wrote their stories post-transplant, and it is possible that the further removed the recipient is from the transplant, the lesser the focus on psychological wellbeing. See Table 4, p. 55 for a summary of these concepts. The results from the survey tool in this area are noted in Chapters Six, Seven and Eight.

Table 4: Recipient Concepts in Relation to Wellbeing

<p>PHYSICAL WELLBEING</p> <ul style="list-style-type: none"> • Exhaustion (physical and mental) • Fatigue • Sleeplessness • Lack of strength and mobility • Pain 	<p>SELF PERCEPTION</p> <ul style="list-style-type: none"> • Loneliness (isolation) • Uniqueness • Personal concepts of health • Justice
<p>AUTONOMY</p> <ul style="list-style-type: none"> • Dignity • Inhibited • Loss of independence (dependence on others) 	<p>FAMILY RELATIONS AND HOME LIFE</p> <ul style="list-style-type: none"> • Stress in family relationships • Stress in intimate relationships • Tension
<p>MOODS AND EMOTIONS</p> <ul style="list-style-type: none"> • Appreciation • Jubilation • Positivity (attitude) • Fear • Institutionalization (where the hospital bed provides the feeling of safety). • Scared (night of the call) • Trepidation (re testing donor liver for viability for transplant) • Anticipation • Boredom (forced inactivity) • Waiting 	<p>PSYCHOLOGICAL WELLBEING</p> <ul style="list-style-type: none"> • Blame (in respect of the genetic transfer of diseases) • Self-contempt (re weekend road wrecks) • Denial (of seriousness, of past transplant) • Drug reaction – irrationality and fear • Upset (recipients or waiting list patients who do not survive) • Spirituality (also in relation to “donor presence”)
<p>FINANCIAL RESOURCES</p> <ul style="list-style-type: none"> • Disclosure (to employers? How to move into the future) 	<p>PEERS AND SOCIAL SUPPORT</p> <ul style="list-style-type: none"> • Denial (by family and/or friends)

A Spanish study, focusing on liver transplant recipients’ experiences in the Intensive Care Unit (ICU) of a major teaching hospital, has explored some other concepts including:

- Bodily discomfort;
- Religious beliefs;
- Body image;
- Transformation;
- Family support;
- Security).

(del Barrio et al., 2004

A study on heart transplant recipients indicated that there was a difference between the physical and emotional wellbeing of recipients in the longer term, with the recipients' emotional wellbeing worsening. The study also stated that "...quality of life (QOL) and psychologic wellbeing have been shown to increase morbidity and mortality" (Kaba et al, 2005, p. 612-613). I have not focused on concepts of morbidity or mortality to any significant extent in this research, as this would introduce a more clinical approach into research that was focused on being recipient-driven.

Transplant recipients in New Zealand, were found from the far north of the North Island to the south of the South Island, and most regions in between. This led me to believe that recipients would be found in rural and urban communities. An Australian literature review on rural women identified four themes that may possibly be concepts rural liver transplant recipients may comment on. These themes are:

- Isolation;
- Belonging;
- Coping with adversity;
- Rural identity;

(Harvey, 2007, p. 6).

Whether liver transplant recipients in rural areas feel physically and socially isolated more than their urban counterparts was a question for me. In addition, there might be social support issues in smaller communities, and work choices might be fewer or less appropriate to the recipient's physical health situation.

A further concept explored was that of gender. Werner and Malterud (2005) wrote of the experiences of women with chronic pain from undiagnosed causes through qualitative research of a group of 10 women. The research covered concepts of vulnerability and control. Whether a difference existed between the indicator focus of female New Zealand liver transplant recipients from male recipients was studied (Werner & Malterud, 2005, p. 41-46). A Swedish study identified that "...post-operative recovery was described by all female respondents as a phase full of contradictory feelings" (Forsberg et al., 2000, p. 330).

My earliest conclusions from this review that I would take forward were:

1. Concepts of wellbeing at a strategic level **may** be portable to the New Zealand liver transplantation group.
2. Concepts of wellbeing from a transplantation perspective (in particular liver transplantation) will be portable to the New Zealand liver transplantation group, even if not all concepts apply to all recipients.
3. Meaning given to concepts, when taken from **qualitative** research of liver transplantation recipients, will most probably be the same general meaning given to these concepts by New Zealand liver transplant recipients.

The literature from academic writing that included an interest in quality of life or health-rated quality of life still comes from the clinical paradigm. Johnson and Hathaway (1996, p. 130) looked to "...better understand and provide care for these patients." Research by recipients, or inclusive of a recipient "voice" or perspective, is rare across

transplantation, especially in the area of liver transplantation, and is most commonly found in memoir or biographical writings.¹⁴

Writings of this nature are very personal, and reflect a “lived experience”. Klug wrote that:

We couldn't help but read the newspapers and see where someone had been killed in an automobile accident and wonder if I would get a call that night or the next morning. After the Fourth of July holiday we read that a dozen people had died in car accidents in Colorado. But there'd been no calls, and we were left to wonder if the victims' internal injuries had been too severe, if they simply had not wanted to be donors, or if their families couldn't make that difficult, but lifesaving, decision (Klug 2004, p. 204).¹⁵

Caregiver experiences in the environment of liver transplantation also assist in building a context around the lived experience of the recipient. Pam Murray wrote that “telling my son the extent of his Dad's illness was one of the worst things I have ever had to do. My heart felt as if it were breaking and I was about to make his feel the same way” (2007, p. 60).

¹⁴ Examples of these in the area of liver transplantation from a recipient or caregiver perspective include:

Clendinnen, I. (2000). *Tiger's eye: A memoir*. New York: Scribner.

Klug, C., & Jackson, S. (2004). *To the edge and back: My story from organ transplant survivor to Olympic snowboarder*. New York: Carroll and Graf Publishers.

Murray, P. S. (2007). *Hit the ground running! An insider's guide to surviving Hepatitis C, liver transplant and beyond*. Arden: When Pigs Fly Books.

Yomtoob, P., Yomtoob, L., & Wepler, D. (2005). *The gift of life 2: Surviving the waiting list and liver transplantation: The inspirational story of one man's triumph over terminal liver disease: A guide for transplant patients and their families*. Deerfield, Illinois: Rainbow International Press.

¹⁵ This is supported by van Manen who wrote that “It is not unusual for biographic texts to contain rich ore of lived-experience descriptions for phenomenological analysis...” (van Manen, 1990, p. 72).

Parichehr Yomtoob (2005), the mother of David Yomtoob, has written two books on her experiences of caregiving for, and watching, her son undertake three liver transplants. When David had setbacks after his third liver transplant, she wrote:

I turned to the pages about infections and began to read about them and the medications used to treat them. One sentence jumped out at me, “With better selection of patients, a lot of these infections can be eliminated.” It occurred to me that this book was probably written by doctors for doctors. The mother of a severely ill infection-weakened transplant patient was not the intended audience for this book. That sentence had only one meaning to me. It was telling doctors to stay away from high-risk patients like David! If doctors chose healthier patients as their transplant candidates, they wouldn’t have to worry about infections. I closed the book (Yomtoob, 2005, p. 324).

The literature related to the general area of quality of life and health-rated quality of life was pertinent to my research, and my review of this literature also highlighted the lack of recipient perspectives within the research.

Although liver transplantation is well recognized as a lifesaving procedure, questions remain regarding its comprehensive long-term effects on transplant recipients. Various studies have measured post-OLT [orthotopic liver transplantation] quality of life by examining specific domains among its recipient populations, primarily employment, physical and cognitive abilities, emotional and social wellbeing, role limitations, self-image, and health perceptions. Emphasis has typically focused on the abilities and limitations of liver recipients following transplant, rather than on what the recipients actually do during the course of their daily lives (Cowling et al., 2004, p. 93).

Amongst the international research literature on quality of life related to liver transplantation, a Danish study (Aadahl, Hansen, Kirkegaard, & Groenvold, 2002) used the SF-36 tool also implemented by Bielby (2003) in New Zealand. This study noted in relation to anxiety and depression scores that “liver transplant recipients may relate their assessment to the OLT [orthotopic liver transplantation] and their perception of these concepts may differ from that of the general population. Having survived a lethal

disease may markedly change the experience of anxiety” (p. 257). A key point in the Danish study is their comment that “...the prevalence and severity of specific symptoms and problems after OLT may not have been sufficiently covered by generic questionnaires used in this study” (p. 258).

A Swiss study, also using the SF-36 tool, noted that “liver patients remained below the norms in most of the SF-36 subscales. Social functioning in all three organ groups [lung, liver, allogeneic bone marrow] was reduced before as well as after the transplant” (Goetzmann et al., 2006, p. 281). A study on fatigue post-liver transplant in the United States indicated that “In the majority of reports, however, the average HRQL [health-related quality of life] for a group of LT [liver transplant] recipients (both short- and long-term) is still reduced when compared to age- and sex-matched general population data” (Talwalker, 2006, p. 899).

An early Canadian study acknowledged that “...there is a growing recognition within the field that survival is not the only yardstick by which to measure treatment effectiveness. Improved quality of life is necessary in order to justify the personal and societal costs associated with this most invasive of surgical procedures” (Littlefield et al., 1996, p. 36).

Another recent study specifically on liver transplant recipients with Hepatitis C noted that “A major limitation to fully understanding psychological wellbeing after liver transplantation is the almost exclusive use of quantitative methods of enquiry. The methodological rigidity of this approach has been criticised for excluding phenomena that are difficult to define or measure” (Dudley, Chaplin, Clifford, & Mutimer, 2007, p. 1300). They noted the exceptions being qualitative studies that included patient

descriptions of their own experiences. The authors went on to comment on the weakness of the health-related quality of life approach, stating that “factors measured often are not weighted to reflect their relative significance for the individual” (p. 1305).

This emphasises to me that the Heideggerian concepts of Dasein and Being-in-the-World with the associated phenomenological focus on the lived experience of each liver transplant recipient is the appropriate methodology for this research project. From my anecdotal personal communication with fellow liver transplant recipients, the general populations’ experience or normative data provide limited value to our understanding of our wellbeing and what it means for us to “be well.” In the next chapter, I discuss my research design, methodological approach and field work methods.

Ethical Issues in Transplantation

Organ Donation New Zealand Clinical Director Dr. Stephen Streat FRACP noted¹⁶ that 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. pathological grief) to extremely serious (e.g. stalking), and that the behaviour is not predictable, nor reversible once contact has been made. With deceased donor organ donation, there is a well thought out ethical process to ensure the anonymity of both donor family and recipient for a number of reasons.¹⁷

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

¹⁶ Personal communication May 4, 2010.

¹⁷ Excellent information on this point is available from Organ Donation New Zealand.

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. As part of our "common language", we recipients talk of the "gift of life", which is also the terminology we hear at Thanksgiving services (see Chapter Nine: Accepting the "Gift of Life", p. 216), and within the hospital environment. I have used this terminology in the thesis to reflect this.

Chapter Three: Research Design

Ten hours after I was back in the ward, I was up walking around. They came in to get me to sit up, you put your legs over the side for a while and let everything dangle, and then they get you to stand up, and they had these two to come in and help me, and I told them to take their hands off me, I'm going to do it myself. And they looked at me and laughed, and I gradually stood up by myself, and I was standing there and my knees were (gestures). And I started laughing, and they said to me: "what are you laughing at?" I said: "My knees never knocked like that since [date long past, and place], when I [competed] in front of seventy thousand people." I said: "that's when my knees knocked." But I stood there, I refused help, and then I suppose I would have walked probably [a few metres]. I walked over there, and walked back, unaided.

IP#13

Introduction

My research was phenomenological and had an emergent design. Additionally my experience was reflected through my auto-ethnographic approach, and reflexivity in my process. My exploration started with *Social Science Research in New Zealand: Many Paths to Understanding* (Davidson & Tolich, 1999) where I first came across the theoretical introduction to quantitative and qualitative research. A key comment of value to my research question was: "To qualitative researchers, the world they wish to explore is not awash with discrete, measureable variables but is a whole that must first be experienced, by standing – as it were – in the shoes of those being studied" (Davidson & Tolich, 1999, p. 97).

The research included an on-going literature review, prior to and throughout the data collection phase. Data collection was in two phases. Phase one was a subset of all eligible liver transplant recipients, who had been invited to participate in a one-to-one qualitative interview. Emerging from the interviews, and the ongoing literature review,

were the key concepts of the lived experience of liver transplantation. Phase two was a qualitative survey of all eligible recipients, based on these concepts. This triangulation of sampling and data collection also assisted in establishing the validity of the research findings.

The rationale for undertaking this research in two phases was to ensure that the key concepts to be explored in the qualitative survey were identified by and through the liver transplant recipients. By using the data from the experiences of the interviewed recipients, the qualitative survey then explored and reflected the key concepts or the essence of our experiences. As van Manen (1990) pointed out, collaborative discussions are helpful in generating deeper insights and understandings. This assisted in ensuring rigour in my research.

Phenomenology

This research is phenomenological by design. Phenomenology, a philosophical movement with its roots in the nineteenth century, was adopted in the late twentieth century as a common methodology for qualitative nursing research. Current philosophical discussions within phenomenology are still indebted primarily to two writers: Edmund Husserl (1859-1938) and Martin Heidegger (1889-1976). Other eminent writers include Franz Brentano (1838-1917), Hans-Georg Gadamer (1900-2002), Maurice Merleau-Ponty (1908-1961) and Jean-Paul Sartre (1905-1980).

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 the liver transplant recipients, with the additional enhancement of having

shared this transplant experience. A phenomenological approach may be applied using a modern interpretation of the philosophy of Husserl (1859-1938) or Heidegger (1889-1976), such as that of van Manen, who wrote that:

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 (1990, p. 36).

Unlike the phenomenology of Husserl (1859-1938), a Heideggerian approach does not require “bracketing out” of my own experience. If I had taken an approach rooted in Husserl, my own experience would have less impact and validity in this research project. Bowie (2003) wrote that:

Husserl next makes the decisive move of “suspending” or “bracketing” anything that we accept as “adequately given” to our intuition, in what he terms the “epoche”...The idea is to exclude any evidence from the sciences or from everyday experience, as part of his project of arriving at philosophically solid foundations (p. 189).

Van Manen also observed that lived experience can never be grasped in its immediate manifestation but only reflectively as past experience (1990, p. 36). My research is influenced by the approach taken by van Manen, rooted in Heidegger’s philosophy, which allows me to incorporate my own experience into my research. Van Manen wrote:

In drawing up personal descriptions of lived experiences, the phenomenologist knows that one’s own experiences are also the possible experiences of others (1990, p. 36).

Integral to my research is constant reflection on the data and the research question. As van Manen noted “Heidegger talked about phenomenological reflection as following certain paths, “woodpaths,” towards a “clearing” where something could be shown,

revealed, or clarified in its essential nature. However, the paths (methods) cannot be determined by fixed signposts” (1990, p. 29). This emergent design added to the excitement of doing this research; as a step into the unknown.

Phenomenology as a movement contains multiple potential pathways to assist the researcher in achieving phenomenological research. As mentioned, Husserl and Heidegger, although having much in common, differed in their approaches. Heidegger, the younger of the two, was influenced by Husserl, but had an alternative perspective to Husserl on whether one could bracket out or suspend beliefs and pre-suppositions. He focused on the concept of “Being-in-the-World” and not being able to separate subject from object. Rapport and Wainwright¹⁸ (2006) differentiated between them by noting Husserl as a transcendental phenomenologist and Heidegger as an interpretive phenomenologist.

There is current criticism in the literature that phenomenological nursing research is frequently phenomenological in name only (McNamara, 2005; Paley, 2005). Much of the phenomenological nursing research that I have located, is, in theory, influenced by Husserl. Paley (2005) wrote that “...phenomenologists in other disciplines now view Husserl’s conception of bracketing, the ‘phenomenological reduction,’ with scepticism”. My reading and my experience led me towards a Heideggerian phenomenological approach for my research project, which I applied using van Manen’s framework. My interest is that of a liver transplant recipient. As van Manen wrote “when one orients to a phenomenon one is approaching this experience with a certain interest” (1990). He also stated that “It is better to make explicit our understandings,

¹⁸ No relation.

beliefs, biases, assumptions, presuppositions, and theories.” I undertook this exercise in an initial piece of writing in October 2007 for my chief supervisor on “Why me and why this subject?”

Baron (1985) provided a succinct rationale for why phenomenology is important in medicine when he wrote “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” (p. 609). Although I am not a health specialist, this statement supported my rationale for using phenomenology as my research methodology.

McNamara (2005) wrote that “at the heart of the phenomenological approach is a critique of the subject-object split of scientific naturalism.” For my research, I specifically wanted to document the lived experiences of liver transplant recipients within their context; this is driven by the desire to illuminate what the essence of the experience of liver transplantation is, with a focus on potential policy and process change.

The intent of my research is not to provide a subjective collection of narratives. As van Manen wrote “The meaning or essence of a phenomenon is never simple or one-dimensional” (1990, p. 78). Living through a liver transplantation is a multi-dimensional experience. Using van Manen’s approach of “...interpreting its meaning...” through a “...process of insightful invention, discovery or disclosure...” (p. 79) will achieve the aim of phenomenology of transforming “...lived experience into a textual expression of its essence...by which a reader is powerfully animated in his or her own lived experience” (van Manen, 1990, p. 36).

McNamara (2005) considers the participants in phenomenological research as co-researchers. I am not taking the research to this level, as this could be too great a burden and imposition on the eligible recipient participants. As a peer of the recipient participants, I have an understanding of why this research would be useful and recipient support has been strong through both interviews and the survey. My experience of interviewing fellow recipients emphasises the mutual benefit that sharing our “stories” has. An interview was a meeting between peers: my experience was of interest to them; their experience was critical to my research.

Methods

A qualitative interview approach was important in this research. As van Manen pointed out “Most people find writing difficult. They will talk with much more ease and eloquence and with much less reserve than they will write their thoughts on paper” (1990). The richness of the data from the qualitative interviews, of which excerpts are included in this thesis, also added depth and assisted in the validity of the research for some of the audiences of the research: current and future liver transplant recipients. Gadamer (1975) described the method of a conversational relation as “the art of testing” (p. 330). And the art of testing consists in the art of questioning – meaning “to lay open, to place in the open” the subject matter of the conversation (van Manen 1990).

Sampling and Participants

It is important that I acknowledge and accept my experience of liver transplantation in this research. I want to be seen as an experiential peer of the recipient-participants I engage with, and not someone in a position of power or control over them. The research

was to be participative and supportive of the experiences each liver transplant recipient has lived, and lives now.

Autoethnography is a process that enables me to effectively include my own experiences of liver transplantation within this research. Ellis and Bochner, quoted in O'Byrne (2007), wrote:

One such modification of the ethnographic process is autoethnography, that is, the study of a culture that involves the self (Ellis & Bochner, 2003).

O'Byrne describes four possibilities within autoethnography:

As a general rule, autoethnography requires that a researcher study (a) his or her own culture... (c) the culture of the self (O'Byrne, 2007, p.1382).

It is the possibilities in (a) and (c) that apply to my inclusion of myself as a participant in this research.

De Witt and Ploeg (2006, p. 216) wrote that "The researcher is considered inseparable from their assumptions and preconceptions about the phenomenon of study; instead of bracketing and setting aside such biases, they are explicated and integrated into the research findings (Cohen & Omery 1994, Ray 1994, Annells 1996, Draucker 1999, Le Vasseur 2003, Lopez & Willis, 2004)." This is a viewpoint I support for my research. Liamputtong and Ezzy (2005, p. 37) added that hermeneutic realism and subtle realism approaches "assume that there are independent knowable phenomena, but our knowledge of them is shaped by culture and socially constructed".

I determined eligibility criteria for participants in my research based on my own experience and my preliminary literature review. These were:

1. Recipients must be adult, not paediatric. My test interview of a paediatric recipient showed there would be significantly different challenges to face as a child; 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 et al., 2006, p. 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 a “gift of life” from a stranger. Living Donors in Liver Transplantation (LDLT) has been available through the NZLTU since 2002. With deceased donor organ donation, there is a well thought out ethical process to ensure the anonymity of both donor family and recipient for a number of reasons.¹⁹

3. Recipients should have received their (first) liver transplant between 1998, when the NZLTU commenced delivery of liver transplantation services through Auckland Hospital, and 2005. Prior to 1998, New Zealanders who required liver transplants went overseas or died without transplant. The experience of going to Brisbane, Australia, for a liver transplant has been well documented by Margaret Chalmers in her book²⁰ 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 part funding.

¹⁹ Excellent information on this point is available from Organ Donation New Zealand.

²⁰ *Extra time: A story of a liver transplant.*

Stopping the eligibility to participate at the year 2005 allows the recipient to have distance from the transplant, in order to be able to reflect on it 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 at least four years, if not more, between the date of the interview and the earlier date of the transplant.²¹

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. For that reason, the NZLTU 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.

²¹ 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.

Once the NZLTU 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 NZLTU made available their annual reports for the period of my research, which was informative primarily as to the reason for transplantation. There were limited ethnic and age data available. To ensure an appropriate mix of ethnicities for the phase one interviews, the ethnic data available (see Table 5, below) were used, along with discussions with both supervisors, one of whom had access to the NZLTU's database as their chief Hepatologist.

Table 5: Ethnicity of Liver Transplant Recipients 1998-2005

	European	Maori	Pacific Peoples	Asian	MELAA²²	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 percentages are approximate.

²² Middle Eastern, Latin American, African.

Candidates for interview were initially selected by Dr. Ed Gane, my second supervisor. Based on the eligibility criteria he posted twenty 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 in a conversation at a Liver Clinic. In order to achieve a 10% sample of the total number eligible for this research, a further technique was employed, that of snowballing. I was able to achieve a representative sample for interview through these approaches.

As an eligible recipient, I did interview myself, which allowed me to check my interview questions and get an indication of my own response as a patient, and the length of time the interview took. Additionally, seventeen liver transplant recipients were interviewed which provided 30 hours 25 minutes of data. The shortest interview was 44 minutes; the longest was 2 hours 54 minutes, with a median interview time of 1 hour 47 minutes.

Nine men and eight women were interviewed, and of these five were in the South Island, five in the North Island (outside of Auckland) and seven were in Auckland. There were 11 New Zealand European recipients interviewed, four Maori recipients, and two of other ethnicities. The three longest interviews were with non-New Zealand Europeans, of which two were female, while the New Zealand Europeans are represented in the eight shortest interviews; five of these recipients were male.

Maximum variation sampling was used to select the participant recipients for qualitative interviews. Patton (2002) stated “Any common patterns that emerge from great variation are of particular interest and value in capturing the core experiences and central, shared dimensions of a setting or phenomenon” (p. 235). Patton suggested the

creation of a matrix to assist in the selection of participants, to ensure maximum variation. I created a matrix that I have found very helpful.

The matrix (Table 6, below) was discussed with the NZLTU on Friday 11 July 2008, to ensure that it reflected the actual eligible recipients transplanted between 1998 and 2005. I discussed with my second supervisor (Dr. Ed Gane, Hepatologist, NZLTU) the desire to reflect the wider group of eligible liver transplant recipients within the smaller sub-group of qualitative interview participants. This enabled the qualitative interview findings to be generalised back to the whole group of eligible liver transplant recipients.

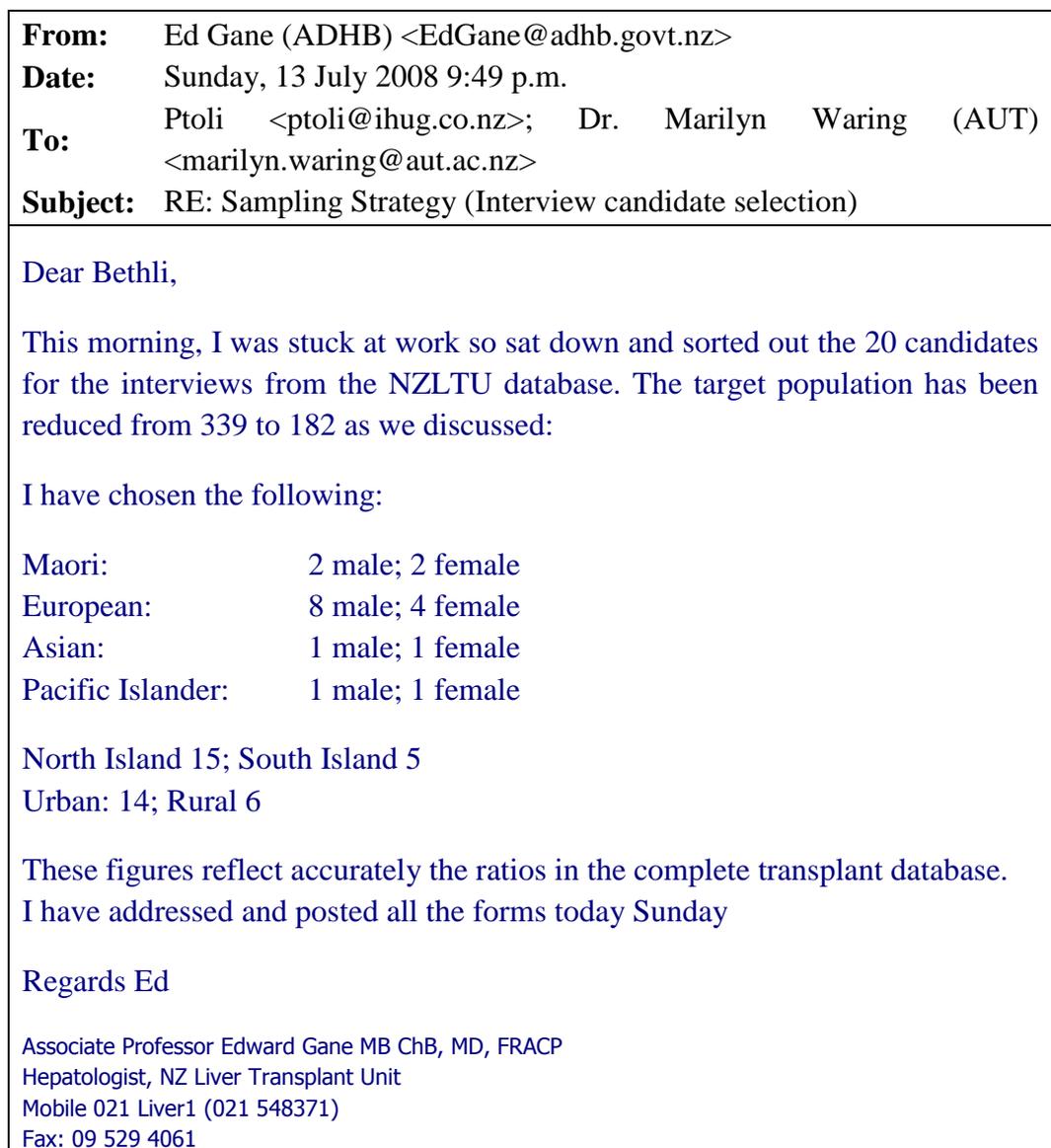
Table 6: The Matrix

			Age band at time of research	
			20-50	51+
Pakeha	Rural	Female	1	
		Male	1	1
	Urban	Female	1	1
		Male	1	1
Maori (approx. 17% of recipients)	Rural	Female		1
		Male	1	
	Urban	Female	1	1
		Male	1	1
Pasifika (approx. 10% of recipients)	Rural	Female		
		Male		1
	Urban	Female	1	1
		Male	1	
Asian (approx. 10% of recipients)	Rural	Female		1
		Male		
	Urban	Female	1	
		Male		1
		Totals	10	10

Once the matrix was finalised, the NZLTU selected (and addressed envelopes for) the twenty eligible participant recipients, and posted the information sheet and consent form to them on Monday 14 July 2008.

The email in Figure 3 below is from my second supervisor, commenting on the selection of recipients for the purpose of inviting them to participate in the one-to-one qualitative interview.

Figure 3: Email from Ed Gane July 13, 2008



The initial results I had from the mail-out of consent forms and information sheets for both the focus group and the qualitative interviews are listed in Table 7, below.

Table 7: Initial Responses from Mail-out

Focus Group	
Positive Response	Nil Response
Female – Pakeha (Auckland)	Male – Asian (Auckland)
Female – Maori (Auckland)	Male – Maori (Auckland)
Male – Pakeha (Christchurch)	
Male – Pakeha (Christchurch)	
Male – Pasifika (Auckland) <i>verbal</i>	

Qualitative Interviews	
Positive Response	Nil Response
Male – Pakeha (Auckland)	Male – Maori x2
Female – Maori (Auckland)	Female – Maori x1
Male – Pakeha (Tokoroa)	Male – European x6
Female – Pakeha (Auckland)	Female – European x1
Female – Pakeha (Bluff)	Female – Asian x1
Male – Asian (Christchurch)	Male – Pacific Islander x1
Female – Pakeha (Invercargill)	Female – Pacific Islander x1

Owing to the poor response rate to the mail-out of 14 July 2008, I extended my sampling method to include the technique known as “snowball or chain sampling.” Patton (2002) describes this technique as an approach where key, well-situated people are asked who the researcher should talk to, and in this process the “snowball” increases in size. I used myself and a member of my focus group as key persons. Using this technique contributed six additional recipient participants who consented to participate in a qualitative interview.

The personal connection/relationship was of great value in recruitment. An “anonymous” request to participate in a qualitative interview got a 30% success rate, while a member of the focus group contacted two people with a 100% success rate, and I contacted seven people with a 57.14% success rate (four out of seven). This led to the updated tally (Table 8 below) where the snowball sampling recipient participants are noted in *red italics*.

Table 8: Responses Including “Snowballing” Recruitment

Qualitative Interviews – with snowball sampling in <i>italics</i>	
Positive Response	Nil Response
Male – Pakeha (Auckland)	Male – Maori x2
Female – Maori (Auckland)	Female – Maori x1
Male – Pakeha (Tokoroa)	Male – Pakeha x6 (<i>now x2</i>)
Female – Pakeha (Auckland)	Female – Pakeha x1 (<i>now x0</i>)
Female – Pakeha (Bluff)	Female – Asian x1
Male – Asian (Christchurch)	Male – Pacific Islander x1 (<i>now x0</i>)
Female – Pakeha (Invercargill)	Female – Pacific Islander x1
<i>Male – Pakeha (Rotorua)</i>	
<i>Male – Pakeha (Rotorua)</i>	
<i>Male – Pakeha (Napier)</i> [FG contact]	
<i>Male – Pakeha (Canterbury)</i> [FG contact]	
<i>Female – Pakeha (Auckland)</i>	
<i>Female – Pakeha (Palmerston North)</i>	
<i>Male – Pacific Islander (Auckland)</i> <i>verbal</i>	

The challenge in recruiting eligible participant recipients for both the focus group and the qualitative interviews was in recruiting those who were Maori, Asian and Pasifika. Anecdotally my second supervisor had already advised me of the NZLTU’s own difficulty in maintaining adequate long-term contact with liver transplant recipients who

self-identify as Maori, and for that reason ensured that four out of twenty (20%) potential interview participants were of Maori ethnicity.

I discussed this recruitment issue with my second supervisor on Friday 17 October 2008. A further endeavour by this supervisor to recruit eligible participants was made in late October 2008.

<u>Interview Group</u>	<u>Focus Group</u>
Ed will contact: <ul style="list-style-type: none"> • 2 x male Maori • 1 x female Asian • 1 x male Pasifika • 1 x female Pasifika²³ 	Ed will contact: <ul style="list-style-type: none"> • 1 x male Asian • 1 x male Maori (less essential)

I also received one response from a liver transplant recipient I know, who, although very supportive of the research, stated:

“I’m not interested in participating and revisiting the past thank you.”²⁴

I ensured this recipient was excluded from phase two of the research, when the invitation to participate in the qualitative survey was sent out, which reduced the overall eligible number to 181.

This chapter has shown how participants were recruited. For Chapter Four, I move to the ethical issues in my proposed data collection methods, and how data were collected.

²³ From File Note for the Supervision 17 October 2008.

²⁴ E-mail to researcher from liver transplant recipient, Wednesday, 3 September 2008 5:00 p.m.

Chapter Four: Data Collection and Ethical Considerations

You really hit a topic I've been dealing with – the nightmares and hallucinations. I think someone should tell you about them. No one told me and I still have them. Shocking and intense and frightening. I didn't know other people had them as well. Where I work, the patients are having hallucinations and nightmares – assoc. with morphine meds and that post-ops. And they don't get “pre-warned” about the possibility of these things happening. My experience is probably the extreme of the overall experiences of people like me. But it is a problem. Thanks for letting me tell you these things.

SP#6

Introduction

This research project had two components: the experience of the researcher (liver transplant recipient #62) and the experience of the liver transplant recipients eligible for the research project. In the previous chapter I explained that:

1. I used an auto-ethnographic approach to ensure my experience was included in the research,
2. I used a phenomenological approach to capture the lived experiences of the liver transplant recipients eligible for this research project. This meant focussing on the “things themselves” or the actual experiences. This approach was based on the philosophy of Heidegger as it is applied in current qualitative health research.

The research project was triangulated by approaching the concept of “what is the lived experience of liver transplantation for New Zealanders transplanted between 1998 and

2005 who received a liver from a deceased donor” by using three methods to obtain data:

- A small, purposively selected focus group – the data were used in such a way that all participants’ identities were kept **confidential**.
- A proportion of the total eligible liver transplant recipients (10%) that were selected for qualitative interviews by the NZLTU – the data were used in such a way that all participants’ identities were kept **confidential**.
- A qualitative survey was provided to all eligible liver transplant recipients, where the data were **anonymous**.

The rationale for undertaking this research in two phases was to ensure that the key concepts to be explored in the qualitative survey were identified by and through the liver transplant recipients. By using the focus group to explore what the lived experience of liver transplantation was and is for a small group of us, and adding to that data the experiences of the interviewed recipients, the qualitative survey then explored and reflected the key concepts or the essence of our experiences.

Although the key concepts from phase one were used in the qualitative survey, it also allowed for new concepts to be exposed. The data analysis was ongoing from the commencement of phase one to the final analysis of the qualitative survey results.

Research Ethics

Two ethics applications were made to the AUT Ethics Committee (AUTEK). The first expired on 25 June 2011, (see Appendix 1, p. 261) and it covered phase one of the research, the qualitative interviews, and the establishment of the focus group. This

ethics application approval included approval for the participant information sheet (see Appendix 2, p. 292), and consent forms for the qualitative interviews (see Appendix 3, p. 296) and focus group participants (see Appendix 4, p. 297). Included also was the approval of a confidentiality form for any typist or transcriber I might use (see Appendix 5, p. 298).

Provisional approval granted by AUTEK (see Appendix 6, p. 299) included a number of further requirements. The response to AUTEK (see Appendix 7, p. 301) described how focus groups would be convened in the AUT Karen Suite (see Appendix 8, p. 302), provided an outline of indicative questions for both focus groups and qualitative interviews (see Appendix 9, p. 304), showed how the questions were developed (see Appendix 10, p. 306), and gave protocols for researcher safety (see Appendix 11, p. 308). See Appendix 12, p. 310, for the final ethics approval for the first phase of the research.

A subsequent ethics application was made to AUTEK once the phase two qualitative survey tool had been developed. This approval (see Appendix 13, p. 312) included approval for a survey consent form (see Appendix 14, p. 315) and the survey tool (see Appendix 15, p. 316) that had been developed once analysis of the data captured in phase one revealed the themes or concepts to explore further.

There were a number of ethical issues that I addressed in undertaking this research. Grbich wrote that "...the dimensions of research ethics range from basic protection of participants' rights to active endeavours to improve their lives" (1999, p. 71). My research ensured that participants' rights were protected at all times.

Holloway and Wheeler referred to Beauchamp and Childress's basic principles of autonomy, nonmaleficence, beneficence and justice (2002, p. 52). My research ensured the autonomy of the recipient participants by not only gaining their written informed consent prior to the research commencing, but also by ensuring that information sent prior to the focus group (where to meet, expected duration, questions to think about, etc) would include a reminder that they may withdraw from the research at any time. In addition, I obtained oral consent at the commencement of each qualitative interview, which reinforced the recipient participant's autonomy and understanding that they could withdraw from the research at any stage. This reiteration of autonomy and ability to withdraw from the research was also included when the qualitative survey was mailed out.

Avoiding harm (nonmaleficence) was a focus of my engagement with recipient participants in the focus group and as I undertook one-to-one qualitative interviews. It is possible that in reflecting on the past experiences of their illness (facing death, waiting for a transplant, receiving a donor liver, recuperating, and life post-transplant) recipients might awaken memories that might be traumatic. If any recipient participant at any time appeared to be becoming a little upset or emotional about their past experiences, I paused the research engagement and checked with them whether they wished to continue, take a break or stop completely. Generally, the interviews were positive experiences for the recipient participants, with a lot of laughter, sometimes wry, sometimes humorous, coming through. One interview in particular, appeared to be cathartic for the recipient, who noted that friends and close family had avoided talking about facing death and other issues that this person wanted to talk about.

It was important to have a mitigation strategy in place for any recipient participant who may become upset owing to revisiting past, potentially traumatic events. My mitigation strategy was that the NZLTU's social worker was aware when each research activity was occurring, and was prepared for phone calls from recipients, and was also prepared to offer support and de-briefing, if required. I carried the social worker's phone number with me. The social worker was familiar to all the recipient participants as he has been involved with the NZLTU since it commenced liver transplantation services. This mitigation strategy was not required.

Providing benefit to current liver transplant recipients, or the concept of beneficence, was one of my aims. My experience, and my anecdotal knowledge, is that sharing our experiences can be a healing and useful experience for us. A fellow liver transplant recipient has written about this in the story of their experience.

I have kept in contact with two of my journeymen, also people with complications, because despite the expertise of the medics, the familial support, the bonhomie of all comers, they're the only ones who understand the loneliness and the uniqueness of the on-going transplant journey. Sometimes, you need to discuss it.²⁵

A study by Wainwright (1995)²⁶ noted the importance of other liver transplant patients as a major source of support, and that "Many informants also felt that they learned about the recovery trajectory of liver transplantation from other patients rather than from health professionals."

The principle of justice was more challenging for this research. If justice is taken to be the fair distribution of benefits, risks and costs (Holloway & Wheeler, 2002, p. 52), then

²⁵ http://www.livers.org.nz/Our_Stories/Lyns_Story.htm (retrieved 15 June 2008).

²⁶ No relation.

it depends on what is taken as the primary motivation for the research. In my experience as a liver transplant recipient, there is an information gap. This was reflected in the e-mails I received on my website (<http://www.livers.org.nz>) from New Zealanders who are related to potential liver transplant recipients, or are people actually facing a liver transplant in their future.

To discover and document the knowledge I believed liver transplant recipients would value, I used a formal university research environment, including appropriate joint expert supervision. This gave me a structure and an ethical process to follow, in which to undertake this research. I believe this research to be unique in New Zealand, and I hope this research benefits a number of individuals, families and agencies. Any research risks were shared between myself, my supervisors and AUT University. The bulk of the research costs were borne by myself, including all costs of interviews in the geographic area of New Zealand. This may be argued as being inequitable, however, any investment of time, effort and money into this research, is a way of contributing back to New Zealand for the taxpayer investment that has been put into keeping me alive.

One significant ethical challenge related to my employer, and the need for appropriate messaging around this to provide confidence to any recipient participant. I was extremely clear in my Information Sheet (see Appendix 2 p. 292) that, although I work for Work and Income, a service line of the Ministry of Social Development, I am not part of “front line.” I stated clearly what my role was, and also that my own experience of Work and Income’s services during my liver transplant was not positive. I hoped this mitigated any potential fear that recipient participants might have had about whether they could be open and honest about “WINZ.” In one of my interviews, when financial support and benefits were mentioned, I reiterated that the interviewee could say what

they liked about Work and Income, stressing again the difficulty I had with this agency, and I believe I received honest feedback from the interviewee.

An ethical challenge for me was to ensure that in every engagement I had with recipient participants I did not comment in any way on any hint or suggestion of potential benefit fraud. My relationship with each recipient participant was one of honesty and trust. This created a potential dilemma. My responsibility to my employer (as noted in our Code of Conduct) requires vigilance in identifying and notifying the appropriate internal investigators of any benefit fraud situations. In this research, the interviews were not specific enough to provide any strong guarantee that benefit fraud may have taken place.

From my experience, it is more likely that participants may not always have received their full and correct benefit entitlements or indeed accessed income support at all. I have already seen instances where respite care, home help and caregiving services, although needed, were not accessed, as the recipient and/or their caregiver were unaware of assistance able to be accessed.²⁷

²⁷ At the time of interview there appeared to be no longer any need to access these services, therefore I did not, as a rule, provide information on available services to interview participants. There was an exception on Wednesday 10 December 2008 when a recipient I had interviewed phoned me from hospital, after receiving my Research Update #1. This person wanted to talk about their current situation and asked for specific information on the Invalid's Benefit, which I provided by looking up the benefit rates on the Work and Income website. Additionally, through my website www.livers.org.nz I received queries from New Zealanders newly listed for transplant, and provided information to them relevant to the questions they asked via e-mails to the website e-mail address. There were two detailed e-mails from one listed patient on Monday 8 December and Tuesday 9 December 2008.

The research group is recipients of liver transplants. It is possible that liver transplant recipients view themselves as members of a vulnerable group. This may be because of the experience they have gone through (including probably facing death), the lifestyle changes they may be asked to make, the medication they are on, or other reasons. As Bethli Wainwright, transplant recipient #62, I was personally aware of at least two other transplant recipients who had other significant health issues, which these recipients *may* self-assess as making them members of vulnerable groups. However, these two individuals may also see themselves as “ordinary New Zealanders”. Any self-assessed vulnerabilities remained unknown until the eligible recipient group was contacted (once the Ethics approval was achieved).

This research did not target Maori participants exclusively, however Maori were actively included in the research cohort as Maori are recipients of liver transplants. The most recent information from the NZLTU was that there had been 325 liver transplant recipients by this date, of whom 54, or 17%, were Maori. As there are a disproportionate number of Maori needing liver transplants (17%), compared to their proportion of the New Zealand population (14.6% identify as Maori in Census 2006), it was important that the NZLTU ensured that 20% of the information sheets and consent forms for the qualitative interview were sent to Maori recipients. The reason²⁸ for this over representation of Maori was their high rates of hepatitis B virus infection acquired in childhood (i.e. not related to lifestyle factors).

During the thesis research work, The NZLTU celebrated its 10th anniversary with a lunch for all liver transplant recipients. I was able to utilise this opportunity to have

²⁸ Personal communication with the NZLTU May 2011.

further one-to-one conversations with recipients whom I knew, and make new acquaintances, to assess the support and need for this research to be undertaken. One eligible recipient and new acquaintance I spoke with was Maori. This recipient had had a very traditional Marae upbringing, through her grandparents. She explained the conflict and stress that she had faced when told a liver transplant was required. This went against her culture and traditional upbringing. The decision to proceed with the transplant was based on the feedback from her children, and her Christian faith. I was aware that conversations around organ donation and the receipt of a cadaveric organ requires cultural sensitivity.²⁹

A psychological risk to me as a researcher and a recipient could have been an “overloading” of experiences with which I could identify and empathise, with my requirement to listen and understand but not “drown” in the experiences. Mitigating this was the timing and pacing of the interviews, and regular supervision.

Rigour

The area of rigour, reliability, validity, relevance, generalisability and other concepts in the area is an area open to much debate, multiple viewpoints and discussion over more than two decades, with Lincoln and Gruba’s text *Naturalistic Inquiry* held by many authors to be the gold standard (Whittemore, Chase & Mandle, 2001, p.527). Meyrick who has undertaken much research in this area initially looked for a common set of

²⁹ See Te Puni Kokiri (1999). *Hauora o te Tinana me ona tikanga: A guide for the removal, retention, return and disposal of Maori body parts, organ donation and post mortem*. Wellington: Te Puni Kokiri.

quality criteria, concluding that although this was impossible “some similar core principles did exist” (2006, p.801).

My reading has also shown that a technique recommended by many authors is that of the research being ‘auditable’ or having an audit trail. “Auditability necessitates explication of the rationale for every step of the research process” (Sandelowski, 1986; de Witt & Ploeg, 2006, p. 223).

Grbich wrote that “The questioning of the terms of ‘objectivity’, ‘validity’ and ‘reliability’ has polarised positions between those who have emphasised the importance of rigorous qualitative research and those who regard ‘rigour’ as appropriate” (1999, p. 61). This polarisation has continued when exploring the concept of rigour in phenomenological research.

Koch (1994, p. 976) wrote that “Guba and Lincoln (1989) claim that a study is credible when it represents faithful descriptions and when co-researchers or readers confronted with the experience can recognise it”. She continued that for “for Guba and Lincoln (1989) confirmability is established when credibility, transferability and dependability are achieved” (p. 978).

De Witt and Ploeg stated the “Rigour in phenomenological nursing research is a controversial topic in the literature” (2006, p.216) and then noted two dominant themes, the first being “arguments over philosophical interpretation” (p. 216) and the second being “a dialogue about which criteria fully express the rigour of phenomenological nursing research” (p. 216).

The literature highlights the widespread acceptance of the work undertaken by Guba and Lincoln on achieving trustworthiness and rigour in qualitative research. The key criteria are credibility, transferability and dependability (Koch, 1994, p. 91). Similar criteria proposed by Sandelowski (as noted by de Witt and Ploeg) are credibility, fittingness, auditability and confirmability (2006, p. 217). Following criteria outlined by de Witt and Ploeg I have strived for rigour through addressing balanced integration, openness, concreteness, resonance, actualisation, transferability and external checks.

Further, my research supports the approach noted by Mays and Pope (2000, p. 52) that “the basic strategy to ensure rigour, and thus quality, in qualitative research is systematic, self-conscious research design, data collection, interpretation and communication.”

De Witt and Ploeg (2006, p. 226) described resonance as being “the moment when understanding meaning of the text is juxtaposed with self-understanding.” Data from the focus groups and qualitative interviews primarily provided this opportunity.

Of the specific techniques and approaches used in phenomenology to ensure rigour, Ferrari (2006, p. 132) wrote that “a lack of social and professional boundaries between researcher and recipient improves the quality of dialogue (Colaizzi, 1978 cited in Forsberg, Backman and Moller, 2000).” In my research I hope that the recipient-participants will view the research as “by us, for us” and that there will be a relationship based on shared experiences. Rashotte and Jensen (2007, p. 107) stated that “the research should show evidence of both a movement towards fluidity in the boundaries and a process to decrease hierarchical differences,” given the typical power differential between researcher and participants.

Research Methods

The research process used to describe and understand the lived experience of liver transplant recipients in New Zealand was as follows:

- Ongoing literature review;
- Focus group meetings brainstorming concepts for recipients around their experience of liver transplantation;
- Qualitative one-on-one interviews with 10% of eligible liver transplant recipients;
- Development of a qualitative survey tool;
- Piloting the survey tool;
- Administering the survey.

Participants in all phases of the research were advised of the voluntary nature of participation. A participant could choose to stop an interview, leave a focus group or not complete the survey. As the researcher, I stressed that it was OK to take a long time to complete the survey and that a no-response to one or more areas was fine.

Ongoing Literature Review

The literature review sought the recipients' perspective and experiences within the wider context of qualitative literature on organ donation, transplantation and wellbeing.

The literature review stopped in September 2010.

Focus Group

Discussions with the focus group covered their lived experience pre-transplant, the transplant experience (hospitalisation) and their post-transplant experience. The focus group comprised a small number of liver transplant recipients.

The focus group was to use the video-conferencing technology i.e. the Kiwi Advanced Research and Education Network (KAREN), using the AUT access grid. The information technology strategy advised that it was possible to record sessions on KAREN and play them back on a computer application. It was expected that the KAREN process (including recording) would be trialled in a dummy run, to see if it worked well. A note-taker would be used alongside the recording facility to ensure that the content was captured. This was considered expensive and complicated.

The eventuality was that focus group members in Auckland met together and much of the other work was conducted by email or conference call. A confidentiality agreement was signed by all members of the focus group.

Qualitative One-on-one Interviews

While at my liver clinic appointment (outpatients, Auckland City Hospital, 17 September 2008), I got into conversation with another liver transplant recipient who knew me. I invited this recipient to participate in my research as a ‘test’ recipient for the purposes of practising interview techniques. Owing to her eligibility to be included in the research cohort, this recipient agreed that the data from the test interview be counted as an interview for the purposes of the research.

Three test interviews were completed. These were:

1. Interview of self: 31-page transcript. I practiced interview techniques in a precise role-play interview with myself (including swapping chairs from questioning to responding) and checking on technology and length of the interview.

2. Interview of recipient not eligible for research cohort: 25-page transcript.
3. Interview of recipient eligible for research cohort: 84-page transcript. I noted to my supervisors after this interview (email 28/9/08):

“I had a really interesting interview today, with a recipient transplanted in 2002, so although a test interview, she has agreed to have this interview used as part of the actual data, or if that’s not ok, to be reinterviewed for capture in the data.

What I found fascinating was, as she spoke, different themes or concepts flashed up in my mind, and I could see the connections between her story, my story and the previous test interview. The interview was nearly an hour and a half, so I hope I will have it all transcribed by the end of the week!!! That’s the really slow bit. Fascinating little snippet is how she denied needing a transplant and was still waiting for the doctors to come and tell her that they’d made a mistake, and she was healthy and didn’t need a transplant, even when she was in the elevator en route to theatre for the transplant! Also really interesting to listen to the fear and anxiety she still has, as post-transplant she has not re-engaged in the labour market – really concerned about ability to cope. Her motivations have also changed.”

The Interview Process

The indicative outline of questions for the key informant interviews was developed from my first three pilot interviews, and after discussion with my focus group. I visited interview candidates at a venue or location of their choice from Kaitaia to Invercargill. AUTECH required me to draft a research safety protocol for use when visiting participants in their homes. The anonymity of all interview participants was protected, unless they requested to be identified by their liver transplant recipient number (e.g. mine is 62). Using this number, they would be identifiable to anyone who knows their number e.g. the NZLTU, their immediate family and friends to whom they have disclosed their number. Further, all data in the appendices was cleaned of anything

thought to identify a person, carefully assessed to see that identifying information was deleted (such as the reason for transplant). This was particularly important when the reason for transplantation may be limited to only one or two recipients. For example, I am one of two Wilson's disease participants.

As I conducted interviews participants were overwhelmingly hospitable, generous with their time and resources, which included videos, scrapbooks and media clippings. Only one interview a day was ever undertaken. Participants would meet me at the airport and drop me back again after the interview. I was always eager to get transcribing.

All interviews were recorded using a digital recorder. I transcribed half the data myself; my sister transcribed the other half. Interviews were completed by April 10, 2010. Over Easter 2010, I coded the transcripts of two interviews manually to establish a hierarchy of thematic codes. Subsequent to that I imported transcripts of interviews and started coding them on NVivo 8. All the written comments were typed up into Word documents. All other data was entered into Excel, and tabulated at individual question level.

Survey

The qualitative survey was sent out to all eligible liver transplant recipients. It asked for minimal demographic data. This included:

- Gender (male or female);
- Geographic location (North Island or South Island);
- Lifestyle (urban or rural);
- Age band at time of survey (20-35, 36-50, 51-64, 65+);
- Ethnicity (New Zealand European/Pakeha, Maori, Other).

This allowed the contextual situating of the lived experiences, when analysed. All information was carefully read to highlight concepts and patterns. As phase one (the qualitative interviews) influenced phase two (the qualitative survey), the survey data was read and analysed in the context of what was learned in phase one.

As with the interview process, all survey participants were anonymous unless they asked to be identified by their transplant number. The data in appendices was carefully assessed and cleaned. Again only minimal demographic data was sought. This was to allow free and frank disclosure of liver transplant recipients' lived experiences, including controversial areas such as alcohol.

It was not anticipated that the survey responses would require transcribing, but many of the recipients wrote a great deal in the open sections. Van Manen's supposition that people might find writing difficult was not borne out in the responses to the survey. Many participants wrote many pages in the spaces provided. This enriched the concept development. As I developed the survey, I thought it might be possible to use some of the key informant quotes around particular concepts, as examples that could be 'ticked' by participants if they reflected their experience, with room for free text if this was not the case. This also seemed to encourage further written contribution.

All written comments from the surveys were typed up into Word documents. All surveys were collated into an Excel spreadsheet as soon as responses were received. Forty-nine responses were fully entered as of September 24, 2010: 25 men and 24 women.

Data Analysis

The data were written and condensed, analysed and reduced to its essence, using a personal computer, Microsoft Word and Microsoft Excel. Although key concepts from Phase 1 were used in the qualitative survey, analysis also allowed for new concepts to be exposed.

Data analysis was ongoing from the commencement of transcribing interviews to the final analysis of the qualitative survey results. Data were inventoried as they were produced to ensure that all the data from the focus group, qualitative interviews and surveys were available for analysis.

Inductive analysis was the approach taken. The data was thematically coded, and the content of the themes analysed. The thematic coding included pattern recognition: searching for recurrent words and practices. Once this was completed, thematic coding was interpreted to attempt to reveal the essence of the phenomenon.

Communication with Participants

During the period of the research, I wrote updates to participants. There were four in all: December 2008, June 2009, December 2009 and July 2010. They were simple one pagers and the first has been included in the appendices (see Appendix 16, Example of Monthly Research Updates, p. 345).

Participants were advised that some form of written report (synopsis) with key findings would be provided to all participants. In addition, the consent form allowed for e-mail progress reports to be provided during the course of the research project. Findings will

also be made available to liver transplant recipients who were not eligible for the research project, for their information if they are interested. In addition, preliminary findings from the interviews for this study will be published in *Sites*, a peer-reviewed journal.³⁰ A final outcome is for key findings to be made available in pamphlet, brochure or booklet form to new patients of the NZLTU who may face a liver transplant in their future.

³⁰ This article was published September 2011.

Chapter Five: Past Research and Developing a Survey Tool

This survey has been a pleasure to complete. It is so different answering the questions of a person who understands, rather than cold clinical questions I have answered before (that leave me shaking my head).

SP#24

Introduction

Following on from the discussion on triangulation of data in the previous chapter, this chapter looks in detail at the process I undertook to develop a survey tool relevant to my research, which would provide significant data from liver transplant recipients in New Zealand for this research project.

This chapter aims to provide clear process information in relation to the creation of the survey. Other researchers who read this chapter should be able to replicate this process, as much as they wish, if the approach is valid for their work. The actual survey tool can be found in Appendix 15, p. 315.

In this chapter I briefly comment on patient outcomes, where clinicians have a changing focus from quantity to quality of life post-liver transplant, along with a snapshot view of medical literature on quality of life. The dominance of the Short Form 36 survey tool is looked at briefly, given that I deliberately chose not to use this tool. The New Zealand study (Beilby, Moss-Morris & Painter, 2003) that did use the Short Form 36 is noted, from a “user” perspective, as I was one of the participants in this research project. I detail the process I went through to develop, test and implement my survey tool, and I

conclude with suggestions for this type of approach to be used in other patient-focused research settings.

Patient Outcomes

“Medical outcomes belong first and foremost to patients.”

(Paterson, 1996, p. 1016)

Liver transplantation is now an orthodox treatment for patients with end-stage liver disease (Gotardo, Strauss, Teixeira, & Machado, 2008), following the development of surgical expertise and the discovery of effective immune suppression medications such as Cyclosporin, Tacrolimus and Sirolimus, among others. Cyclosporin was approved for use as an immune suppression medication by the United States Food and Drug Administration in 1983. As already noted, the surgical expertise required for orthotopic liver transplantation had been successfully developed over the previous twenty years by pioneers including Dr. Thomas Starzl and Sir Roy Calne. From 1983 onwards patients' survival rate potential improved owing to these new immune suppression regimes.

The latest developments in liver transplantation and especially the introduction of new immunosuppressive agents [7,8], the better selection of recipients and grafts, innovations in surgical techniques [9,10] and perioperative care of patients have led to continuously improved patient and graft survival rates.

(Kousoulas et al., 2008, p. 1052)

From the traditional measure of liver transplantation success of patient survival rates (Bucuvalas & Alonso, 2005), the focus has shifted to measuring the quantity and quality of time survived post-transplant (Jay, Butt, Ladner, Skaro, & Abecassis, 2009). This is clearly demonstrated with a search of the **EBSCO Biomedical Reference Collection** for articles related to quality of life for liver transplant recipients.

The search string *SU (QoL or HRQOL or “quality of life”) and SU (“liver transplant” or “liver transplantation”) not TI (children or pediatric or infant or child)* retrieved the following results (16 September 2010):

From 1979 to 2010: 549 results in total;

From 1990 to 2010: 516 results (94% of 549 results);

From 2000 to 2010: 336 results (61.2% of 549 results).

Only thirty-three results, or 6% of the search results, were from the period 1979 to 1989. Over 61% of the results came from the last 10 years, 2000 to 2010. Of the most recent 10 years of research (336 results) 31 were written in a language other than English, while a number of research studies were reported in more than one journal. However there are still a significant number of studies looking at quality of life outcomes for liver transplant recipients.

Looking at the search results for 2000 to 2010, it is also clear to see the clinical context of the research undertaken. As an example selection, all thirteen articles of relevance that commenced with the letter “A” are shown in Table 9 (p. 100). Note that the background for all authors is health-related, whether health economics, transplant surgery, nursing or psychology. None of these authors are described as recipients of liver transplants. Additionally, six of the thirteen articles used or referred to the Short Form 36 (SF-36) tool, showing its dominance within this field.

Table 9: Sub-set of Articles with Titles Starting “A” – 336 Search Results

Title	First Author	Author Background	Year	Journal	Tool(s)
A comparison of surgical outcomes and quality of life surveys in right lobe vs. left lateral segment liver donors.	Humar A	Surgical	2005	American Journal of Transplantation	SF-12
A comparison of the WHOQOL-100 and the WHOQOL-BREF in detecting change in quality of life following liver transplantation.	O’Carroll RE	Department of Psychology	2000	Quality of Life Research	WHOQOL-100 and WHOQOL-BREF
A qualitative study exploring patients’ perceived quality of life following an emergency liver transplant for acute liver failure.	Sargent S	Hepatology, Institute of Liver Studies	2007	Intensive & Critical Care Nursing	SF-36 and semi-structured interviews
A randomised trial of exercise and dietary counselling after liver transplantation.	Krasnoff JB	Department of Physiological Nursing	2006	American Journal of Transplantation	SF-36 and exercise and nutrition measures
A review of quality of life instruments used in liver transplantation.	Jay CL	Surgical	2009	Journal of Hepatology	Literature review
Adult right-lobe living liver donors: quality of life, attitudes and predictors of donor outcomes.	DuBay DA	Liver Transplant Unit	2009	American Journal of Transplantation	SF-36
Aerobic capacity, muscle strength and health-related quality of life before and after orthotopic liver transplantation: preliminary data of an Austrian transplantation centre.	Pieber K	Department of Physical Medicine	2006	Journal of Rehabilitation Medicine	SF-36 and exercise measures
Alternative therapy use in liver transplant recipients.	Tickerhoof L	VA Pittsburgh Healthcare System	2006	Progress in Transplantation	SF-36
An assessment of the impact of informative dropout and nonresponse in measuring health-related quality of life using the EuroQol (EQ-5D) descriptive system.	Ratcliffe J	Sheffield Health Economics Group	2005	Value in Health	EQ-5D
An empirical comparison of EQ-5D and SF-6D in liver transplant patients.	Longworth L	Health Economics Research Group	2003	Health Economics	SF-6D and EuroQol EQ-5D
An exploratory investigation of quality of life in adult liver transplant recipients.	Bean KB	School of Nursing	2005	Progress in Transplantation	Face-to-face interviews

Title	First Author	Author Background	Year	Journal	Tool(s)
Are physician-derived disease severity indices associated with health-related quality of life in patients with end-stage liver disease?	Kanwal F	David Geffen School of Medicine at UCLA	2004	American Journal of Gastroenterology	LDQOL 1.0 in association with MELD and CTP scores
Assessing health-related quality of life pre- and post-liver transplantation: a prospective multicenter study.	Ratcliffe J	Health Economics Research Group	2002	Liver Transplantation	EQ-5D and SF-36

It is beyond the scope of my research to review all quality of life measures, or audit every author's background who writes in this field. Literature is available that reviews quality of life measures, such as *A review of quality of life instruments used in liver transplantation* by Jay, Butt, Ladner, Skaro, and Abecassis (2009). These authors "conducted a systematic review of the MEDLINE database and Cochrane library... [and] ...identified 128 relevant articles utilizing more than 50 different QOL instruments" (p. 949), none of which allowed comparison between studies. This paper, more than any other, provides strong support for the development of a QOL instrument which specifically targets patients undergoing liver transplantation, in order to accurately measure QOL in the population.

The examples of quality of life research in relation to liver transplantation illustrate the clinical background of the researchers, in contrast to my approach as a fellow liver transplant recipient, researching with my peers from a non-clinical background. I also consciously opted to develop my own research tool, rather than using the Short Form 36 tool. I will briefly comment on the Short Form 36 tool owing to its dominance in health-rated quality of life research, before discussing the process I went through to develop my survey tool.

Short Form 36

The Short Form 36 survey tool is widely used in the health sector to measure individuals' quality of life indicators within eight areas. These include physical functioning, emotional wellbeing and general health perceptions. An online search of the **EBSCO Biomedical Reference Collection** for subject references to the

Short Form 36 or SF-36 tool retrieved 4,187 results (September 15, 2010). This demonstrates its extensive use within medicine and health.

The Short Form 36 was developed by the RAND Health group within RAND Corporation, as part of a research project called the Medical Outcomes Study (MOS), and it is defined as:

SF-36 is a set of generic, coherent, and easily administered quality-of-life measures. These measures rely upon patient self-reporting and are now widely utilized by managed care organizations and by Medicare for routine monitoring and assessment of care outcomes in adult patients (RAND Health, 2010).

Although it has wide-spread acceptance, there is on-going discussion in the literature about the benefits of standardised measures versus disease- or issue-specific measures. Additionally the Short Form 36 tool was not designed specifically for transplant patients, but is a universal tool within the health context.

There is undoubtedly a role for standardised measures of outcomes as assessed by patients and for more methodological work testing such measures. It is too early, however, to focus all energies on the SF 36. In particular, **routine in-depth qualitative research is needed to listen directly to what patients have to say** [*emphasis added*] rather than their voices always being channelled through templates of the experts' making (Hill, Harries, & Popay, 1993, p. 449).

Some researchers have included assessment of the usefulness of the SF-36 survey in relation to liver transplantation, such as the work of Dudley, Chaplin, Clifford, & Mutimer (2007) who focused on the quality of life outcomes for Hepatitis C patients in Birmingham, United Kingdom, using a phenomenological approach rather than the SF-36 tool.

The first study which evaluated quality of life outcomes of solid organ transplant recipients in New Zealand, including liver transplant recipients, was undertaken by Beilby, Moss-Morris and Painter in 2001/2002 and reported in the *New Zealand Medical Journal* in 2003. The researchers used the Short Form 36 to measure quality of life, and compared this to the New Zealand population as a whole, as normative data were available (Beilby, 2003).

As mentioned in an earlier chapter, I was excited to be asked to participate in the Beilby study, and I looked forward eagerly to my interview in 2001 with the researcher. However, although the interviewer was pleasant and friendly, the environment was relaxing (my own home), everything was explained clearly and I felt at ease, at the conclusion of the interview my overwhelming emotion was that of frustration. My experience of liver transplantation and my subjective view of my quality of life did not match the questions I was asked to respond to, and there was no place within this structure for me to add in what was important to me. Additionally, I was not able to ascertain from the researcher then, or later through the published report, whether thoughts and experiences I had were common to transplant recipients (particularly liver transplant recipients), or unique to me. These were not clinical experiences, but related to thoughts about the donor, my own changing priorities and concerns about employer and societal prejudice for example.

Developing My Own Survey Tool

“This survey is so real, down to earth; it’s really like reliving all of the op again.”

SP#33

In the intervening years, from being part of the Beilby research to commencing my own research project, I continued to wonder to what extent my experiences reflected those of other liver transplant recipients. I was curious how many others found the experience transformative; how many of us changed priorities, undertook new activities or felt our personalities had altered because of our transplant experience. To give a minor example: living in Auckland and commuting to work on the motorway pre-transplant caused stress, but post-transplant was relaxing owing to my feelings of gratitude for being able to be stuck in traffic and being able to work.

Shortly after my own liver transplant in 2000 a fellow recipient (#27) and I jointly developed the website www.livers.org.nz. The website remains active, and has provided an “e-mail us” function which is used by people within New Zealand and internationally. As a “market research” tool, the queries from New Zealanders e-mailed through to the website (which come to my e-mail box) were valuable for providing me with an idea of a “knowledge gap” which should be addressed. Queries were all about the quality of post-transplant life, whether the person asking was the potential recipient, partner, or other family member. Concerns were raised: “should I accept this opportunity, if my future will be lying on a couch watching TV all day” when potential recipients had led previously active lives.

From this background, I believed that I would have the support of my fellow transplant recipients to look at our view of our wellbeing post-transplant, and that our collective experiences would provide useful supporting information for other New Zealanders as they were listed for transplant. I was convinced that my data collection should be done in two phases, which required ethics approval to be sought separately for both stages. I did not want to use the Short Form 36 tool that I had found so frustrating, and as I believe that New Zealand liver transplant recipients are experts in their own transplant experiences, I wanted to draw on our collective experiences and knowledge.

Using my own experience, I developed my semi-structured interview template. This covered seven thematic areas in the chronological order recipients typically experience them. The high level areas had possible follow-up questions in four out of seven areas. The interview template is available in Appendix 9 Indicative Questions – Focus Group and Interviews, p. 304. The seven thematic areas were:

1. Do you remember how you felt when you first found out you had a liver problem?
2. Do you remember how you felt when you were told you *might* need a liver transplant?
3. Can you tell me how you felt when you *were* listed for transplant?
4. During your transplant / hospital experience, how did you feel?
5. How did you feel when you were allowed to leave the hospital, either for Domain Lodge/Transplant House/other accommodation or your own home?
6. When you think of your first three to six months post-transplant, how would you describe your life?
7. How would you describe your life today?

Chapter Three has already covered my participant selection process. Seventeen semi-structured interviews provided me with over thirty hours of data from New Zealand experts in their own experience of liver transplantation. All interview participants were briefed at the start of the interview that the interview data would be used to develop the survey, as well as being an important data set for the thesis. This group was geographically and ethnically representative of the wider liver transplant population in New Zealand (a valid sample), as well as representative of age bands and gender. After transcribing the interviews, I uploaded the transcripts into NVivo 8 in order to code them. The “nodes” created in NVivo 8 were then exported into Microsoft Word documents. This allowed me to have lists of relevant key quotes from interview participants that illustrated the major concept areas that had emerged from the interviews.

Much of the material I read which covered experiences of liver transplant recipients in the United States had a significant focus on costs of transplantation, health insurance issues, costs of medication, and other financial imperatives. Looking at the experience of New Zealanders needed to be in the local context of a socialised healthcare service where the liver transplant (and follow-up care and medication) are provided at no charge to the recipients, and where the New Zealand welfare system also provides income support to eligible New Zealanders through the Sickness Benefit and the Invalid’s Benefit (among others).

The final survey had nine sections with a total of 32 questions. The concept areas were caregiver support, being unwell, listed for transplant, having the transplant and time in hospital, the first three months after transplant, life today, the donor, and community. There was also a section for high-level demographic information. The survey was

anonymous. The demographic data captured was limited to ethnicity (using Census 2006 classifications); age band in ten-year bands starting with the first year of eligibility which was 20 years of age (band 20 to 29), apart from band 50 to 64 and 65 years plus; gender; and normally resident geographic location grouped in seven high-level groups, such as North Island – urban, South Island – rural.

There were more possible questions within each concept area than I was comfortable using, as I was aware of “survey fatigue”, and I did not want recipients to find the length of the survey so onerous that completion would be difficult. The length of the survey was due to my requirement to have the recipient “voice” come through clearly, which necessitated the use of many quotes directly from interviews. This is exemplified in Table 10 p. 109.

My supervisors’ advice to me, when designing this survey, was to ensure that I had a mix of “tick box” answers as well as areas for written responses. Additionally, if there were a number of “tick box” answers towards the front of the survey, it could assist the participant in seeing the survey as less onerous than having too many comments required in the first few pages. For this reason the demographics section came first.

Once I had draft one of the survey completed, I obtained my supervisors’ permission to send it to my focus group participants for their feedback. This was sent by e-mail on Monday 10 May 2010. Recipients were a mix of urban/rural, North Island/South Island and male/female. One recipient phoned in his feedback, saying that the survey kept his interest and engaged him the whole time, it was not too long, and a question on pain should be included. He also noted his fascination with reading the quotes from other recipients. Another recipient commented on the question about the main caregiver, as

she had three caregivers – two during the week and a different caregiver on the weekend. She also thought more questions could be included. A third recipient said: “I think that there are enough questions but because you have a set of people who will probably all be keen to do the survey, perhaps you could have included a few more.” This recipient also commented that the quotes were a good idea and would be useful to recipients when they were completing the survey.

Table 10: Example of Response to Question 10

<p>Question 10 How did you feel once you were called to hospital to have your liver transplant surgery?</p> <p style="text-align: center;"><u>Statements from liver transplant recipients</u></p> <p><i>“I thought I might die on the operating table...I think that’s one of the reasons why I had to believe it was really unreal, like I definitely felt that way the night that I was in hospital – waiting when I’d been called in.” (Female)</i></p> <p><i>“As they wheeled me into the theatre on the trolley there was a photograph on the wall of a Pacific island, white sand, coconut trees, and when I saw that, I thought: ‘It’s going to be good.’” (Male)</i></p> <p><i>“... [Name] had already told me they’d never lost anyone on the operating table. Which was the main concern at that point...the look on my daughters’ faces will forever haunt me, I’ve just never seen the <u>fear</u>.” (Female)</i></p> <p><i>“...they were in at quarter to six, woke me up, ...so the family come in, and...I said to my family: “If anything goes wrong, you are <u>not</u> to blame the hospital.” I said: “You hear that?”” (Male)</i></p> <p><i>“I still thought, I mean I honestly thought as they were wheeling me to the operating theatre, like when I was in the elevator, I still thought they were going to realise they’d made a mistake.” (Female)</i></p> <p>Your response:</p> <hr/> <hr/> <hr/> <hr/> <hr/> <hr/> <hr/> <p style="text-align: right;">Please use extra paper if you need to.</p>
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Following this feedback I lengthened the survey by including three new questions: one on time, one on pain and a “catch-all” question (Question 32) where fourteen other question areas were noted. The introductory wording for Question 32 is shown below:

Question 32

I do not want you to feel that there have been parts of your liver transplant experience which you have not been able to comment on, because my questions did not always match your experience.

These pages are an opportunity for you to share anything else about your experience that you wish to. For your information, I sent this survey (in draft form) to seven liver transplant recipients across New Zealand, in order to gauge feedback as to length, appropriateness of questions and so on. From this feedback I have added two questions and provided additional information here for you to consider commenting on.

It was important to me that the survey was as inclusive as possible of all liver transplant recipients’ experiences. I believe I achieved this, with the unsolicited feedback I have received through the survey, particularly the comments from SP#24 which open this chapter, and SP#33’s at the start of this section.

With hindsight, I would have re-sent the survey to my focus group participants for their further feedback. The two questions added into Section 5 were not piloted. Section 5, on having the transplant and time in hospital, was answered with little confusion except for the new Question 12 (pain) and new Question 13 (time). 43 out of 49 survey participants added comments to Question 13, however of these comments, a number reflected on the overall experience of Intensive Care especially having the tube down the throat, rather than reflecting on “time” such as the inability to distinguish day from night. For those who could not recall pain, or felt they had pain below or above the scale used in hospital, the pre-testing of Question 12 would also have been valuable.

The final version of the survey was approved by my supervisors prior to being submitted to AUT Ethics Committee. It received ethics approval on 10 June 2010, AUTEK 08/81. The ability to ensure anonymity of responses to the survey meant that I was not able to send this out myself. As described in Chapter Three, the NZLTU went through their database to identify eligible participants, and posted the packs that I prepared. Each pack contained the Information Sheet, the survey which was printed in booklet form, two copies of the Survey Consent Form (one for the participant to keep, one to return to me, noting if they wanted a copy of the findings and research updates), along with a pre-paid envelope for the consent form, and a larger pre-paid plastic envelope for the survey.

Packs were sent to approximately 178 recipients. The actual number sent cannot be guaranteed, owing to my inability to be part of this process. I supplied 181 packs, and I understand from the Liver Transplant Coordinator who undertook this huge job that a couple of recipients originally thought to be eligible, were not. There may not have been 178 recipients, but 178 liver transplants, as I heard from one recipient who had received two liver transplants, that two copies of the survey arrived in this mailbox. Another recipient noted in her survey response that she had had two transplants, and she may also have received two copies of the survey, although this is a surmise.

Survey responses were originally due to be in to me by 1 September 2010, however when an update to participants was posted out, this was extended to mid September. At 20 September 2010 I had received 49 surveys. No further surveys were received. This was a pleasing response. The respondents are representative of the total recipient population. Recalling the discussion of participant selection in Chapter Four, there were 37 European (75.5%), seven Maori (14.2%), and five other ethnicities (10.2%), which

reflected the overall demographics of the eligible recipients from 1998 to 2005. The dominant age band (at time of transplant) was 50 to 64 years of age (25 respondents or 51%), followed by 40 to 49 years of age (12 respondents or 24.5%), while the gender split was 25 male respondents and 24 female. Auckland dominated with 24 respondents, however there were 12 from North Island – urban and a total of six from the South Island, of which four were urban and two were rural.

From information provided to me by Associate Professor Ed Gane, when he interrogated the NZLTU's database of recipients, in the period from 1998 to 2005 was that there were approximately 17% Maori, 10% Pasifika, 10% Asian, and the balance were European patients. Approximately half the recipients were in the age band 20 to 50 years of age, and the other half were aged 51 plus.

Once survey responses started arriving, some immediate design flaws became apparent. Question 6, on caregiver income, did not include an option for relying on the other partner's income such as sick leave or pension, but had assumed that caregivers would have an income stream of their own. Question 12 did not cater for those recipients who felt no pain throughout their transplant journey, nor did it effectively demonstrate a range of pain levels within the designated time period. Question 16 did not allow for transplant recipients re-commencing driving after 12 months. Question 17(b) should have allowed for a "not applicable" response, as should Questions 25(b) and 25(d). Questions 26(c) through 26(g) should have allowed for an "I know" response in relation to information about the donor, as a number of recipients knew some details. Irrespective of these design flaws, respondents answered with additional comments and notes of explanation, all of which have been transcribed into MS Word documents, question by question. The "tick box" data has all been entered in MS Excel.

From the very positive feedback received through the surveys, by e-mail and in phone calls, I believe this survey has achieved the objective of being an inclusive and relevant tool to ascertain the impact of liver transplantation on New Zealanders' quality of life. It reflects their lived experience, it is subjective and at times their reflections are emotional and raw. Some thanked me for giving them an opportunity through this survey to talk about their experiences.

Thanks for the opportunity to answer these questions. Best wishes for the research.

SP#11

Dear Bethli, You are an example to all of us. Hope you can decipher my responses and some are helpful. All the very best with the survey and your thesis. Warmest regards.

SP#26

I believe the approach I took with this survey could be used in other research, particularly other solid organ transplant recipients in New Zealand such as lung, heart and kidney transplant recipients. It might be possible for this survey to be adapted to Australia and other countries which have socialised healthcare systems. I hope it is useful to other researchers and encourages other recipients to do work in this area.

Chapter Six: Experience of Becoming Unwell

I lost a lot of physical condition but convinced myself it was due to other factors: age, change of employment, and weight gain. I had a car accident which landed me at the Emergency Department of the [Name] Hospital, where I had blood tests done, and eventually I was given a diagnosis of liver failure.

SP#35

Introduction

This chapter, on becoming unwell, is closely linked with Chapter Seven which looks at waiting to be listed for transplant and waiting for a transplant after being listed. In this chapter I look at the period of time from feeling well to feeling sick, **before** being listed for a liver transplant. It is a period of change and transition, with patient responses ranging from fear and disbelief to anger and acceptance.

This chapter focuses first on the available literature, then details the experiences of liver transplant recipients as they reflected on this time of transition in the interviews and in the surveys.

Literature Review on Becoming Unwell

“In contemporary academic usage, I was becoming other to the person I had been and to those who knew that person” (Frank, 2001, p. 354).

Using all the database sources in EBSCO’s medical set, and Google Scholar as well as Google, it is very challenging to find academic literature that discusses the patient’s perspective of hearing the diagnosis of a serious – sometimes potentially fatal – disease or illness, at the specific transition point in time of moving from “well” to “unwell.”

Search strategies can provide literature on doctor/patient communication, communication models and training packages, all aiming to enhance the experience of communication between medical practitioners and their patients. However the impact of the “communication point,” whether written or oral, around the patient’s transition to becoming “unwell” is not covered within the literature to any great extent.

One study by Maynard and Heritage (2005, p. 430) noted patterns clinicians use when providing “diagnostic news about HIV infection” to patients, where the focus is on how the clinicians deliver the good or bad news, rather than how the patients receive and process this information in the short and longer term.

In discussing the quality of doctor/patient communication, Hagihara and Tarumi (2006) noted that “several measures, such as the frequency, duration and ratio of quantitative communication behaviours, have been used to evaluate doctor/patient communication (pp. 7-9). A major shortcoming of these measurements is that a quantitative method cannot measure critical elements of the interaction process or patient perspectives” (2006, p. 143). For this reason, it is important to turn to the published phenomenological and autoethnographic writings of academics who have themselves become ill, and the memoirs and biographies of patients. This provides some very limited coverage of this transition point. The second and third parts of this chapter offer much more detailed information – using interview and survey data that were included – from the patient’s own perspective about this transition period.

One study of interest relates the experience of Carol Ann Rooks, who experienced receiving a donor kidney as a patient in the United States of America, but within her context of being a nurse. Kavanagh wrote that the focus of that study about Rooks’

experience was “about narrowing the gap between critical illness as it is understood by those experiencing it and the meaning of critical illness for those who care for patients” (2002, p. 49). Kavanagh also noted that, while narratives about the lived experiences of transplant patients was scarce, “even scarcer is the experiential account of a patient who, as a healthcare provider, understands the meanings of transplantation from both perspectives” (p. 50).

Rooks did not reflect significantly on the transition point of becoming unwell; her experience of being sick, hospitalisation, transplantation and care in the context of her role as patient and her knowledge as a healthcare practitioner was the focus area of the study. Rooks commented that:

I’m learning a lot about being truly sick. If I was ever truly sick before, I don’t remember. I am 41, and I have had diabetes for 33 years, but I have not been *truly sick* until now. Being truly sick is to be so helpless that you can’t lift your head up off the pillow and you don’t care what they do to you...Waiting interminably. Of having nothing to do and to be about. The days are long but the nights are longer. Every five minutes can creep into hours, each moment, each hour hyper-extended. Waiting for care when what I really wanted was caring, *time spent caring*. Care is scheduled, caring is not (Kavanagh, 2002, pp. 65-66).

Although Rooks was not discussing the point of transition, the knowledge displayed about the need for caring rather than care does reflect the emotional intensity that this change of status brings with it.

Varela (2001) reflected on the experience of receiving a donor liver in France, and the change in perception of boundaries, his body and existence in the immediate post-transplant time, in his essay *Intimate Distances: Fragments for a phenomenology of organ transplantation* (2001). He wrote that:

Years before the transplant, during a biopsy the surgeon came to see me: “I saw your liver, it looks very sick, you must do something about it.” The statement made this silent organ suddenly un-me, threatening and already designated to be put at a distance in the economy of the body’s self. Seeing from outside had penetrated me as a blade of alterity, altering my habitual body for ever (pp. 262-263).

Moving to a larger body of work, autobiographical accounts of liver transplant recipients have been published including those of Chalmers (1995), Parr (2000, 2001), Yomtoob (2005), Murray (2007) and Kuhn (2008). An extensive database of works of this genre is listed in the Bibliography. Three relatively well-known men from the United States who received liver transplants and documented their life journeys within this transplant context bear special mention here, namely:

- **Frank Maier**, *Newsweek’s* Chicago Bureau Chief; transplanted May 1987, memoirs © 1991.
- **Robert P. Casey**, Governor of Pennsylvania; transplanted June 1993 (heart and liver), memoirs © 1996.
- **Larry Hagman**, Actor; transplanted August 1995, memoirs © 2001.

All three men commenced their memoirs with their life-changing transition point, however in the cases of Maier and Casey, this related to their transition from being “well” to being “unwell”, whereas for Hagman, the transition point was around current and future employment, with the prospect of becoming unwell (in the future) much less dominant in his narrative.

Governor Robert P. Casey reflected on the time when he went from a second-term Governor to someone facing his own mortality.

Often the greatest tests in life are those we do not even notice until they are upon us. There is no chance of escape, appeal, or relief. One moment we're going along our way; the next moment we're surrounded on every side by trouble. No time to prepare. No transition. No warning, no bargaining, no debating, no equivocation. The problem just surrounds us and begins closing in. All the things and titles and powers we have gathered up in life fall away. What remains is the raw desire to survive. At such moments we meet ourselves for the first time (1996, p. 13).

The only time I'd ever felt so completely numb was a decade earlier, when I was told Ellen had a malignancy which could kill her. That news had been like a sledgehammer delivered to the head. And now I was being told I had a rare disease that would surely kill me (1996, p. 15).

Frank Maier, a successful journalist with a great career at Newsweek, openly wrote about the transition point of becoming "unwell," and noted where he could have identified and discussed symptoms with medical practitioners, but for his strong reluctance to connect with medical professionals in relation to his own health.

Something wasn't quite right. Maybe it was the car, a rented Oldsmobile instead of my little Chevette, which was in the shop for repairs. The morning rush-hour traffic on Kennedy Expressway was whisking along at a brisk 55 miles an hour toward the sun-sparkled buildings of Chicago's Loop. For some reason I felt uneasy in the middle lane with cars surging on either side of me. I looked for an opening and eased into the far left lane where I could nestle up comfortably to the retaining wall.

That's when and where life changed for me. At 10 minutes before 9 on a bright June morning in 1984, where the inbound Kennedy merges with the Edens Expressway, I learned in the space of 10 seconds what I should have known from fifty years of living: that life is as fragile and uncertain as your next breath (1991, p. 5).

How could I know then that the incident on the expressway that morning was an early warning sign that I was seriously ill, that I was, in fact, starting to die? But at that time, death was not real for us, just a story to be told at the next dinner party (p. 6).

So determined was I to avoid all contact with medical practitioners that I even developed my own all-purpose diagnosis that fit any symptoms of any ailment: “a touch of the flu.” It covered everything from sniffles to appendicitis... The former Ginny Ryan did not share my aversion to doctors. Consequently, after my near fatal spinout on the Kennedy Expressway, she made appointments for physical and eye examinations (p. 13).

The only warning sign – and I didn’t get the impression it was anything more than a blinking sign – was that blood tests showed a slight elevation of my liver enzymes. But that was enough of a concern for the internist to tell me to abstain from alcohol and avoid aerosol sprays or chemicals like cleaning fluids and degreasers, all substances that can damage the liver.

I never bothered to tell any of the doctors about my occasional lapses of concentration or episodes of confusion. I’m not sure today whether that was out of stupidity, male stubbornness, or simple fear of what the symptoms might be disguising. Patients, I came to learn, can be very selective in what they tell their doctor (p. 14).

Larry Hagman, famous for his television roles in *I Dream of Jeannie* and *Dallas*, commenced his 2001 memoir with the anecdote of his post-school teenage job situation, and the push that gave him towards acting. Within the opening pages he touched on his liver transplant, as from this context he appeared to have been frequently asked about its impact on his life. However his approach was very matter-of-fact and did not appear to have been the transition point in his life that it was for Casey and Maier.

Everyone has a moment when life pulls a U-turn. Mine occurred in Weatherford, Texas.

It was the summer after my senior year of high school. I was seventeen years old. Two years earlier, I’d left a comfortable liberal school for rich kids in bucolic Vermont to be with my dad, a prominent lawyer in the small Texas town. I’d said I wanted to work as a cowboy. That time had finally come. I had my hat, my jeans, my boots . . . everything but a job.

My dad got me work in the machine shop at the Antelope Tool Company, a stultifying hot Quonset hut where I made a tool used in oil drilling that a machine behind me spit out at a rate a hundred times faster than I could make them by hand. The only horses I'd seen all summer were in the local rodeo. The hell with trying to be a cowboy.

"I think I want to be an actor," I told my dad (2001, pp. 9-10).

I'm often asked how my liver transplant operation changed my life. Aside from saving it, nothing changed. It confirmed what I've always tried to do – live my life as fully as possible before the clock runs out. My happiness comes from being a husband, father, and grandfather of five, not from stardom, which is a fluke...So little is in our control. I was once asked what were the three luckiest things that happened in my life, and I said, "Being born white, in the U.S.A., and in the twentieth century." Even with all the luck in the world, you can't ignore fate. Sometimes fate requires you to need a liver transplant (p. 11).

Australian historian Inge Clendinnen's memoir opens along the same lines as Casey and Maier, with the turning point of becoming ill the opening, defining moment in her life.

A decade ago, when I was in my early fifties, I fell ill. "Fall" is the appropriate word; it is almost as alarming and quite as precipitous as falling in love. It is even more like falling down Alice's rabbit hole into a world which might resemble this solid one, but which operates on quite different principles. Pain, death and loneliness are domestic presences there, in grey-green masks and gloves. So are humour and kindness, which come in all sorts of uniform. You are granted the dubious privilege of being a child again in a place which sometimes resembles a child's nightmare, and at others a well-run nursery.

It is also a world in which, like Alice, you are subject to unscheduled and surprising transformations.

This is not the story of a medical crisis. If it were, it would be for medicos to write. To lie still as a crusader on a tomb while dreams spin behind closed lids, to surf the tumble of disordered memories as they dolphin away, to feel the mind disintegrate and to fear the disintegration of the self, is to suffer an existential crisis, not a medical one. And to try to understand any of this by transforming inchoate, unstable emotion and sensation into marks on paper is to experience the abyss between fugitive thought, and the words to contain it.

This is the story of what happened when I fell down my rabbit hole
(2000, p. 1).

Olympic snowboarder Chris Klug did not use a transition point from being “well” to being “unwell” in his 2004 memoir, as his health status was precarious from his birth, followed by severe asthma, and problems with his feet before being diagnosed with a liver disease. However he does comment, after a routine physical at a medical clinic, on being “...stunned when I got a call the next day from the nurse at the clinic. She said my blood work indicated that I had ‘elevated liver enzymes, which could be serious.’ I was still digesting that when she asked, ‘Do you drink a lot?’” (Klug & Jackson, 2004, p. 104). He goes on to ask himself “And what in the heck were elevated liver enzymes? It sounded like a commercial for Tide detergent, only scarier” (p. 104).

As mentioned above, other memoirs of liver transplant recipients exist. It appears that with the passage of time, liver transplantation has moved from the newsworthy to the treatment of choice for end-stage liver disease; therefore the high profile memoirs of the 1980s and 1990s are less likely to be written in 2010. What I will now highlight is the lived experience of this transition point for New Zealanders becoming aware of their liver issues/disease through their own words shared in interviews and surveys for this research.

Interview Responses on Becoming Unwell

I thought I was just really run down and depressed and...I just couldn't work anymore, I was really tired. And that was when I found out that I had Hepatitis C.

IP#1

For most liver transplant recipients there is a transition period between being “well” and living outside the medical system, and a time when the everyday life disappears and the future recipient becomes an out-patient or an in-patient within the hospital system. Exceptions to this are those recipients who had acute conditions, and may have been in a coma pre-transplant, awakening in the DCCM to discover they have received a donor liver. Others may have had chronic liver conditions or co-morbidities that have seen them already connected to hospital systems.

In this section the experiences of liver transplant recipients throughout New Zealand whom I interviewed for this research, allow their voice to be heard. The experience of becoming sick, prior to being listed on the waiting list for transplant, is not well covered in the literature. This period of time can require a lot from patients, caregivers and their family members. Suddenly something serious, if not life threatening, has disrupted the normal ebb and flow of life. The concept of illness and of liver transplantation may be introduced into the family, with the dual hope/fear surrounding the idea of transplant itself. Additionally, the power to put the patient's name on the list rests with medical experts, who families hope will support their situation, given the scarcity of organs.

From the seventeen interviews undertaken in this research, the experiences of New Zealanders “becoming unwell” have some similarities in relation to liver disease.

By identifying the key concepts in the interview sections relevant to this topic, and using NVivo 8 to code the data, a number of common concepts were highlighted. These are illustrated with quotes from the interviews, to allow the “voice” of New Zealanders to be heard.

One of two leading concepts relates to denial of illness and its seriousness, and the other to the mode and delivery of information by medical practitioners to New Zealanders becoming unwell. The first concept is illustrated in many of the comments that highlight the second, and I return to illustrating the first concept at the end of this section. Focusing on the second concept, there are some interesting examples that show the subtlety of communication methods and the impact this can have on people. IP#1 noticed the change in the stationery that the hospital was sending. I have underlined key areas for emphasis in the following excerpts.

I was very uninformed. I was really uninformed. And I think the doctors were too. I don't think it was that they weren't telling me what they knew, I think they didn't know. It was kind of funny because I'd been going to see Dr. Gane at the hospital as a liver specialist.³¹ And then suddenly I'd noticed a couple of weeks before that the stationery had changed to the Liver Transplant Unit. And that's one of the things that made it seem even weirder. It's sort of like: “Oh, they've set up this liver transplant unit now, and they're saying that I need one, well isn't that a bit strange!” It just seemed even more like an episode of the *Twilight Zone* and not real. How can a healthy, well I wasn't healthy but I thought I was healthy, how can a reasonably healthy person need such a major thing. They're wrong. They'll find out they're wrong, you know. So, I suppose disbelief is what I felt, I wasn't that scared I suppose at that point, because I didn't believe it was going to happen. It was just like so scary that I wouldn't even take it into consideration.

IP#1

³¹ The NZLTU reported that they have changed letterheads to remove reference to “Liver Transplantation” when sending out appointments to clinic.

IP#6 similarly has an experience where, without even feeling that the doctor has looked at him or discussed his health, he is advised of being booked into hospital and needing a liver transplant.

It all happened rather quickly with me, I suppose. At the start of 2000 I wasn't feeling all that marvellous. We went for a holiday, and I knew I wasn't really feeling very well. By October I was decidedly yellow and I didn't feel well at all, so I took a fortnight off work, and went straight to the doctor, who shot me straight to a specialist. This all happened within three or four days. Within a week I'd actually been to my GP, seen a specialist, had about five blood tests, and the specialist sent me to another specialist in Auckland, to verify what he'd said, and they started talking liver transplants. Which I'd never heard of! I didn't believe them. The Auckland guy, when I went in to see him, he said: "Right, first thing I'll tell you, I've booked you into Auckland Hospital. You'll be hearing from them within the next couple of days." I just stopped. He hadn't even looked at me, let alone talked to me or anything, you know, and he said: "I think you'll need a liver transplant." Because he had all the information, you know. He did another blood test and had another look. We got home and that was the only day I'd felt really well for quite a long time. And we drove up to Auckland, saw the guy, had lunch, and came home again. I was just blown away. I didn't know whether to believe them or not.

IP#6

Some of the communication between doctors and these participants is remembered as being quite abrupt. The next participant describes how sudden it was to hear that she could die prematurely, which she was not aware of.

I had a very bad dose of hepatitis and I was off work for a long time, but I can't really remember when they first told me there was something wrong with my liver. I kept complaining that I was unwell and they gave me all the tests under the sun. And I wasn't allowed to have ordinary milk, I had to have soy milk and all these different foods. I remember going to [Name] and he tested me and I do think he said something was wrong with my liver. But this is a long time ago, I can't remember. I do know that I did go to the hospital one day for a

check-up and there was a doctor there, [Name]. He said to me: “Well, you’ve got liver trouble and one day it might get so bad that you’ll just die.” You know, just like that. And that was a real shock, because I came home and talked to my husband about it. And we got our son and daughter to come. And we told them this, at that time. But as I didn’t get any worse, and just carried on, we didn’t worry too much about it. But I had to keep going to the doctor’s all the time for blood tests.

IP#11

Written communication on diagnoses can also lead patients to search for further information themselves. In an information environment, with internet access readily available, books and journals accessible through libraries and electronic means, it is not to be wondered at that some patients may look up information or terms provided to them by their doctors. The example below shows a participant looking for information on a new diagnosis, and being shocked by what was found.

Then the first specialist came around and said: “Oh, yes, you’ve got that.” And then I saw the other specialist and she said not a great deal: “We just monitor this.” I got a wee letter, confirming this saying I’ve got PSC [primary sclerosing cholangitis], blah blah blah. They didn’t go into details. And I thought: “Oh, I wonder what this is? Do I want to look it up?” I thought: “Oh, I’ll go look it up.” I went to the public library and the first thing I pick up, and it says: “This is nearly always fatal.” Fatal. Liver disease. I thought: “Oh, \$%^&.” Excuse my French. You know, when you read that “fatal liver disease”. I thought: “Oh.” And so I didn’t want to read about it from then on. So I just, I didn’t look it up again.

IP#12

Within the communication between doctors and patients, there are also examples of miscommunication, where patients may become frustrated owing to “knowing” that they are unwell, but not being able to adequately explain their situation. One participant discussed the impact a wrong diagnosis had on her, which impacted her post-transplant life significantly as well. Her story of becoming unwell follows:

I couldn't say how I felt once I was told I had a liver problem. I had gone into a coma. I woke up in the morning feeling not too bad, but as the morning ventured on, I realised I probably shouldn't go to work. I can remember it all. Thinking 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." As I understand it I was going into hypoglycaemia and wobbling everywhere. I went to the doctor in the morning and the nurse that worked at the Medical Centre took a sneaky little blood test off me which I don't remember. The doctor had made a decision, an embarrassing decision, that what he was witnessing was a mental breakdown – which I don't like saying to too many people. By the time I got to the doctor I was actually swelling, and staggering everywhere. I couldn't even sign anything, and I was vomiting apparently. And that's a mental breakdown! And I can remember that. And I can remember sitting in my seat, looking at him, and trying to talk to him about that, because I knew it wasn't. And of course you cannot have an ambulance if you're having a mental breakdown. The doctor gave my mother an 0800 number to ring, and some sleeping pills. I refused to take them; I knew not to take them. I was actually bordering on comatose, and, I think, aggressive at that stage. I was hyperventilating, and the doctor thought it was because I was having a breakdown. He told me to blow into a bag. My dad must have just persevered and in the end the local ambulance came. Then somebody got my blood results, and it was all on from there. My liver functions were very, very, very, very, very high. I have still got the records because they were really, really high. The family did panic; the priest was there. They had the priest because I was dying of course. I was taken to [city] hospital and airlifted to Auckland in the Child Flight plane, quite quickly. I can actually remember waking up, and seeing Dr. Munn and another doctor, they were staring at me. But they must have known I was stirring, because he was looking at me and it was just like angels. I could see angels.

IP#10

Similarly other lifestyle factors may mask what is going on for the people concerned. This new mother knew something was "wrong," but again, could not effectively obtain the assistance she required early on.

I felt really sick. I don't think I was scared, I just felt ill. It was just a feeling that I wasn't getting any better. I knew the difference between

getting the 'flu because I've had the 'flu many times, but it just kept draining me. Before my stomach started inflating I went to the doctor, and I said: "I'm sure I've got *something*." The doctor asked what my symptoms were, and said: "It just sounds like you've got a pretty bad virus, you're a new mum, go home, drink lots of fluid and see how you go. If you don't feel well after that, come back in a couple of days." I let it go for a little bit longer because I was tired, having a newborn baby, but I never picked up; I never got better. I went back to the doctor, who said: "You *have* got a very bad virus, it's really, really bad. Go home and rest as much as you can." I hadn't started going yellow at that point. After I went to the doctor, I went to a health shop, because I thought I could get some healthy things into me, and it would work its way out. That was on the weekend, and I'm sure it was on the Monday, when my mother-in-law came to see me, that she said: "Your eyes are yellow." She was the only one that ever said it to me. She said: "Your *eyes* are yellow!" She looked at me. And I said: "Really?" And she said: "Have you not noticed it?" And I said: "No!" She said: "Are you not well?" And I said: "Nah, I've been feeling really unwell for *days* now!" It must have been late that afternoon that things in my body just started giving up, and I think the next day my stomach had really blown up, and I went back to the doctor again, and my GP said to me: "I want you to go home, I want you to pack your bag, and I'm going to write a letter for you and you're going to go into hospital." I said: "Why?" The GP said: "Because I'm not happy with how you are. You have been here a couple of times, and your eyes are quite yellow." I said: "What does that mean? What does that mean?" The GP goes: "Well I don't want to, I can't say, I'd rather let a doctor down there see you." And I went down there, I went down there really worried, and I never came back, I never came home. [Until after transfer to Auckland Hospital and a liver transplant.]

IP#4

As already mentioned, denial of illness, or its seriousness, is a leading concept. The participant's story that follows is typical of many of the interviews. It is particularly interesting as the participant was asking for advice, did receive information from a family member that he was unwell, and did visit a doctor, although he did not follow through immediately on the medical advice given. He also shows how information can be given, but not "received," and how isolating the transition from "well" to "unwell"

can be, particularly once the serious, life-threatening nature of the transition is understood.

My illness began around Easter nine years ago. But for about a month before that I was feeling really, really unwell. Actually the biggest sort of sign that I felt was loss of appetite. I just wasn't eating at all, I didn't want to eat, and I didn't want to drink very much. At the same time I had actually stopped drinking coffee, I had been a bit of a caffeine addict. I said to my friend at work: "I've lost a lot of appetite." And he said: "Oh, it's probably withdrawal." At the same time I was doing public health and injury prevention work, and I was in a car at one stage with a colleague of mine and I said to her as well: "I've lost my appetite." And she looked at me and said: "You might have a touch of Hepatitis B." She just gave me that look, and of course I just didn't think of it and carried on for about a month. But the big thing was the loss of appetite and I was also really, really tired. I felt really tired and I didn't know why. I slept quite a bit. I was basically falling asleep at work and not wanting to be there, almost disengaged. In the evenings I was OK, I was sort of floating around at home, and that's probably why I didn't think there was anything wrong. Why I thought I was just going through some kind of phase or something, and at times I felt like I wanted to vomit, and I didn't, so that was there as well.

I went to a conference in [city]. I came back to [city] feeling unwell; I just thought I was going through a phase. And then the week before Easter I went to the doctor's and I said: "I'm not feeling too good." And he said: "Go and have a blood test." So then I was too lazy to go and get the blood test, I didn't do it. Then I woke up one morning about nine years ago and my Auntie said to me: "Hon, you're looking yellow." So I went back to the doctor's and got the blood test the following day, and the doctor called me and said: "You need to get to the hospital immediately." I went to the hospital, and I still didn't know what was going on. They were rushing me around, getting these scans done. I had all these doctors come through and see me, and then one doctor came in and sort of explained things to me and said: "Well, it looks like you've got some problem with your liver!" And of course I still didn't think there was anything wrong other than the fact that I was yellow. I'd never been sick before that, never been ill once. And I was the kind of person that sees something and dismisses it, I didn't bother to worry. And of course I didn't know how serious it was!

In fact it first hit me when Dr. Ed Gane [at Middlemore] came to see me and explained things to me and said: “You’re really, really ill.” And he was very upfront when he said: “One of the options is a liver transplant, if you don’t get better.” And at that time I was really, really scared. I basically didn’t know what a liver transplant was, other than the fact that you’re receiving a body part from somebody else, and it was really at that moment that I began to sit back and think: “Actually, there’s something really going wrong here.” And it hit me again when I went down to get a scan, and I said to the doctor: “Oh, how’s it looking?” And 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 flashed in front of me, in front of my face. Those feelings all sort of come, those are really strong, and, you know, trying to grapple at that moment with the idea that I’m going to die, because I figured: “Well, once you lose your liver, then you’re going to.” 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. Those feelings were there, you know. I didn’t tell them that I was afraid either. I didn’t tell them any of that. I did ask one of the doctors what a liver transplant was, and he sort of quickly explained to me what it was, that basically you’d be accepting a liver from another person, and you go through the operation. It probably would have been a quick two minute explanation from one of the junior doctors, and I just lay back and pretended I knew what he was saying. But I certainly didn’t tell anybody that I was afraid. Actually I didn’t tell anybody what my feelings were at all, I didn’t share those with anyone. It’s probably fair to say that I just pretended things were OK. Actually I didn’t talk to my family about that either, throughout that entire time, and death was one of the things that I’d never spoken to anyone about. But I spent all that time basically really, really afraid, and I suppose with me, I didn’t want to, I wouldn’t share my fear with others. But I was just quietly afraid and thinking that I was heading towards that time.

IP#16

In my own experience of becoming unwell in 2000, I had the same rationalisation process going on – my symptoms were not symptoms of illness, but lifestyle factors that I needed to adjust and improve. I comment on my experience more fully in the next section. This attitude is echoed in IP#15’s experience of becoming unwell.

I still wasn't sick. The reality of being sick, because I didn't feel sick. Because the itchy stuff is the itchiness of liver failure, you don't know that's one of the first signs until it happens to you. So when I was itchy, I wasn't "sick", I was just itchy. But once you started scratching you couldn't stop. I didn't know why. So I didn't feel sick. When my tummy bloated, obviously there was something wrong but I didn't feel unable to do anything. I didn't have a cold. I didn't have a runny nose or a cough or a sore throat or a headache or all those things that you relate with being sick. All I had was this tummy, this pregnant looking tummy. And I knew I wasn't pregnant. So I knew there was something wrong but if I didn't have that, I wouldn't have known I was sick. And I was *really* sick. Because I don't think I turned yellow. But then, maybe I did but I wasn't looking for it because I didn't know I was sick. I was working.

IP#15

In some cases members of the extended family noticed that their family member was unwell; these included a wife, a sister, a mother-in-law, an aunt. In two of 17 cases work colleagues also noticed illness, or recommended that the person visit a doctor. Time taken to get an accurate diagnosis is also a common thread, with eight of the 17 recipients noting the time required to achieve this. Two examples illustrate this as given below.

It was a very circuitous series of events that led me to finally get diagnosed, in fact it wasn't until about two years later, after several false starts, and false diagnoses of the condition...

IP#3

and

in respect to my liver he referred me to the [city] hospital, and they did tests for six years.

IP#5

Almost all the interviewees demonstrated a lack of understanding of the symptoms of liver disease at the time of becoming unwell, along with an equal discussion of their symptoms of feeling unwell or below their optimum. Although ascites (swelling, looking pregnant), vomiting, haemorrhaging, and jaundice (yellow skin or yellow eyes)

were noted, most of the symptoms discussed in detail were “lifestyle” related such as tiredness, loss of appetite, fatigue and weight gain. Even when participants knew of existing medical conditions, including four known hepatitis cases, the link between their current situation of feeling unwell and previous medical situations was not made. One participant commented strongly.

I found out I had Hepatitis B after having my daughter. In terms of managing my Hepatitis B, once the whole family were aware, they were all immunised. But then that was it, it was just left. And what became more prominent, in terms of my medical history, was my diabetes. I was being tested on a regular basis, blood tests and everything, for that. I wasn't able to comprehend when I was told that I had a real liver problem. It wasn't until later on, after having the transplant, that I realised, and that's a bit of a backward thing, isn't it? Not until after the initial operation itself, and then you begin to sit and think, how did this go undetected? Because that's how it was, I was able to think like that, whereas in the build-up to the liver transplant itself, I wasn't able to. What happened was one evening I just woke, and I felt terrible pain so I went to the toilet. When I went to sit on the toilet all of a sudden I started vomiting and I called out to my husband, because I was sitting on the toilet and I could feel thick stuff coming from my back passage. Little did I know that what was coming out of my mouth was actually the same gunk coming out of my back passage. I was put in hospital and my varices had to be banded, because that's what had busted. And not even then was there any talk about my liver failing. From that point on, it's like the whole world changed for me. It was just at that point I started not being able to focus, for want of a better word, other than to say that I thought I was going mentally insane. Very frightening.

IP#14

The link to mental health comes through two interviews. In the above interview, the presumed onset of encephalopathy leads the participant to believe she is going “mentally insane,” whereas this is seen as the false diagnosis made by the GP in the experience of IP#10. In my own experience, I was very disturbed by my reactions to everyday events the evening before I was urgently admitted to hospital. I had been in

Wellington on business, and in the Koru club I could not hold a plate: they just dropped from my hands. When we landed in Auckland, it did not look like Auckland to me, and it was only because the pilot said “Welcome to Auckland” that I got out of the plane and believed I was home. Additionally, although my car was valet parked, I could not see it. I walked around and past it for fifteen minutes before I asked someone for help, and they took me to it, right in front of me. I am not sure how I drove home. I felt very upset and “freaked out” by this, although I did not think I was unwell. I was frightened and scared as I did not know what was happening.

Twelve out of 17 participants actively discussed being shocked, scared and surprised when finding out they were unwell. There were further discussions of shock as the concept of a liver transplant was introduced into the doctor/patient communication. Some participants felt it was too scary to be true or be believed. However with time, or from the start, some participants also accepted their future with a “that’s life” approach, as illustrated in the four quotes below.

Naturally it is a little bit of a shock, but, you know, it was no *real big deal*. I knew that I was in good hands, and they’d look after me.

IP#2

This quote illustrates a coping mechanism which assisted her in dealing with her diagnosis.

It was a matter of acceptance, and I went into robot mode of what happens next? What do I have to do next? Which is my character I guess. Let’s just get on with it. What are the options from here?

IP#7

This male took a very practical approach to his diagnosis and ill health, from the 1970s onwards.

It was about the mid 1990s that things got really bad. I never ignored it, but I just thought: “Well, you know, what will be, will be!”

IP#8

This other male wanted to work with the doctors and prepare as best he could for an unknown future.

I must face and sort out the problem. I must trust the doctors and use the limited time to prepare everything for the future.

IP#9

Again, from my own experience, I know that I was so unwell when first hospitalised, that I was not concerned about anything except drawing my next breath. I trusted my family, who were with me, and started to get to know the NZLTU staff, who at that time were all strangers, and grew to trust them over the following weeks. Accepting the situation was accomplished with little difficulty, because in my case it would have taken too much energy to rebel against it.

In the next section I look at the results of the survey participants to the question of becoming unwell. Before moving to this section, however, I want to highlight two areas that I will discuss further in my recommendations. These are: firstly, the importance of understanding how patients will receive life-changing information in print and in person; and secondly the probability that patients are more scared and less informed than they may wish to allow to be perceived.

Survey Responses on Becoming Unwell

I felt so tired that I took two weeks' leave and went to the doctor mid-October and after seeing two specialists who both told me I needed a liver transplant (which I had never heard of before), I was rushed into the Liver Transplant Unit...

SP#13

Section 3 of the survey focused on being unwell. It contained a selection of quotes from the seventeen interviews, before Question 7 was asked. Two examples of the quotes from section three are below:

“I sort of wouldn't acknowledge that I was ill, my wife kept saying to me: “There's something wrong with you, you're yellow, you're tired.” All the rest of it” (Male).

“I don't think I really realised that I was as sick as I was until they started talking about liver transplants. I'd been putting on a bit of weight, I thought, around my waist... But then one weekend, I just blew up! And I was so itchy... so I went to the doctor... she thought it might have been sort of a bit of gas or something” (Female).

Question 7 then asked survey participants to reflect on what they remembered of first becoming unwell. There were 49 survey participants, 46 of whom wrote comments. Of the three participants who did not write comments in this area two were male (SP#17 and SP#42) and one was female (SP#10), while all three were of European ethnicity. I copy-typed all the comments for Question 7 into Microsoft Word, and then using NVivo 8 software I coded the comments to provide information as to the commonality and/or uniqueness of the experience of becoming unwell.

Of the 46 comments from participants, 12 participants, or 26%, indicated other diseases. The quote that follows is from a participant with diabetes.

I did not feel unwell at all. After a routine test for my diabetes, I was told to go to the hospital immediately. It came as a shock when I was first told that I had to have a transplant and naturally I felt scared. But after everything was explained to me, I felt positive about the surgery and wanted it to go ahead.

SP#12

The next two quotes from survey participants show that the blood tests required for other unnamed health issues were a significant diagnostic tool for liver problems.

I became increasingly more lethargic and tired with my skin and eyes becoming yellowish. These symptoms, together with results of regular blood tests for other health problems, indicated liver trouble and my then G.P. referred me to a Gastroenterologist who monitored and treated me on a quarterly basis. After a second liver biopsy and three brief periods of hospitalisation he advised me and the family he could do no more for me. A second opinion from my alternative specialist was more favourable and I was referred to the Liver Transplant Unit for assessment, which was successful.

SP#26

And

I was never unwell before my liver transplant. A blood test taken for another condition I had, showed my liver functions to be abnormal. I was sent to Auckland Hospital to see Dr Gane and he advised me that I needed a liver transplant. I was very shocked because I felt so well.

SP#29

Tiredness was a significant factor for 15 of the survey participants, whereas only four participants reflected feeling unwell. Lifestyle factors were also seen as the reason behind the stated lethargy, tiredness or fatigue. From my own experience, I was not aware of the symptoms of end-stage liver disease even though I had been diagnosed with a liver disease at the age of eight. My own symptoms were easily aligned with lifestyle. My symptoms were breathlessness, ascites (with weight gain), tiredness and jaundice. I did not see the jaundice as this occurred gradually; it was not a sensational overnight change. I was working hard, therefore I expected to feel tired. I was not able

to get to the gym for an appropriate exercise regime owing to working late most nights and parts of weekends. My weight gain I attributed to poor eating habits and lack of exercise. I can understand why other survey participants could also see lifestyle issues and not liver disease symptoms. Two participant experiences follow:

I was working 12 hour shifts in hospitals in Los Angeles. I felt very tired and put it down to having the 'flu. However after returning to New Zealand after three months I was still very tired and went to see my G.P. and had blood tests. I had got Hepatitis C. Huge shock. Kept wondering how I could have got it. Eventually it was found that I had been given infected blood some years before.

SP#16

And

Although I had known that I had had Hep C for over a decade, I blamed all my symptoms on things I thought I could overcome, i.e. depression or laziness. Burnout from work. Getting older (in my late 30s). I was not very realistic.

SP#31

Nine of the survey participants commented on jaundice, whether seen by themselves, noted by family members or understood once the diagnosis of liver problems had been made. Jaundice may be something that family and friends are comfortable commenting on, as in the next quote, or less so, demonstrated by the following quote. In my own experience, no one commented to me on my jaundice until after I was in hospital. Others becoming unwell experienced similar comments.

Initial feeling of tiredness; I put this down to stress of secondary science teaching. Seeing blood test results steadily climbing away from normal range. Having people commenting on my skin colour out of concern for me. Yet not really accepting that I was sick until being sent to Auckland City Hospital for tests etc.

SP#11

It came on fairly quickly about 1-1½ months before I saw the doctor because I had no energy at all and was unable to work much after midday. I must have been turning yellow then though nobody really said anything. Once I saw my doctor, had a blood test, it moved very rapidly and I found myself in Auckland Hospital facing a liver transplant. Within 10 days of seeing my GP and two specialists.

SP#13

Many survey participants noted confusion:

I became extremely sluggish and very confused mentally.

SP#39

Others were losing weight. One had an hereditary disorder, but no idea what hereditary Hemorrhagic Telangiectasia would do, even though one parent had died 10 years earlier from liver disease.

Very little was understood about my mother's illness.

SP#39

Conclusion

I had been unwell for years. I had forgotten what it was like to be well. I went to the GP repeatedly and he told me to go to bed earlier, that it was just stress and being tired. I tried naturopaths, and luckily the third one worked out that there was something wrong with my liver. She said to go back to the GP and ask for a referral to the liver specialist. He saw me, and on the second visit he sent me to the Transplant Unit. I had my transplant about eighteen months or so later. I had felt like a hypochondriac.

SP#48

I was starting to come back to normal after three strokes, then I put heaps of weight on and was itchy. Then the organs in my body started packing up. I went from not needing a liver transplant, to needing one that year.

SP#49

Many interview and survey comments are reflected in SP#48's comment above. Patients keep saying it's the lifestyle they have, or have doctors telling them to have more rest and less stress. Once diagnosed, there is a great deal of denial about their illness, and the seriousness of it. Chapter Six has also highlighted a need for focus on the communication point and the mode and delivery of information by medical practitioners, to New Zealanders becoming unwell.

In Chapter Seven, the focus is on the period post-diagnosis, up to the moments before liver transplant surgery.

Chapter Seven: Experience of Waiting for a Liver Transplant

Every time the phone rang, my heart skipped a beat.

SP#37

Introduction

This chapter covers the experience of waiting to be called for a liver transplant. Using my own experience, I briefly outline the process of being listed for a liver transplant and waiting to be called for surgery, in order to establish a context for the literature and research data which follows. I then look at the comments made by interview participants about their own experiences of waiting for the call. I next comment on my final data set, the responses to Section 4 of my survey. This asked participants to reflect on how they felt once they were listed for a liver transplant and were on the waiting list. I conclude with a summary of what the various data sources have enabled us to learn, along with possible recommendations for implementation by the NZLTU.

“Waiting for a lifesaving liver transplant is a unique yet largely unexamined experience. Little is known about how liver transplant candidates manage their health and what assistance they may need for life and health during the waiting period” (Baker & McWilliam, 2003, p. 47).

The experience of waiting for a liver transplant in general has three stages, although some acute patients may proceed directly to hospital and/or theatre bypassing these. The stages are:

1. waiting to be listed for a liver transplant;
2. listed – waiting to be called;

3. called – waiting for theatre.

As patients with end-stage liver disease or other serious liver conditions that make us eligible for liver transplantation, our first experience of waiting once within the transplantation context is waiting to be listed for a liver transplant.³² Not every person with serious liver disease can be, or is, listed for transplant, for reasons known to the NZLTU which may include health status – both physical and psychological. Donor organs are a scarce resource that have to be allocated according to protocols and in line with the contract for liver transplantation services. One recipient (below) commented on how it felt to be referred for the assessment, noting that she “passed it” like a test or exam.

I went to see my specialist one day, because I was seeing him by then, and suddenly the tests which had been doing this [flat lines] went like that [raises hands high] and he said: “OK, it’s time for you to go and see Ed Gane.” And I thought: “Oh, what does that mean?” And he said: “Well, he will decide whether you can be listed.” Up to then, I thought that you automatically got listed if your liver got bad. And I thought: “I didn’t know about these being tested and going through the work-ups and everything.” So we got an appointment, probably about three weeks later and I went to see him and he said: “Yes, well, definitely, and I’d like to do a work-up, when would you like to do it?” And I said: “Well, I’ll start as soon as possible.” So we did it more or less the next day for a week, as you do. And passed it. And they said: “OK, you’re on the list.” Mmm, 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.

IP#3

From my own experience, when I was acutely ill in March 2000, a liver transplant was being discussed with my family as an urgent response to my serious situation. Over time, as different medical conditions came under control and others became more

³² Some patients may be seriously ill, even in a coma, and be transplanted without the usual process of the assessment week “work-up” and formal listing on the waiting list for a donor liver.

serious, it became a “waiting game” to see whether or not my medical condition could be stabilised to the extent that a liver transplant would be viable. From April to July my family and I waited to see whether I would actually get to the point of being assessed, or would I have to reconcile to being in the “too difficult” basket and being terminally ill.

During this time I also felt like the above recipient, that I was in a test or exam situation, for which I could not study or prepare myself, it was up to my body to get me to the “starting gates” of the assessment week. Knowing that I could not influence the outcome of my body’s condition in a very tangible way, owing to the extent of my illness, I could only choose to “go with the flow,” stay positive and hope to make it to a point where the NZLTU would assess me.

This did occur, and the five days of the assessment were also a period of time of waiting – waiting for the results of the various tests, hoping they would be “passes” and then towards the end of that week having a major “fail” result, in that the ultrasound disclosed the seeming technical impossibility of connecting up a donor liver owing to the state of my liver and surrounding arteries and veins. Waiting seemed to be the pastime that I and my family were most used to between April and July. However, in August, one period of waiting ceased, as I was listed for transplant. I was extremely fortunate that I was called for transplant only two weeks after being listed.

My experience of being listed for transplant, having the pager at home, and being told to prepare a bag, was similar to other recipients. As one interview participant commented:

I was getting sicker and sicker and tireder... and I just wasn't doing a lot of anything. I was mostly sleeping and watching television, and that's not really like me, or hadn't been like me before.

IP#1

My bag was only half prepared, as being listed for transplant still felt surreal, and packing the bag made it seem real and tangible. I know I also packed the wrong things, not being fully aware of how transplant surgery would differ from previous surgeries that I had had. I packed a cross-stitch to do while recuperating, as I had no understanding of the tremors that I would get from the immune-suppression medication Tacrolimus (Prograf), which meant that being able to hold a needle and put it through a small hole in a tapestry cloth was not possible! I also packed fleecy clothing rather than plain cotton, again not thinking of the 72 staples post-transplant that could get caught in the fleecy cloth! Another interview participant compares the waiting time to being at a bus stop, and also notes that not packing the bag for hospital can be part of the denial that this whole “thing” is happening and that you are seriously unwell.

There was kind of a feeling of waiting, like being at a bus stop, just wait, this change was going to come, and I was waiting for it... And I wasn't really planning ahead, in any way, like getting my bag packed. Well I didn't have a bag packed actually, I had to pack it on, I was supposed to have a bag packed to go to the hospital, but I hadn't done it. You know, there were all sorts of, there were just stupid little things, like I wanted to go and buy a new pair of slippers and I just hadn't done it.

I don't know if that was part of the denial, but if I admitted I needed slippers, I was admitting I needed to go to hospital, or if it was because I was just so tired and so worn out that going to The Warehouse or wherever to get a pair of slippers was just beyond my capabilities at that point. I could have asked someone else to do it. I didn't ask anyone for help. I mean, I'd asked my parents to be my caregivers, and I had to call them on the day that I got called in because I was supposed to be packing a bag and leaving and I was just wandering around the house going: “I don't know what to do, I don't know what to do.” Kind of thing.

IP#1

After being listed for transplant, like many other recipients I started thinking about the donor, the donor family, and what situations might arise that would lead to a donor liver

being made available to me through a sacrificial gift from another (unknown) family within Australasia; similar to the response of one of the survey participants shown below:

I had a feeling of guilt that I was waiting for someone to die. It was wrong and almost a surreal experience. I also had a sense of panic that it may not happen and I may get sick and die while waiting.

SP#29

I was told that on average it would take three months³³ to be called for transplant, so when the Transplant Coordinator phoned me on the 14th August 2000, while I was lying on the sofa watching the news and thinking about whether I had enough energy to get up and eat something for dinner, I was not prepared for the transplant to occur so soon. It did not sink in until the phone call was over, what had actually just happened. I had been expected in the next day at a liver clinic, and when I heard the Transplant Coordinator on the phone, I assumed that it was in relation to the next day's clinic appointment. Once I had processed the information that there was a donor, and I had been called for a liver transplant, I had to phone my primary caregiver (my mother) and other family members who then did a "friends and family telephone tree" ring-around. Like me, my mother was unprepared for the wait to be over so quickly, and for the next stage of waiting to commence. This next stage is whether or not the donor liver is viable.

Where the waiting list stage is dominated by the pager and telephone, and being within a certain time/distance of Auckland Hospital, the next stage is hospital-based and is within a compressed time-frame. The Transplant Coordinator is the key communicator

³³ The NZLTU reported that as of May 2011 the average waiting for liver transplantation is now approaching 12 months.

to both patient and family in this waiting period; we await news of whether the donor liver is suitable for transplant. It is a finger-nail biting time; is life or death coming? There are the standard processes and procedures that you go through as a patient pre-surgery, but all the time these are going on, the thoughts are still with the donor and donor liver and its condition. In my situation, being technically complex for a number of reasons, I also had the surgeon remind me that I may wake up post-surgery with my own liver, or not wake up at all, so I, unlike some recipients, was also planning my funeral the evening I was waiting for my transplant surgery. Now that my experience has provided some context, I will look at this period of time in the academic literature.

Literature Review on Waiting for Liver Transplantation

Most published studies based on qualitative data focus on how patients manage life and health some time after transplantation (see, e.g. Wainwright 1995; Forsberg, Backman and Moller 2000; Bean 2005). There is a dearth of studies exploring patients' experiences in the period of waiting before transplantation (Bjørk & Nåden, 2008, p. 289).

This section of the chapter explores some of the limited academic literature relating to waiting for a liver transplant, written by clinicians, and then concludes with the "voice" of the patient awaiting transplant through a selection of excerpts from memoirs and autobiographies.

The authors of the four articles that I now look at did their research during the time the patients were waiting to be transplanted. "Few studies explore patients' experiences of waiting in the actual waiting period" (Bjørk & Nåden, 2008, p. 289). This addresses the

concern some researchers have about recall bias when researchers ask participants to reflect on past experiences. In 2008 Bjørk and Nåden wrote:

A thorough search in Medline and Cumulative Index to Nursing and Allied Health Literature resulted in only six studies that focused on the waiting period. Of these studies, three explored the waiting period in retrospect that is after the patient had been transplanted (Johnson and Hathaway 1996; Wainwright 1997; Robertson 1999) (p. 290).

Table 11 (below) shows the details of the articles, including the spread of countries and methodologies used.

Table 11: Representative Articles on Patients Waiting for Liver Transplants

Authors	Year	Title	Methodology	Country	N	Gender
Baker, M. S., & McWilliam, C. L.	2003	How patients manage life and health while waiting for a liver transplant	Grounded theory	Canada	12	Women=5 Men=7
Bjørk, I. T., & Nåden, D.	2008	Patients' experiences of waiting for a liver transplantation	Exploratory design	Norway	21	Women=4 Men=17
Brown, J., Sorrell, J. H., McClaren, J., & Creswell, J. W.	2006	Waiting for a liver transplant	Phenomenology	United States	6	Women=2 Men=4
Jonsén, E., Athlin, E., & Suhr, O., B.	2000	Waiting for a liver transplant: The experience of patients with familial amyloidotic polyneuropathy	Phenomenology	Sweden	14	Women=10 Men=4

The next table (Table 12, below) briefly outlines the major themes the researchers found and discussed in each of their articles.

Table 12: Major Themes from These Articles on Waiting for a Liver Transplant

Authors	Major themes
Baker, M. S., & McWilliam, C. L.	Three core categories (2003, p. 52): <ul style="list-style-type: none"> ● experiencing confinement <ul style="list-style-type: none"> ○ limits imposed by society <ul style="list-style-type: none"> ▪ surveillance and expectations of adherence ▪ stigma ▪ caregiver burden ○ limitations imposed by self <ul style="list-style-type: none"> ▪ feelings of being a burden ▪ diminishing functional status ▪ other discomforts ● disciplining the self <ul style="list-style-type: none"> ○ engaging the social system <ul style="list-style-type: none"> ▪ following instructions ▪ presenting the self positively ○ engaging the self <ul style="list-style-type: none"> ▪ seeking information and support ▪ controlling symptoms ▪ distracting and denying ○ reframing one's world view <ul style="list-style-type: none"> ▪ changing attitudes ▪ setting and achieving new goals ● surrendering the self <ul style="list-style-type: none"> ○ isolating the self ○ entrusting the self to another
Bjørk, I. T., & Nåden, D.	Four major themes (2008, pp. 292-293): <ul style="list-style-type: none"> ● uncertainty related to life and death ● mental wear and tear due to reduced energy ● existential brooding about the meaning of life ● feelings of being mentally strong
Brown, J., Sorrell, J. H., McClaren, J., & Creswell, J. W.	Eight themes (2006, p. 126): <ul style="list-style-type: none"> ● transformation ● doctors, teams and trust ● elation to despair ● loss ● questioning the process ● searching

Authors	Major themes
	<ul style="list-style-type: none"> • coping • paradox of time
Jonsén, E., Athlin, E., & Suhr, O., B.	<p>Two theme categories (2000, p. 65):</p> <ul style="list-style-type: none"> • waiting for a decision • waiting for the operation <p>Seven themes:</p> <ul style="list-style-type: none"> • bargaining with oneself • no influence/powerlessness • relief and joy • impatience • agony • time to prepare • need for information and support

Unlike my research, each of these participants was recruited once they had been listed for transplant, but before they had received their liver transplant. In fact, some participants died pre-transplant.

Being placed on the waiting list is not a guarantee for a new life. As it turned out, 6 of the 21 patients either died while waiting or during surgery, or they were “opened and closed” in surgery due to inoperable cancer (Bjørk & Nåden, 2008, p. 296).

My research allows liver transplant recipients to reflect back on their experiences, therefore there may be recall bias, but the power and impact of the experience on them and in their lives is clearly evident in quotes such as the survey participant below:

It was all very frightening at first, overwhelming. The wonderful support given to us from the liver transplant team was great. We knew I was going to get a second chance at life. A very special gift. The waiting was the hard part. I waited 10 months with deteriorating health.

SP#39

As Bjørk and Nåden remind us, patients who are listed for a liver transplant are not a homogenous group and have come to that point through a variety of illness trajectories

(p. 297). For this reason, themes that are important for one patient, may be less important for another, owing to their personal background. In Bjørk and Nåden's research, patient reactions to being listed for a liver transplant varied with a number of patients who had a lengthy history of liver failure expressing relief and joy, while other patients who had only recently become ill or symptomatic commenting along the lines of "I don't have any choice in the matter, do I" (pp. 294-5).

It is beyond the scope of this research to compare and contrast international health systems with New Zealand's public health system, however the four articles noted here do reflect different medical systems, with the United States being one where waiting to be listed for transplant may also involve major financial implications. On the other hand Norway has a public health system that ensures all required treatments are free. The systems within each country impact on whether a patient can be listed for transplant, and on waiting times, and therefore on the experience of each liver transplant patient. Some patients may think of waiting in terms of years, and others months, depending on where they are situated. Patients' perceptions of time may change; one of the participants in the research undertaken by Brown, Sorrell, McClaren and Creswell felt that he had been on the waiting list for four years, whereas his wife reminded him it was actually only two years (2006, p. 130).

Looking now at the "voice" of liver transplant patients through memoirs and autobiographies we see firstly in the United States of America the role the insurance companies play before people can even get on to the waiting list. There are two quotes below that illustrate this.

"I marveled at the machinery, the high-tech equipment that dissected my body without leaving so much as a scratch, and thanked my lucky stars I had the insurance to pay for it" (Hagman & Gold, 2001, p. 239).

Patients need to understand whether there are differences between what their doctor thinks would be best for them and what their insurance company is willing to cover (Yomtoob, Yomtoob, & Wepler, 2005, p. 62).

The next quotes reflect the feelings of two American liver transplant patients once they had been listed for transplant.

On July 19, my name went on a nationwide list along with five thousand other people awaiting a new, healthy liver. The news got out and spread quickly. I got calls from friends. Baseball great Mickey Mantle had just undergone a liver transplant amid criticism that his notoriety had helped him, a lifelong alcoholic, receive a liver quicker than others. I looked up the statistics. The average wait was between thirty days and a year. Decisions on who got a liver were based on medical condition, blood type, size, and proximity to the donor organ. I had no idea why Mantle got his. Nor did I know when *or if* I'd get mine (Hagman & Gold, 2001, p. 242).

I knew that my name had been put on a list. But what Starzl knew that I didn't know was that there was a separate list for heart-liver transplant combinations; and because a heart and liver dual transplant was so rare, I was the only one on that list.

Looking back now, even this deeper plunge into danger seemed a saving grace. My needing a new heart to handle the new liver actually saved my life. If I had been forced to wait the month or more for my name to come to the top of the single transplant list, I probably would have died (Casey, 1996, p. 67).

Patients may also feel dubious about accepting a transplant, and do their own "risk-benefit" analysis. A patient in the United Kingdom demonstrates this below:

I had no other alternative, but to choose between, a new liver with the risk of rejection and infection, and taking the risk of having a slim chance of surviving for another year. It was difficult to decide (Ahmed, 1999, p. 44).

After many considerations I reached a conclusion: there was no other alternative but to have a liver transplantation even though it was risky (Ahmed, 1999, p. 49).

The period of time on the waiting list can be very hard for patients, and the quotes (below) from patients in the United Kingdom and the United States illustrate this.

The waiting period was the most frustrating and stressful time. I was not sure for how long I would be waiting for the transplantation. I was told that the average waiting time was between six to eight weeks. But nothing was certain. In my case, it took the hospital more than eight months to find a suitable donor (Ahmed, 1999, p. 56).

Not knowing what the next hour would bring, made me worry all the time. It was dreadful not even being able to organize my daily life. I was living minute by minute, taking whatever came (Ahmed, 1999, p. 58).

Despite everything, the waiting period made me forget the risks that were involved with the liver transplantation. All I wanted at that stage was to be called into hospital either for the transplantation, or for any form of medical treatment. Staying at home doing nothing but watching my health deteriorating rapidly and waiting for the worst to happen, was awful (Ahmed, 1999, p. 59).

But in spite of my carefully applied makeup, my eyes and the new lines on my face betrayed the pain and agony I was feeling inside. Joe was right – this was not the face of a happy mother-of-the-bride. It was the face of a mother who was spending day and night waiting for the phone to ring, waiting for the news that the waiting was over, waiting for the news that they had found a liver for David (Yomtoob, Yomtoob, & Wepler, 2005, p. 84).

Talking with people who have had successful liver transplants already may help some people on the waiting list. This gives them a person they can ask questions of, that they may not want to ask their medical teams, and may also provide inspiration that they, too, can get through this to the “other side” of a hopefully relatively normal life again.

“The wait is hard,” Dallas Taylor³⁴ told me. “It’s like being a condemned man on death row waiting to hear if the governor will grant a reprieve.”

In 1990, Dallas had been in the same position I was in. He wore a beeper and hoped a matching donor liver could be found before it was too late. Makowa had performed his transplant surgery too. Dallas told me what to expect from the operation and was a great inspiration (Hagman & Gold, 2001, pp. 245-246).

Once “the call” comes, people may react in a number of different ways. Below are two examples from two families in the United States of what it was like when the call came.

At 1:30 in the afternoon on Thursday, May 7, 1987, fourteen days after my name went into the United Network for Organ Sharing computers, my beeper went off. I switched off the television set and turned to Ginny, who was frozen in the doorway to the kitchenette in our motel. My face flushed hot, and my stomach started to ache; my heart pounded until my eardrums hurt.

“I knew this was the day,” Ginny said.

I gave her a blank look as I picked up the phone to call the transplant coordinator, Dorothy Kaese” (Maier & Maier, 1991, p. 191).

When we were all dressed and ready to go, the telephone rang. It was Saturday morning and we thought it might be Ben, Rebecca, or Sara’s sister Christy. David picked up the phone. Joe, Sara, and I all watched David, secretly wondering if this could be the call we’d been waiting for the last 17 months. David smiled, and for the first time in the last 17 months, I saw the light of joy in his eyes. He gave us the thumbs-up, hung up the phone and told us that, instead of Miami Beach, we would be going to the hospital (Yomtoob, Yomtoob, & Wepler, 2005, p. 259).

³⁴ Dallas Taylor, the original drummer for Crosby, Stills and Nash, received a liver transplant from the same surgeon who operated on Larry Hagman. Post-transplant, Dallas ran a men’s group for recovering alcoholics and drug addicts. Larry Hagman’s transplant coordinator asked Larry to meet with Dallas (Hagman & Gold, 2001, p. 242).

Once you receive the call, you may think particularly about whom your donor is, and their family, who has just made this call possible. You also may recognise that in times like this, gender and race may seem irrelevant. If it is a healthy liver, that can save your life, you are thankful for the donor family's decision irrespective of "superficial" attributes.

I'd been on the United Network for Organ Sharing (UNOS) list thirty-three days. Now I had less than thirty-three minutes to get to the hospital.

Right then I paused, the first of countless such pauses I've made since, to think about the person whose liver would soon be mine. You aren't permitted to know anything about that person. Nothing. Not whether they're male or female, black or white, rich or poor, happy or unhappy, and I think that's good. It's proof that we're all the same, all here to help one another if we can. I thanked that person profusely for signing their donor card (Hagman & Gold, 2001, p. 248).

When I was dying, I didn't ask the color of the donor's skin, and when she was signing the document to donate Michael's organs, Mrs. Lucas didn't ask the color of the recipient. We were all just people in trouble and pain, left with nothing but our own humanity (Casey, 1996, p. 133).

Although we all have unique experiences, the memoirs and biographies demonstrate a level of commonality around the experience of being a liver transplant patient that still resonates with a New Zealand reader, even within a different policy environment.

Interview Responses on Waiting for Liver Transplantation

Looking forward to a successful liver transplant outcome as the only way to keep me going kicked in when I was sharing a room with a gentleman who had also gone through a transplant. I think he might have overheard me and one of my family talking about the transplant, and he just yelled out and said: "The only way you're going to live, mate, is the transplant. Take it!"

IP#16

Firstly, the information in the interviews relating to actual waiting times, and impressions of waiting times, is shown in Table 13 (below).

Table 13: Interview Participant Responses on Waiting Times for the Transplant

Interview Participant	Waiting Time	Impression of a long waiting time	Impression of a short waiting time	No impression re waiting time
IP#1	6 months	no	yes	-
IP#2	7 months	no	yes	-
IP#3	3 weeks	no	yes	-
IP#4	7 weeks	yes	no	-
IP#5	6 months	yes	no	-
IP#6	A few days	no	yes	-
IP#7	3 calls – 3 rd call, 3 months from re-listing	yes	yes	-
IP#8	Couple of months	no	yes	-
IP#9	3 months	no	yes	-
IP#10	Less than 48 hours	no	no	yes
IP#11	A few weeks	no	yes	-
IP#12	9 months	no	no	yes
IP#13	3 ½ weeks	no	yes	-
IP#14	9 months	no	yes	-
IP#15	1 st call – 1 month 2 nd call – 6 months	yes	yes	
IP#16	8 weeks (in hospital)	no	no	yes
IP#17	4-5 months	no	no	yes
		No=13 Yes=4	No=6 Yes=11	Yes=4

From 17 interviews there are 56 pages of interview quotes relating to the interview participants' reflections of waiting to be listed for a liver transplant and waiting for the call for the transplant surgery. Using NVivo 8 and Microsoft Excel, these 56 pages have

been reduced to four pages of themes and sub-themes, with those most commented on by interview participants being those which will be discussed in this chapter.

This demonstrates the individuality of response in relation to time, where one participant (IP#1) can see six months as a short waiting time, and another views seven weeks (IP#4) as a long waiting time. The impression of waiting and time is subjective to the individual participant.

I look now at the key themes which emerged from the interviews within the three categories of:

- waiting to be listed for a liver transplant;
- listed – waiting to be called;
- called – waiting for theatre.

The first category of “waiting to be listed for a liver transplant” had two key themes emerge: these were (1) thinking about death and dying; and (2) relief at being listed for a liver transplant.

Thinking about death and dying:

After a while I thought of death, I mean, how long? And I said: “When do I, when am I going to get one?” And he said: “That’s the other point as well, because you need a donor. You need a whole new liver.”

I was terrified of death, because you know what it was? The pain. Having a painful death. So yeah, death was very scary for me. It was only because of the pain. If I didn’t have the pain I think I would have accepted death. That is because if I could have just gone to sleep and not woken up I would have been fine.

IP#4

It was the painful death that I was scared of actually, it was a painful death. Because I'd also heard other stories, and there were a family of mine, who died from other things like cancer, and they had sort of suffered during that time, and it was really probably not death itself, but the experiences you have when you're going through death that were probably the issue at the time.

IP#16

Relief at being listed for transplant

I didn't have to wait long, I was lucky. They diagnosed me in the November of 2001, and I got my liver in May 2002.

IP#2

So as I was getting worse, Ed knew, he said to me: "We're going to put you on the list." He said: "In your case, you're going to be a different case for us, because normally the assessment takes place over a period of three months, it can take up to three months. You're going to have yours done within a very short period of time." There was a bit of relief once I was listed for transplant, because I knew there was a kind of a light – I knew what was coming up, because Ed and Steve and John McCall, were all very very thorough with me.

IP#4

I know I went on to the transplant list not long before Christmas because it was ever so clear in our minds, and this may be mis-thinking of Christmas time road accidents – more chance of getting a transplant. So, now I know that's not so true, but I'm pretty confident it was probably like four months between diagnosis and going on the transplant list. It wasn't long, really, when you look back. So then I had that four months of not knowing whether there was a possible future or not.

IP#7

I was listed for transplant in 1999, about 12 years after I was first told about it. I was under Dr. Gane, though, from about 1995 onwards. He used to come down here and monitor all the patients every six months, and I would go and be a patient of his. He said that: "It's going to happen sometime, but we're going to have to just not let it get too bad. We've got to make a fine line sort of between how well you are and how bad you are." He told us when the Auckland unit opened. We felt much better about going to Auckland than Sydney or Brisbane. Very much so! Very much so! Well, we never actually had much time to

think about going to Auckland, to tell you the truth! It wasn't long after I was listed that I was called up as a back-up.

IP#8

I remember Dr [name] and Dr Gane both saying: "You were very sick." So I presume I must have been, for them to say that. And I was pretty scrawny. When I came out of that, I went back up to Auckland and they assessed me again. Then they put me on the list. That was in February I think. I stopped work then. I just couldn't go back to work. I was lucky I didn't get crook again. I asked Prof. Munn when I had my transplant, how long would I have lasted? And he said: "Oh, the next time you were crook, you would probably have died." I wouldn't have come back.

IP#12

And so my wife and I went up to Auckland, went in there and I went through all these different checks... and on the day I was due to come home they took me into the liver transplant office and Professor Munn, Dr Edward Gane, and John McCall, they got me in there, and they looked at me, and I looked at them, and I said: "*Don't* beat about the bush! Spit it out now!" And they looked at me, and out it came. Because when I said that the whole three of them looked at one another. So they told me what actually happens and all that, and they wanted to look at transplanting, because they hadn't had a look at all the checks and all that. So they left us for about half an hour, my wife and I, sitting in the room there, and then they come back, and they sat down, and they said: "Yes [name] we can do a transplant for you, *but* – this is what you've got to do." And I said: "Oh yeah, yeah". They said: "Number one." And I said: "Yes." "No more alcohol!" From when they said that to now I'm sitting here, I've never touched it, and that's going on to just about seven years now. I've never touched it.

IP#13

I know I was thankful to be listed for transplant, I know I was, because it had to do with the religious background I come with. I know I was very thankful, but I think I understood that for me to have that transplant would mean for somebody else's life to be taken. And the other thing too, being [ethnicity], with some of the cultural background, the baggage you come with actually. Which I now, I really believe it's not an appropriate, you know, what you're taught to believe – I'm talking culturally now. It's not always the right thing, it was a bit of an effect there, but once I *knew* that if I *didn't* have it that I *would* die, I think that's what helped me make the decision, for my husband and I to say: "Yes, we'll take it, thank you." I can't remember ever involving my family in the decision-making, I don't think we did. It was just a

choice that came, well – if you don't, you're not going to live. If you do, you've been given a second chance. In that moment, when I knew that, I wanted to see my grandchildren.

IP#14

I got assessed in the October and they told me that I was on the waiting list, and they gave me a pager. They said the normal wait is about three months, but you could be called up at any time, so wear the pager at all times and we'll contact you. Things like that. So we went home and a month later I got a phone call, and we panicked, because it wasn't three months. Three months hadn't gone past, you know? The normal waiting time's three months, so it can't be right!

IP#15

I was listed on a Friday. Ed Gane came in and said: "We'll share the notes with London or Australia. We have to teleconference; we've decided we're willing to put you on the list." And I knew I was number one on the list. That was the Friday, and on Sunday evening my church minister came in and said prayers and I realised my family had said end days. Monday afternoon Ed Gane came in and said: "Might need to ring your family, we've found a liver, we're going to transplant." That was on the Monday so I was that quick. Actually John McCall said to me that they'd found a liver earlier but it was a little bit fatty so they couldn't do the transplant. So I was just amazed at how quickly things went.

IP#16

I went up to Auckland for the assessment week and they did all the usual things. Alright, if it had to be, it had to be. I realised that if I didn't have one, I'd die. But that sort of thing, you don't dwell on it, put it that way. I mean I was still walking, still running. And I passed the assessment, and then it was just a matter of waiting.

IP#17

The second category of "listed and waiting to be called for a liver transplant" has a number of themes within it, some of more importance across interview participants than others. Two initial dominant themes are (1) family support (including spousal support), and (2) being informed and prepared, including hearing from other recipients.

Family support (including spousal support)

So they gave me the pager and I came home, and sort of said to [spouse]: “Well, we just have to be prepared and have this on at all times, but don’t worry.” Then about nearly three weeks after they’d 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 he said: “Well you think, sleep on it, don’t be rash. You know, just sleep on it.” That was the Friday night, OK, Saturday we were just getting ready to go take our grandson out and the phone rings and it was the Transplant Coordinator. I’d been thinking about [the Transplant Coordinator] for some reason, I had a question I wanted to ask her, and I said: “Gosh, that was telepathic, I hadn’t even got around to ringing you with my question.” And she said: “Well, look, never mind about that, can you come in?” And I said: “Well, what for?” And then big gap – and I said: “Oh, there’s a liver!” And she said: “Well, there is a potential liver.” And that was three weeks. And [spouse], who could hear the phone conversation, suddenly he stood up, and the chair fell over, and he strode in looking absolutely like death. He said: “Oh, we can’t do it, we can’t do it.” And I said: “Now you sit down, I’ll get you some lunch, and then I’ll drive you to the hospital...”, I was sort of really taking over. And so we did, and we got there at 3 o’clock, and the operation was at 1 a.m., Sunday morning. And when they took the liver out, they said: “Gosh, that was just such a stroke of luck, because you wouldn’t have survived, it was much, much worse than we thought. You probably wouldn’t have lived another month.” That’s sort of the emotional reactions, I suppose. After that feeling on Friday night I hadn’t got round to thinking about it again, it just seemed very strong on the Friday night. I hadn’t sat down to think about it again, because we were quite busy. I didn’t have any hesitation, like when she rang. I didn’t have any hesitation, so I guess I must have processed it in the night.

IP#3

So I had lots of lots family around me, and they were just wonderful. You reach out and all you want to do is for them to take the pain away. But what kept me *there* was my kids and my husband, that’s what. Even though I felt death so close; I saw the light one night I tell you, and I haven’t felt like that since after my surgery....It was the thought of my children, I saw the light and I chose between my children and light [starts crying]. That’s what brought me home.

IP#4

That was all OK staying in Auckland for about a month in a motel in Parnell before the transplant. I get tearful; they told me I’d get tearful,

when I think of family, and what I was putting them through at that stage. And yet, I mean they were just supportive right through and we just journeyed this together. Most of the time my wife was with me. She would try and come home on weekends, and [son] would stay up there with me. At that stage, I mean pre-operation I was still able to move around, it was just simply, it was getting more and more difficult to go distances.

IP#5

I also had good family support on both sides, so I knew that we'd get through for anything from three to six months. So all being well, that would be fine. In terms of home support for me, I knew that also would be fine, because I had family so I was lucky that my mum would be here as well as [spouse]. And we planned that [spouse] would keep working, and mum would come here, so that [spouse] could keep working, so there was still money coming in.

IP#7

I wasn't very good this particular weekend, and I was trying to change the bed. I had the sheet all mixed up, all round the wrong way. And [spouse] came in. And he said to me: "What are you doing?" And I said: "I'm fixing this up." And he said: "You've got the sheet round the wrong way." And I said: "No I haven't. It's all right." And so I couldn't get it right. And I don't know. I wasn't very good at all. But [spouse] went outside to the garage with the phone to ring our son. He rang our son, who came around, and they tried to get me in to see a doctor. He couldn't get hold of the specialist, or our own doctor because he was not on duty that weekend. So then I was taken to the weekend doctor that was on duty. So we went. And I was supposed to go straight to [town] hospital. When I got there, they growled at me because I'd taken so long. Because I'd come home here and got my son lunch. My husband went up on the plane with me and he was there the whole time with me. The whole three months. He went into Grafton Lodge – was a wee motel there. And he stayed in there until I come out and then we both went into Transplant House.

IP#11

I got the phone call on the Friday afternoon. Just out of the blue. Out of the blue, [transplant coordinator] rang up and she said: "We think we've got you one." Oh, cripes. So I rang up [spouse]. Rang up a few others, you know, mother, sister, parents-in-law. [Coordinator] said: "We'll book your tickets. You come up tonight." Obviously they've only got a certain time. And I said: "Yep. That's fine." And we're very lucky because [spouse's] parent's live in [suburb]. And what they did is, basically they just left their house while we were away, and they just

came and lived in our house, so the kids didn't have to shift. It was absolutely fantastic having them. Because [spouse] came up. Luckily, she got off work and came up with me on the Friday night.

IP#12

I think I was home three and a half weeks and I got the call. They said to me, oh, [transplant coordinator], she said: "Oh you don't know me [name], I was away when you come up for your assessment, we've got a liver for you here, do you want it?" I said: "Give me five minutes and I'm on the road from [town]." In a quarter of an hour the whole family was in the van. Before I hung up she said: "What time do you reckon you'll be here?" I said "Between half past 12 and one o'clock in the morning." And they told my family to go outside, get some sleep. They said: "You can stay out in the visitors' room." They were in at quarter to six, woke me up, better go have a shower, come back, and they said: "Righto, you're ready to go." And I said: "Can I have a moment with my family?" They said: "Yes certainly, no problem." So the family came in, and these fellows that do the pushing, they went out, and my son, my wife, her sister and her two grown up kids, they were there, and I said to my family: "If anything goes wrong, you are *not* to blame the hospital". I said: "you hear that?" "Oh, but what if...?" "You are *not* to blame the hospital!" Because I said: "They're only doing their best for me, all right?" "Yeah, yeah, righto then." "Right, that's settled."

IP#13

We were in [town] when we got the call. I even remember I had just finished grilling sausages and chips in the oven! With my daughter close by. I think they rang [spouse] at work, which was just around the corner, and he came home, so that was it! We just packed *everything* up, everything! The dish, everything in the car, because the suitcases were already packed, and the call was all we were waiting for. We just put everything in the car, well [spouse] and [daughter] did, along with the sausages and chips and the dish! And I'm sitting in the back, with [spouse] and [daughter] in the front, and I just kept thanking God. I just kept thanking God, that's all I kept doing, was just thanking Him.

IP#14

I also got to the stage where the hospital would arrange for my family to be there, and they'd bring a social worker and a translator, as my family could not speak English well, and they would explain the process to them. By that stage I was sitting there, but I wasn't really hearing anything. I had just completely lost it, almost, so they did everything they could to let people know. Of course it's probably important to let my family, that were there, know, because for them, or for us actually, the whole idea of a transplant was something

completely foreign. Like my Grandfather's brother had come in and said: "I don't want you to have a transplant." He didn't say why, but I figured that he's very traditional, and because of our conversations, his thinking would have been around the traditional cultural idea that you shouldn't tamper with the dead.

IP#16

Sometimes my wife would ring me at midnight. Oh that was funny. I got up about 1 o'clock and wandered down the passage to go the loo and as I was coming out, one of the cheery nurses is coming down the corridor, grinning away and giggling. I said: "What are you laughing at?" She said: "I've got your wife on the phone. Do you want to talk to her?" I said: "Well, I suppose I better." So, I'm standing at the desk there, talking to my wife at 1 o'clock in the morning. I can't sleep, so you can't. I got my emotional support from my wife.

IP#17

Liver transplant patients appear to be eager to understand what is happening to them, what a liver transplant means, and would mean for them, and value not only the information from the medical teams in their home towns and cities, but also from the NZLTU. They also find reassurance in talking with New Zealanders who have already had a liver transplant, in order to gauge what their own outcomes may be like, and to be encouraged by others' success that they are on the right pathway. Connecting with other transplant recipients may be done formally through the NZLTU brokering this, or through attendance at a support group (intermittently run by the NZLTU) or through personal networking.

Being informed and prepared, including hearing from other recipients:

I'd met one person early on, I think it was on an occasion in Waikato, when a woman who was transplanted, I met her. She'd just been in for a check-up. She'd actually been transplanted a year before that, I can't remember if it was Australia or Britain. And here she was proposing to get married. And she looked fine. And I think that was the first example of a person who had had a transplant, it had all gone well for her, here she was getting married. I think that that was a useful experience, just

seeing her and seeing that, hey, life doesn't stop when you have a transplant. Here she's going to get married. She's a woman, would have been at that stage, my guess would be in her 40s or 50s, 50s possibly. And so she was going to enjoy life as far as she was concerned. And because everything had gone so – as far as I was concerned I was doing OK, I was under care, I wasn't worried.

IP#5

The support group, for me, was my life saver. Because through that I spoke to those who had already had transplant, others who were waiting. I was able to learn through the various speakers they had at the support meetings, how the actual process worked. How your life was going to be after transplant, I spoke to actual real people who'd had a transplant to see physically how, and mentally how they were coping with life after transplant. It gave me every bit of support I needed, and I made some really good life-long, long-term friends out of it, so, yeah, it's fabulous.

Of course dying entered my head. And my coping technique – putting it aside, I guess. You know, it's not going to happen. It can't happen to me, I've got [son] and [spouse] and Mum, it can't happen, there's got to be a way through this. And I guess all of that talking to other people, again, who've been through transplant. You know that the *strength* in that support group and other, and networking with others who've been through it, is *huge*... I talked to everybody I could. And that's huge. Having that network of people around to talk to, including yourself. It's just, that's more important, you get more out of *that*, than you do out of the medical team, I think, as talking about the real cases, the real day-to-day, somebody living with the same condition, and I guess I just blocked out that final straw of: "Yes, I could die, but I'm not going to. Let's get on and see what I can do to get through this!"

In the 1980s my blood results went off. I was under a specialist here for quite a number of years, and they told me then that the long-term outcome would be a liver transplant. It was about the mid-1990s that things got really bad. I never ignored it, but I just thought: "Well, you know, what will be, will be!"

IP#7

I first found out that I would need a transplant when I had an appointment with Dr [Name], and he was not available, and the doctor helping him said to me, and my husband: "Who's looking after your liver?" And we just shrugged our shoulders and said: "No-one, really." Because no-one was. I mean I was going to Dr [name] every six

months, who monitored my blood test results, but every time I saw him he said: “Oh, you’re alright.” And, more or less, that was it. Just let me go. So when she asked me who was looking after my liver, we said: “Well, no one really.” And she told us to wait there while she got another doctor, who then told me that I might have to have a transplant, and that was at the beginning of November 1999. They put me in hospital for a couple of days and gave me injections into my stomach that took over half an hour to go in. And they told me then I’d have to go for a liver transplant. And I said: “No, I’m too old.” And they said: “Oh no, you’re not.”

IP#11

I was seeing a gastroenterologist because of the Ulcerative Colitis. The guy who I was seeing retired and then Dr [name] took over. And I’ve been seeing him since. Later on in the decade, as I was watching my Colitis, they kept doing Colonoscopies to check for cancer. Although I didn’t have cancer it got to the stage that they’d seen too many things, I suppose. And they said: “Well, we’re going to have to take it out.” They did it straight away, so I had my colon out. Then for the next few years I got inflamed bile ducts and I’d get sick and go into hospital a few times, you know, I got really sick. And I think it was about 2003 that I went up to Auckland to get assessed for a liver transplant. And up in Auckland Dr. Gane said: “Oh, not this time. But we’ll probably see you in two years.” And he was dead right. About two years later I got really crook. When you get liver disease your brain can get too much ammonia or something. And I had a really bad one; one weekend I started acting a bit odd. I was ‘out there’. I remember [spouse] saying I got up at 4 a.m. and I was sitting out there eating cornflakes. She remembers I was also trying to set the video and I tried about twenty times. At that stage I couldn’t concentrate, I’d get a book and I’d open it up, and I could read a page or half a page but nothing would go in. Then I’d try to watch TV because I liked certain programmes on TV but I couldn’t get any enjoyment from them. And then on this particular weekend I had a really bad turn. On the Sunday night [spouse] had to ring for an ambulance.

IP#12

I had to wait three and a half weeks before I was called. It was not stressful. I just accepted it. The other thing too, I was very lucky down there, I met a guy who probably had a liver transplant pretty well the same time as you [to interviewer] but he had his in Brisbane, and he come back to [town], and I found out through somebody else that it was him, so I rang him up, and I spoke with him, and he said to me: “Come around, we’ll have a cup of tea, cup of coffee, and we’ll talk about it.” And the more he talked to me, the easier it got. And in the end it was

easy. The liver unit had not connected me with other transplant patients,³⁵ but that's OK, I'm one of these guys who will dig around, if you know what I mean? I go and find out things, and I'm also one of these guys I don't care whose toes I stand on. I went and found this guy, he helped me out, and when I came back from Auckland he came around and saw me, and he said: "You'll get the call to go and we won't be able to see one another, so I wish you all the best." And sure enough, come half past ten, I was away. But no, I'm very grateful to those people, up there.

IP#1

When I got to Auckland Hospital, actually it was amazing. Ron came in every morning and sat down and talked, and I began to share some of the emotions with Ron, and got pretty, really good counselling, that came through all the time. And of course you've got doctors coming in early in the morning. [Doctor] would come in and see me every morning well before the 'rounds' came. So you've got a whole lot of support once you were in the ward. Many of the nurses were also, they also offered a lot of help. Obviously of course they couldn't say very much at times, but some of them were *brilliant*, the ones that I knew who talked to me and shared some experiences. I asked them what liver transplants were, and how they saw patients, and they gave me some really good stories, and so that was really really good.

There was also another gentleman in that room, who sadly passed away a couple of years after my transplant, and he came over to see me several times, he'd come in the morning and talk. When you're seeing and talking to people who've gone through the process, you actually sort of build up a lot of hope, they give you their experiences and I sort of sat back and realised: "Oh, actually this might not be too bad after all, maybe there isn't anything to fear, to be afraid of." But they'd also brought in a woman that was about my age, who'd had the transplant, because by then they'd picked up that I was a little afraid of the transplant, and this woman they brought in, when she'd had her transplant she was in a coma, so she had been in a really really bad situation. And she came in and she told me her story, and that *really* encouraged me even further. So that was good!

³⁵ Personal communication with the NZLTU May 2011. Efforts to match recipients to others is now routine and much easier given that currently there are more than 400 recipients.

I remember being wheeled, and saying goodbye to people, and going through into the theatre and waving out to John McCall, who'd come earlier to say: "Hi, we're going to have the transplant, and I'll do the operation, and this is what we'll be doing." He basically briefed me. Pretty good briefing and I was happy with that. I was also happy because I'd known John McCall since I'd been in hospital, and Steve Munn, and so I knew exactly who they were, what they were doing, in that sense of *trust*, you know, you're trusting them.

IP#16

When interview participants discussed this period of time in their transplant experience, there was a lot of commentary about their illness symptoms, such as ascites, encephalopathy, day/night reversal, inability to sleep, sleeping all the time, tiredness, jaundice, loss of appetite, vomiting and diarrhoea, and so on. It was demonstrable across interviews the significant change in quality of life, and how interview participants were waiting for their call for transplant to effect a positive change in their lives.

Many interview participants focused on the need to stay positive, with one commenting:

I was always positive about it. I just thought: "Yeah, I'm going in and getting a transplant and I'll come out again."

IP#15

Some continued to deny their illness right up to going into theatre, as a coping strategy, while those of non-European ethnicity also discussed cultural issues relating to transplantation. Some noted that they had no financial stress, while others commented on being "down and out". A few noted the use of humour within the waiting period and going into theatre, while others commented on being terrified of the ventilator and not wanting to wake up with the tube in their throat and not being able to communicate. It was common for them to talk about the trust they had in the NZLTU team. Thoughts of the donor and donor family are part of this experience for some interview participants,

but not all of them dwell on the actual donor and family, for some it's about the process of obtaining donor organs as well, such as holidays being times of high road accidents.

An example (below) illustrates a very specific instance of a non-European liver patient experiencing a scary event in relation to fellow patient and a "possible donor."

Thinking about my potential donor really began because the gentleman that had become a friend of mine while I was in hospital was going through a stage where he wouldn't sleep. He'd claim that there were voices within him telling him to come in and look after me, so I would be asleep at four o'clock in the morning, and I would wake up and he's sitting at the end of my bed watching me sleep! I mean! It was really really scary! I'd wake up and he'd say: "Oh, it's okay, it's okay. I've been told to come here and look after you, make sure you don't fall asleep." Well, I'd fallen asleep. For three straight nights I think he'd made claims that there were spirits telling him that he can't sleep, that his role was to look after me. He even had the psychiatrist come to visit him, he had the Maori Kaumatua coming in to do things, and they'd even given him a few drugs, if I remember rightly, to try and get him to go back to sleep, but he basically didn't sleep. This was after he'd had his transplant and been released home for the first time, and had been re-admitted. They were looking for a second transplant for him.

Three or four days later he came in and said to me: "Oh, I sent that guy on his way." And I thought: "Oh, that's good." And he said: "But before I sent him on his way, he said to me, after your transplant you're going to be in *that* room." And he pointed to a room. Oddly enough, that was the room I was in after the transplant! It could have been coincidence, but it was really that experience that made me think about the donor now, who's the donor going to be? Are there any spiritual issues here? Those kind of things. But then they also explained about compatibility issues that were there, so they talked about those things.

Because I'd grown up in a culture where stories are told about evil spirits, and people coming back after death, ghosts all over the place apparently in [place], I was told these stories over and over. I was also really, really scared that these things might happen because those are the kind of stories I grew up with as a child. They were always, *always* talking about people coming back after death, and so because I'd grown up thinking those things, I was really afraid of the transplant, thinking

that the person whose liver I've received would come back and try to reclaim it.

IP#16

This interview participant also struggled with not knowing the age of the donor liver, for cultural reasons.

When Ed Gane came in, he'd said to me: "We can't tell you anything about where the liver comes from, age, or gender of the person." And pretty much left it at that – absolutely no hint at all. And that's the *worry* that I've had. I don't know whether I've gotten a much older person's liver or a very young person's liver, and that's also some of the guilt.³⁶ I see older people, well, I've come from a culture where you don't tackle with older people, they're sacred beings, that kind of stuff. But I would have felt really, really guilty if I'd got a liver from a young person. So I was actually really afraid. A younger person – that's where we're talking another 70 years' worth of life there. How could I? So those were the sort of thoughts that I had. And there are times when I thought: "Well, if somebody's had a car accident because they were drunk..." and gone through those issues, those thoughts have gone through my mind. So it's not actually that easy.

The liver unit gave me absolutely no information about where the liver came from, or gender, age. If I was able to get information about the donor, I would have liked to have known ethnicity for one. And where the liver came from, whether it's from New Zealand or Australia. I'm always curious about the background of the person whose liver I've been gifted. I'm *always*, I've been curious about that quite a lot.

IP#16

Interview Responses on Being Called and Waiting for Theatre

The third category of "called and waiting for theatre" has participants predominantly discussing pre-theatre tests, showers, and other preparations required before surgery, along with the occasional mention of the donor and donor family, feeling positive

³⁶ The NZLTU advised that donor age and gender have very little impact on a liver grant outcome as the liver never really ages. A 90 year old liver will work as well as a 20 year old one (with rare exceptions).

and/or nervous about the surgery and what they can remember of the immediate time prior to being anaesthetised. The importance of the support from family and friends comes through strongly at this point in their transplant journey.

I remember going down to theatre, and my two daughters standing, hugging each other beside me, you know how you go into that little ante-room for a split second. And I was just so upset at the look on their faces, and [spouse] on the other side and I was thinking: “Look, it will be fine, just support each other.” I actually felt that. I thought: “No, it’s going to be all right.” Steve [Munn] had already told me they’d never lost anyone on the operating table! Which was the main concern at that point. But I think the look on my daughters’ faces will forever haunt me; I’ve just never seen the *fear*. That stood out immensely. And then we went into theatre, and I just remember being completely fascinated by the size of the theatre, because it seemed very big. And I said: “Gosh, this is just like a spaceship.” And I was really interested, and I wasn’t scared, not in the least. Not in the least. And I felt very confident, because the staff exuded a confidence, obviously.

IP#3

And it was on the [date] of September, [spouse] had come home... And she’d just gone home, and then I got the ring at about 1 o’clock on the Saturday: “We’ve got a possible liver for you. Can you come in?” Of course I said: “Yes.” Rang [spouse] and burst into tears, and it was all on that night. And eight hours later, oh, I went into theatre about 8 o’clock at night, and 5 o’clock in the morning John McCall came through to see [spouse], all bleary eyed etc. But still, the decent fellow that he is, he went and talked to [spouse] about how things had gone. Still calls tears to my eyes.

IP#5

I think for me the night of the operation – there was the waiting room, there was the lounge in the ward, and my family and friends had entirely filled that ward because I’d asked them to come. I still thought I wasn’t going to make it through the operation. So they’d come in, but that night was actually amazing – nurses coming in and out, running through, taking blood tests, getting me ready, off to the showers, really good scrubbing, all that kind of stuff was happening. By then I was basically gone, you know, close to death. I didn’t know until after the operation, when John McCall said to me: “You probably had about two days to live, we realised, after we opened you up.”

IP#16

But we were over on the Shore looking in a bookshop when the beeper went off and they said: “Get yourself over here.” So that was that. And we were on for theatre about 2 o’clock in the morning, when in actual fact I went in at about 5 o’clock in the morning, Christmas morning. So it was a good Christmas present! My wife said I was the only patient she’d ever seen that would read a book while waiting to go in for an operation! It was a Bryce Courtenay. It was just a relief for it to be happening. It all started from there. I wasn’t thinking about the donor, I was all drugged up, and I wasn’t thinking straight, anyway. I remember being wheeled down to theatre, and that was it! I don’t know what they gave me. They put the needle in my neck and that was it. I remember seeing my wife come down with me. I saw Stephen [Munn], and the crew come in. I think I remember going into theatre and seeing all the lights and talking to the anaesthetist and saying: “Is this where I count backwards?” And the next thing I know, I’ve woken up in the recovery room. I think you’ve got to be positive, if you go in feeling the opposite way, well. I got to see my family again 5 o’clock that night.

IP#17

As I mentioned at the start of this section, there were 56 pages of quotes from the 17 interview participants that reflected their experiences of waiting for a liver transplant.

The key themes were:

- waiting to be listed for a liver transplant;
 - thinking about death and dying;
 - relief at being listed;
- listed – waiting to be called;
 - family support (including spousal support);
 - being informed and prepared, including hearing from other recipients;
- called – waiting for theatre;
 - focus on family and trust in the liver unit.

The next section looks at the 49 survey responses in relation to New Zealanders waiting for liver transplantation, which covers Questions 9 and 10.

Survey Responses on Waiting for Liver Transplantation

When you're stuck between a rock and a hard spot you will grasp at anything to survive. I was told there were no guarantees and they do lose some patients, but you hope for the best. I remember one day there was a multiple car accident and I was wondering if anyone was a donor (then you feel guilty). I was so unwell the wait seemed to be forever, then I had a call just after midnight on my birthday: then a big rush to get to Auckland.

SP#48

Section 4 of the survey focused on being listed for transplant. It contained a selection of quotes from the 17 interviews, before Questions 8, 9 and 10 were asked. Question 8 asked recipients to reflect on how their employment status may have changed as they became unwell; Question 8 asked recipients to comment on how they felt once they were listed for a liver transplant, and were on the waiting list, and is covered in detail below; while Question 10 asked recipients to comment specifically on how they felt once they were called in to the hospital for their transplant surgery. This is covered after Question 9, in this section.

Out of the 49 survey responses, 47 people wrote comments on Question 9. The two survey participants that did not respond to this question were both European females. Using NVivo 8 each of the survey responses has been coded, which has created a list of themes that are common to some, but not all, recipients. For example, the most common theme was commenting on having a second chance at life, which came through in eight responses. Three examples are shown below:

Having a second chance at life

I was really happy that I was given another chance.

SP#4

I was scared, but happy that I had another chance at life. But deep down I never really believed it, until it happened.

SP#15

I had moments of thinking how awful, here I am waiting for someone to lose their life for me. Then I would think: “due to a very generous person and their family, I was going to have a turn-around in my quality of life.”

SP#38

The next two themes had an equal number of recipient comments at six. These themes are the actual waiting time, and guilt about the donor’s death. The following two quotes are examples from the survey of participants’ reflections on the death of the donor and their feelings of guilt.

I was trying not to feel guilty as it was really weird knowing someone had to die for me to get a liver and live.

SP#1

I felt very uncomfortable about waiting for another healthy person to die and I had to keep reminding myself that I was in no way responsible for their fate, which would otherwise be a total waste.

SP#34

The next three quotes illustrate survey participants’ reflections on waiting for the transplant, after being listed.

Waiting for the transplant after being listed

My first thoughts were about the length of time I expected to have to wait, then the realisation came that many activities would have to be curbed, because of the need to be able to reach Auckland within the required time.

SP#11

I was shocked and surprised with the fact that I had only been listed for a short while before I received a liver transplant at Auckland hospital. I didn’t have to wait very long.

SP#20

I was determined to remain positive and patient even though I was hospitalised prior to the transplant and I was constantly worried if I would survive until a donor liver became available.

SP#26

The next most common themes were recipients reflecting on how nervous and scared they were, their relief at being listed for transplant, their trust in the NZLTU staff and the unreality or surreality of the whole experience. Each of these themes was noted by five different recipients within the survey responses. To follow is a survey quote illustrating each of these themes.

Nervous and scared:

It came as a shock when I was first told that I had to have a transplant and naturally I felt scared. But after everything was explained to me, I felt positive about the surgery and wanted it to go ahead.

SP#12

Relief at being listed for transplant:

Once the transplant coordinator finished ticking everything off the list and told us I was on the hit [waiting] list, we were both so relieved because we both knew there was only one shot at this.

SP#21

Trust in the New Zealand Liver Transplant Unit:

I had lots of thoughts about keeping positive, grateful and hopeful. The Liver team were so lovely, helping me to keep this way. Ed, Rachael, Stephen, Val, Margaret and Ron – my lifeline supporters. They will never know how much I appreciated them.

SP#16

Unreal/surreal experience:

I think because I was in hospital and getting sicker it felt unreal.

SP#49

There were five theme areas mentioned by four survey participants in their responses. These are around denial of the illness, the situation; deteriorating health and quality of

life; being grateful and happy; the importance of talking with other liver transplant recipients; and having a positive attitude. A survey quote illustrating each of these themes follows:

Denial of the illness, the situation:

I was scared, but in deep denial. I thought the doctors had made a mistake and they would realise before the operation that there wasn't much wrong with me. I think that's how I coped with the fear.

SP#31

Deteriorating health and quality of life:

I had been very ill after my fifth oesophageal stomach bleed and I was unconscious and on life-support for 7 to 10 days, feeling as bad as it is possible to feel. A Critical Care nurse told me if I didn't have a liver transplant there would be nothing for me. I instantly decided on a transplant. I felt I had this one chance to live.

SP#32

Being grateful and happy:

I was really happy and yet sad for the family that had lost a loved one, so it is my responsibility to treat my liver with great care, in order to honour the gift of a second chance at life.

SP#5

The importance of talking with other liver transplant recipients:

I found talking to someone who had been through a transplant helped a great deal.

SP#17

Having a positive attitude:

I had the feeling that I didn't need the transplant. I was feeling good and I had no pain at all. I was living happily. I went dancing two or three times each week. I was certain that I could get well soon after the transplant because I was in the good hands of the NZLTU and with God's blessings.

SP#9

Other themes that emerged include the importance of being informed, the impact encephalopathy has on patients during this time, some patients who found that their

trust in God was a real support, others who worried they would die before a donor liver became available. This was sometimes overlaid with comments reflecting pragmatism and patience, feeling humbled, being sorry for the donor family and a number of one-off comments reflecting individual survey participants' experiences, such as those who woke up to news of the transplant, or were upset with the number of 'false starts' before their transplant occurred.

Comments about waiting also appeared in Question 32, where survey participants were invited to write about anything they had not already covered. This participant, although very appreciative of the liver unit's support and work, was looking for more guidance through this waiting period.

I found the waiting period between being listed, and donor availability, very trying (also for my family). I was remote from the liver unit and in rapidly deteriorating health. No doubt the circumstances of each patient are different, but looking back some guidance from the liver unit might have been helpful. This comment should not detract from the help they consistently gave, which was wonderful.

SP#26

Question 10 asked recipients to reflect on how they felt once they were called to the hospital for their liver transplant surgery. All 49 survey respondents wrote answers to this question. Using NVivo 8 each of the survey responses has been coded, which has created a list of themes that are common to some, but not all, recipients. The theme that dominates this question is that of trust in the NZLTU, with eight recipients commenting on this. The following two quotes are examples of this.

I felt relaxed, resigned to whatever happened. I had faith in the hospital and all the people involved. I had been told that I had three days to live and this was the second day, so I was peaceful about the whole thing.

SP#13

As it was my third and final transplant call, it was remarkably relaxing to be called finally after 10 months of waiting and preparing. The first call was the most scary and freaky. Negative thoughts about the outcome arose. I felt I didn't know enough, but I put my trust in the liver team completely.

SP#32

The next two themes that dominate responses to Question 10 are about recipients feeling excited about the prospect of the transplant surgery, and the importance of keeping a positive attitude. Both of these were commented on by seven survey participants. Two quotes illustrate each of these themes.

Feeling excited about transplant surgery:

I was apprehensive and excited. I had the determination that no matter what happened, I was going to make this work.

SP#21

I remember wanting to have a shower and wash my hair before I left home. I felt sad leaving my home and my children, but we were all excited that my time had come for me to get well again. My children were very brave.

SP#39

Keeping a positive attitude:

I felt positive and I knew that everything would turn out fine.

SP#12

It is a personal situation, but for myself, you have to have a positive attitude. Think positive – mind over matter.

SP#17

When I was called into the ward the night of my transplant, I felt that there was a real sense of excitement, almost a party-type atmosphere, when the orderlies wheeled me past all the ward rooms and the nurses' station on the way to theatre. This was also commented on by two other survey participants.

“Party” atmosphere:

I was very excited, everyone seemed so happy for me, it was like a party before I went to theatre. Family, friends and staff were all so positive. And I felt that way too. I was just grateful it was going to happen at last.

SP#16

I was already in the DCCM waiting for a miracle. My family knew I had seven to 10 days to live. The liver came on the fifth day. My family were told late the night before that it might possibly happen the next day, but that would depend on the quality of the liver on offer. When the call to theatre came, I felt like I was going to a party. I waved good-bye. Everyone was in good spirits.

SP#24

Six survey participants commented on their feelings of uncertainty as to whether the liver transplant surgery would be successful for them. Two of these responses are below:

I was both happy and scared, because even after reading all the material the liver unit provided, I wasn't sure I would make it through the operation because I was sooo sick I couldn't walk or feed myself, let alone dress myself.

SP#5

I had previously had major surgery, so I had coping skills already in place. However there was a real fear of dying during surgery. Having been told that no one had died during surgery was scary to me, because I knew someone will one day, and I would probably be that person.

SP#29

Five further themes came through in the survey responses of five participants. These were around feeling calm, being scared, glad that it was the end of the waiting time, trust in God, and being very unwell. One quote provides an example of each of these areas, and is shown below:

Feeling calm:

I was on auto-pilot. I knew what I had to do and I very deliberately prepared. I was calm and I managed to keep my mind focused minute to minute without any panic.

SP#8

Being scared:

It was unreal; I felt scared. Because I was in hospital and far from home I was very thankful that my brother-in-law's aunt was there with me before the transplant.

SP#49

End of waiting time:

I was relieved the wait was over.

SP#28

Trust in God:

I was very prepared spiritually. I closed my eyes (operation) knowing that God had blessed me with the best. Doctors and nurses – the lot. I was in capable hands.

SP#7

Being very unwell:

The phone call never came. I was admitted to hospital due to complications long before the actual transplant. At the time my prospects did not look good. A chaplain visited the morning before the transplant and prayed for the Gift of Life. I later regretted this, and asked for forgiveness; I could not wish someone to die, just to save my life. The next day the organ became available. After 11½ hours I woke up. I understand the procedure was a hard-fought battle. I remember having a near-death experience.

SP#42

A further four survey participants commented on the areas of family support, gratitude, panic and the opportunity to have a second chance at life. One quote is used as an example of each of these theme areas.

Family support:

My husband and daughter waited with me until I went to theatre. This was Boxing Day at 3:30 a.m.

SP#14

Gratitude:

I was already at the hospital. They had received a liver from a donor (thanks to that donor and family) and I came off the waiting list. I started losing my memory and stuttering and I had a bit of confusion. I was asked a question from a physician: “What did I want?” And I said: “Ten more years of life so that I can see my two kids turn twenty-one.” It’s thanks to the team that I’m still here to fulfil my dream.

SP#3

Panic:

I was getting tea prepared and I was really looking forward to it. I ran around the house going: “%^&t, #\$\$%t, %^&t.” I felt sick and sad when friends took my daughter away and she was crying and really upset. I was really worried that I wouldn’t see her again.

SP#37

Second chance at life:

I was already in hospital and I felt a great sense of relief that I was to be given a second chance of life. I had every confidence in the surgical team and my Maker that the operation would be successful.

SP#26

Other areas that survey participants commented on included disbelief, false starts for transplant, the suffering of their families, their fear of dying during the surgery, being happy, feeling nervous, being too sick to know and care, and feeling well prepared for the surgery. Less frequently they commented on their determination to make the transplant work, the issues they faced with encephalopathy, worries about rejection, feeling sad, being fearful and the unreality of the whole experience. Individuals also commented on the help they received from other recipients, their feelings of guilt, needing to be in control of minor things, focusing on life minute by minute, and being dependent on others.

Overall the dominant themes from Question 10 demonstrated the overwhelming trust placed by survey participants in the NZLTU, and the positivity and excitement with which they viewed the opportunity of their second chance at life through the liver transplant surgery.

Conclusion

Again encephalopathy was a general mind set, but I was returned to surgery three days after the initial transplant surgery to check my veinous connection, or lack of, and at that time I was very, very weary and frightened.

SP#35

The survey participant's comment (above) comes from Question 10, and leads us into Chapter Eight, which has a focus on patients' time in both the DCCM and the ward, post-transplant. Before we leave the waiting time, though, reflecting back on our experiences through interviews and the survey, the overwhelming impressions are of patients' trust in the NZLTU, patients' appreciation and gratitude for a second chance at life, the importance of family support, being excited and keeping positive about the opportunities presented by a successful transplant, frustration by some at the time spent waiting, and surprise by others at how quick the waiting time is, relief at being listed for transplant and guilt about the death of the donor. The NZLTU may like to consider who communicates to patients initially about what a liver transplant *is*, and continue to do follow-up ensuring that the right level of communication is in place to mitigate any fear and lack of information felt by patients facing this new phenomenon in their lives.³⁷

³⁷ The NZLTU advised that this suggestion will be incorporated in the resource booklet derived from this thesis.

Chapter Eight: Experience of Waking Post-transplant to Discharge

I can remember Intensive Care. Yeah, that was hell, actually, in there. Yeah. It was just something totally out of the whatsername, you know. You felt totally isolated in there, like, there was nobody about. Nothing. You know. Looking straight at a wall. No, I didn't enjoy my time in there at all.

IP#8

Introduction

This chapter covers what we remember of our time in Intensive Care, also known as the DCCM, and when we return to the ward. The focus areas are as follows:

- Nightmares and delusions;
- Pain;
- Time;
- Nursing care.

Each of these areas was identified as a key concept area within the interviews, and has either been explored further by survey questions or through the survey responses. As in earlier chapters, the academic literature is looked at in these areas, before moving on to the memoirs and autobiographies available concluding with an in-depth look at the responses around these concepts in interviews and through the survey.

Nightmares and Delusions

The literature quite clearly illustrates the intensity of the nightmares and delusions suffered by the writers, upon their return to the ward.

Some writers described relatively benign after-effects of the painkillers. Chris Klug (2002, p. 240) felt pretty “loopy” afterwards and was told that “they made me nicer, because every once in a while I’d blurt out some emotional statement with tears in my eyes, like, “I have the best friends and best girlfriend in the whole world.”

Darling (2006, pp. 39-40) described the strong effect such hallucinations had on him:

A year after my surgeries I visited the ICU. I’d been reluctant to go there out of fear. ...I was afraid to psychologically revisit those days of post-surgical distress and my struggle for life. I’d blocked some of those memories out of my mind.

Darling thought that he had seen a ‘guardian’ cat visiting him during the period of greatest illness (2006, pp. 55-56).

Darling, there is no cat. There has never been a cat in here. The hospital wouldn’t allow animals into the building with sick people (Wife).

Nonsense, I knew there was a cat; she had just not seen it.

“Tabby has moved on to other patients now that I’m out of my coma,” I explained.

Most other writers, however, experienced more frightening nightmares, often highly complex and involved.

The first night in the transplant ward I eventually got to sleep, only to have nightmares (Chalmers, 1995 p. 28).

Mine was a murder, clever and complicated, involving many people I knew but who could not have possibly known each other – except in my mind. I was the only witness to this murder and was being pursued from all sides (Chalmers, 1995 p. 25).

My weirdest fantasy during the first hours after transplant was my suspicion that Dr. Perkins and Dr. Hayes were involved in a black-market scheme to sell spare parts of Disneyland characters to theme parks (Maier, F., & Maier, G., 1991. p. 199).

Maier (Maier, F., & Maier, G., 1991. p. 64) succinctly summarised the majority of patients' experiences who, in talking with other patients after their transplants, "discovered that my fantasies and hallucinations, strange as they were, were common after-effects". Kuhn (2008, pp. 77-80) also outlined her violent nightmares, and at one time thought that people were in the room trying to kill her. Kuhn's reaction was so strong that nurses tied her hands to her bed and placed Kuhn on suicide watch. Although these hallucination experiences were apparently frightening and created distress in the patients, other experiences, possibly caused by the patient's medication, were more confusing and restricting.

The nurse gave me a sleeping medication, and I lay there for many hours with the same word running through my mind over and over and over again. Then suddenly I would stop hearing that word and another word would start running through my mind hundreds and hundreds of times and I was unable to stop it. This was how I spent the first day in my room (Kuhn, 2008, p. 64).

This focus on something like a small word was something I remembered and to which I could relate. I remember being fixated on small words like THE and wondering how that collection of letters could ever contain any meaning and be used, and I think this continued at least two to three days once I was back in the ward.

Physical constraints, as well as the psychological ones, caused distress to the patients. Such events are described in the literature. It seems to be the small everyday things that we all take for granted that caused the most distress. The writers used words like frustrated and ashamed to describe their feelings when they found such previously simple tasks almost too hard.

I'd write a sentence but no one could read it. I was completely frustrated. Lying flat on my back, I couldn't see my writing. Months later Kress told me my "sentence" was two inches long and vertical in a series of unintelligible scribbles (Darling, 2006 p. 50).

During the time the ventilator was in I had been communicating by writing on a slate. The printing was shaky and I was ashamed of my efforts but it served the purpose (Chalmers, 1995, p. 26).

I could feel that I had to use the bathroom, and I could feel that I couldn't control it, so I pushed the buzzer. Before they could respond, the entire bed was soaked. And the nurses had to come in, lift me out of my bed, and replace all the sheets. They had to bathe me and put a new gown on me. I told them then, "I don't feel like I can control myself. I guess I need you to put the catheter back in." I'll never forget the male nurse looking at me and saying, "You just don't want to. We know you can do it, but you just don't want to." And I kept telling him, "Why do you think I would not want to? Why would I want to mess all over myself? Why would anyone want to do that? I just don't feel that I can go on my own yet. You need to put a catheter back in." However, he said, "No, we're going to try it without. You need to try really, really hard. Try harder than you ever have" (Kuhn, 2008, pp. 81-87).

A number of other recipients made reference to the frustration of being unable to communicate, even in writing, and for me personally this was a big issue as I was lying flat on my back with the paper above me, with no glasses to see what I was writing, and Tac tremors to contend with. This topic is addressed elsewhere in the chapter in greater detail, but it is worth noting here that the issues expressed by these authors were representative of our experiences here in New Zealand too.

The writers often felt that the medical staff did not fully relate to or understand their post-operative experiences. While Kuhn's nurse might have been deliberately pushing Kuhn to cope, the nurse's actions appeared harsh to the patient. Similar experiences of feeling alone, misunderstandings or a lack of understanding between medical staff and patient were described by other writers.

Transplant surgeons and nurses are familiar with the post-operative mental confusion that occurs when patients experience extensive surgeries and coma. I'm sure they would attribute the following events to such bewilderment. However, when I emerged from my coma, I

believed for days that what I had experienced was real (Darling, 2006, p. 50).

When they came in the room, they asked me, “Did I understand what had happened the night before?” And I told them I wasn’t sure what had happened, but there were dark figures in my room, that I had to escape from them. They all glanced at one another and one said that the dark figures weren’t real. I told them that as strange and as crazy as it sounded, it was real to me. I had seen these forms, and they were trying to harm me...

“I think they’re induced by the sleeping medication. So please do not give me sleeping medication tonight.”

That night I did not sleep, but I also did not have any hallucinations, I did not see people that weren’t there, I did not try to escape, and I did understand everything that was happening around me (Kuhn, 2008, pp. 78-80).

Apart from pain, discomfort was also discussed in the literature and is briefly mentioned in this section. Discomfort as such was not discussed in-depth in the literature, however, it is relevant to include because many interviewees and survey respondents experienced discomfort that they identified separately from pain.

I was starting to eat again and being offered normal meals with milkshakes three times a day. Other transplant patients had told me that food tasted awful after all the drugs involved with the operation, and the staff had told me I must eat all the good food to aid the healing process...What I found difficult was all the drinks. The milkshakes started to mount up in the ward fridge and I resorted to tipping at least one a day down the sink when the staff all gathered in the office for a meeting (Chalmers, 1995 p.28).

I could relate to these experiences of discomfort after the operation and also miscommunication with the medical staff.

In my experience the most amazing thing was waking up after the operation, before my eyes had opened, but my brain had woken up, and hearing people – not feeling them –

but hearing them talk about the ultrasound that they were doing at that time on the liver, so understanding from that point, from the moment that my brain woke up, that I had a new liver. Intensive Care was a bit of a blur, in that I remember the liver unit coming through, and I remember the intensive care doctors, I don't have any memory of any of my family being there at all. And yet I know, because they've told me, that they were there, but obviously not there at a time that my brain comprehended them. Yet, I remember, when I had the second operation, because I had a bleed, which was quite common – one in five will have a bleed apparently – that I was extremely concerned that the nurses contact my mother and let her know that I was having an operation again because I was still aware that the anaesthetic was really, really hard on my heart.

I was feeling quite scared when the doctors would tell me one thing, and then the nurses would tell me another, and I would get very concerned that the nurses might try and take me out of the ward, send me home, before I was ready to go home, and before the doctors had told me that I would be going home. I think the nurses did that, because quite often the patients would leave the liver ward, within a week of their transplant, but they hadn't had the complications that I'd had with my lungs and liver and heart. So, when the doctors had told me I couldn't go home until I was off oxygen, I believed them. Then the nurses would tell me, "No, you'll probably go home this weekend." I didn't feel that I could go home that weekend, and that was really scary. I felt the nurses were trying to force me out.

I was the first liver patient to have Iloprost, and many of the nurses didn't know how to make it up, and they'd tell me that I should make it up, but I couldn't move more than six metres from my bed, because of the oxygen tube, and the Iloprost had to be kept in the fridge, in the nurses' station. So there was a little bit of tension. Sometimes, I felt

that I was being looked on as a difficult patient because of the Iloprost, but, I was concerned about the intensive care nurses not knowing how to mix the Iloprost here in ICU, not necessarily doing the doses at the right time, and because I was intubated, I couldn't talk to them. Because of my experience in Intensive Care with my splenectomy I had a laminated board (see Figure 1: Laminated ICU Card for Post-operative Communication, p. 15), which had key questions, key comments and key phone numbers on it. I could tap it to attract their attention because it was pinned to my blanket. But it's still not the same as talking.

At the same time, possibly because of all the drugs or maybe the legacy of the anaesthetic, I found it very difficult to sleep, because I had psychotic dreams and nightmares, and I wanted to not sleep so that I could avoid having them. Night after night I'd have the television on, with the picture and no sound, and I'd have a little radio with the headphones in my ears, and I'd just be trying to listen to the radio and look at the picture and not sleep, because I was so scared of what I'd dream when I slept. This meant that I got quite sleep deprived. I think the liver unit got quite worried, because they were playing around with the doses of the immune-suppression medication, and they brought another doctor, I think a psychologist in to check me. One weekend, it must have been about the second weekend, I think, after the transplant, I was having a really, really bad reaction to the different cocktail of drugs that I was on, and I thought I was falling out of bed. I wanted the bed to have sides on it, so that I wanted them to put sides up so I wouldn't fall out, and I thought the walls were coming towards me. I was just terrified of what was happening to me. I wasn't falling out of bed, but I believed that I was, and I understand from the nurses that I was screaming at the top of my lungs and scaring other people in the ward. I don't remember the screaming, but I do know that about three nurses came running in, and I was very, very scared of what they were

suggesting that they were going to do to me, because of the fact that I was scaring the other patients. They told me that if I didn't shut up, they would take my bell away from me. That was incredibly traumatising, because I felt that my bell was my only lifeline, my only link to, basically, staying alive. And they were threatening to remove it. So that was extremely upsetting and I didn't have anybody that I could talk to, I didn't have an advocate, I didn't have any family with me on that day. I had had a friend planning on coming up from Wellington to stay with me that day, but because I was having such a bad experience with the drugs, I'd got her postponed. So it was not a really easy time for me.

Interview participants described two themes of hallucination experiences: of difficulty in sleeping, being frightened, and distress after the operation, and secondly more reassuring, less frightening, and perhaps more positive illusions. The more frightening experiences are recorded below followed by the less frightening ones.

I do remember having a couple of really, really bad nights. Just couldn't get comfortable and the pain was intense, and I had those psychotic dreams. Mmm, mmm. Horrible things. Yes. Horrible.

IP#3

Horrible, yeah. The dreams were something, it was all the drugs. I remember patches of what happened. I was in and out of consciousness quite a bit. But I remember not wanting to go to sleep, because these horrible creatures kept coming down on top of me. And all over me, and I just didn't want to sleep. I just sort of, perhaps I didn't really tell anybody what was going on. And the other thing is that the ceiling panels moved. I don't know whether that happened to anyone else, but they shifted like this, you know. And I was in the bed, and I kept going to the edge of the room, and I'm going to fall out the window, any minute now. It terrified me. This thing, you know, I couldn't stop these things moving, every time I looked at them. And then, I'd been [t]here for a few days, three or four days, and they had to give me, must have had to give me a blood transfusion or something, because I dreamt this big fat Russian nurse came in, woman, she said she was Russian. And she said: "We're going to give you, we've got to" do something to me. And they cut me in half. And the top half, and they sliced me, you

know like a bacon slicer, virtually in pieces, and then they put me all back together. But they got me mixed up with the woman next door, and I finished up with a woman's body, oh, God, it was terrible. And I couldn't see anything, and then she left. ... I was terrified, I thought I wasn't going to get out of this place, you know. You know, the drugs, I knew that what I was seeing or hearing was drug-induced. I knew that. But I couldn't stop it. It didn't stop it.

IP#6

I had one really vivid bizarre dream. But I didn't have any others. And it was real, it involved the Everley Brothers, Al Qaeda; it was just out of this world.

IP#12

After my transplant, when I was in the ward, I called the nurses in one night and I said: "Look! The skin's all peeling off my legs." And I went like that on my leg. I said: "Look at it!" And I looked at the nurses and I could tell, just by the way they were looking at me, that it wasn't happening. You know, that I was just imagining it.

IP#15

I remember I was awake when I saw those things happening.

IP#16

Ooohh, yes, I did [have trouble sleeping when I first had the transplant], I did. There was a, I had trouble sleeping at night-time, some breathing problems. One night in particular I did have a nightmare, yeah, one night. This was after I'd got out of Intensive Care, now my [family] had had turns basically living in the hospital with me, and there was one night I had a nightmare that the room was on fire, sort of interesting that the room was on fire, and that was the nightmare, my friend and I were trying to put it out, and the nightmare must have woken my [family member] up, and what had happened was the oxygen thingy had fallen out of my nose, probably because I was moving around so much, and in the dream I saw my friend, instead of putting the fire out, he was throwing petrol at it! ... I yelled out in my dream, and that woke me up as well. ... That was the worst of the nightmares, but that time I was actually sweating when I'd woken up.

IP#16

As with the 'horrible' experiences, the less frightening delusions covered a range of emotions. While one interview participant (IP#5) had what was described as an hallucination, he also recognised that the illusion was irrational and tried to cope with

the effects. But others heard music or thought they had seen events that were disturbing but not so much frightening. IP#16 had both frightening and less frightening hallucinations.

I had hallucinations, and I was in the fishmonger's rooms, of all things. And I was on this bed, in the fishmonger's room, and I was calling out, and nobody came and then I saw this nurse coming through and she came to me and she said: "What's the matter?" And I went to explain, and I couldn't explain it, I became all rational. I went from the irrational hallucination and felt like a stupid fool that I was in this fishmonger's room. Scary at the time.

IP#5

I was too busy concentrating on living, I think, but the drugs of course caused me to see things. I remember asking the nurse who was playing the ukulele, because I could hear the ukulele going, and there really wasn't anything, it was just the monitoring system that was there, beeping.

I remember asking one of the nurses why she was hiding her cigarettes underneath my bed. Because I saw her hiding her cigarettes underneath my bed! And she said to me: "No, no, I do smoke, but I wasn't hiding anything under the bed." Not quite nightmares, just seeing things while I was wide awake.

IP#16

Oh, I didn't. No. I didn't really get nightmares. I got illusions. Um, I had a spray of flowers that were sent up by [spouse's] cousins to me, at Christmas. And there was this little mouse that kept running around amongst them – and everything. And I could see this little mouse. But, of course, it wasn't there at all. But, this dear wee mouse was there. I used to say about it to [spouse] and [son].

IP#11

I had one dream: my father was looking down at me, then he was gone. That's all it was. See my, my dad, he died in 1973, and he was 93 years old. ... I could still remember lying there and he was standing there looking straight down at me.

IP#13

One participant was expecting hallucinations of “pink elephants, and hippopotamuses” but denied getting any. However, she was nervous in expectation and was too “scared to go to sleep” and used the TV to keep her mind off how she felt.

I seemed too scared to go to sleep. Maybe that was my first reality wake-up call that, my goodness me this is what I've just had done! And I could not relax. But, no, I kept waiting for the pink elephants, and the hippopotamuses and everything else I'd heard about, but it didn't happen. I recall being ever so grateful that I had a TV to try and get my mind off how I felt. I think I was agitated, I think I was nervous, I think I was scared, I was definitely scared to go to sleep. I was really stressed and tense, but I don't think I had hallucinations.

IP#7

Pain

Although the literature omitted to discuss any post-operative pain experiences with the exception of the quote below, pain was a real part of my experience and that of many other recipients interviewed or surveyed. The quote below demonstrates not ‘how bad was the pain’ but rather ‘how good it is to be alive to feel pain’.

When I saw a smiling Ginny waiting for me inside my private room, I felt like a groom greeting his bride at the altar. Tears filled my eyes and, despite the bandaged burn on my arm, the metal staples tacked across my body, the dark purple bruises from rib cage to thigh, and the tangles of drainage and IV lines that made me look like a battered octopus, I hugged her with all the strength I could muster. The more it hurt to hug her, the happier I felt. Pain – which I had come to accept as a dull and inevitable companion – now felt as good and God-given as any pleasure could be. Strange as it may sound, experiencing physical pain once more was another sign that I was alive again! (Maier, 1991, p.207).

While I was full of gratitude at the success of the transplant and the chance to keep living, I did not see pain as my friend.

For the first couple of weeks I just wasn't up to having anybody except family visit me, and a lot of that was because physically it was really, really hard. I wasn't sleeping, I had an awful lot of pain, I had tremendously bad diarrhoea and it was just one of those things that I didn't feel very sociable. Just family could cope with that, and I could cope with them because they didn't have any expectations. So, friends were restricted because I didn't necessarily want friends to see me when I was feeling absolutely grotty, and running with my oxygen tube to the toilet, etc. It just wasn't a sociable time.

Many interview participants also experienced extreme pain or discomfort.

Mind you, I was glad to get back into bed too, because you feel as if you've been run over by 24 trains and a couple of big buses!

IP#2

For me the biggest thing was pain, I was in agony. And the next thing I remember about staff and everything else, was this Occupational Therapist wanted to get me up, and get me walking. Get me to the gym. And I was in so much pain! I was really in pain, and whether that was because I wasn't sick before, so suddenly I've had this massive cut, and I was in agony ...

And I think for me the pain was the worst thing. It was just this pain, and it just wouldn't go away. And it was probably all the healing, and they cut through all the nerves and everything, and I just remember being in a lot of pain. It was like I'd been run over by a truck, just belted by a truck in the front. And I think for me it was just that physical whole thing of getting my energy back, getting through the pain.

IP#7

OK I could put up with quite a bit of pain, but by Jove that was pain! You know I've been banged and bashed around the arms, the head, and the legs, but this is a different pain, and I could remember them, I was lying in there, I could remember coming in with the, it must have been the scanner or something, and they were fitting it underneath me and over the top, I could remember all that, but every time I moved, it was just the pain.

IP#13

Although some participants experienced severe pain caused by the operation itself, others were in pain from associated events such as medical procedures or were in physical discomfort.

There was one nurse in particular, who wouldn't listen. I'd just said I didn't want the drain taken out sitting up that I really wanted to be put back in bed, she wouldn't listen to me, and it was incredibly painful when she did it.

IP#1

Even with all the drugs, I felt nothing, I just said, "Look, I'm just really uncomfortable," and they kept saying, "But 'uncomfortable', what does that mean?" And I said, "It's about a 2 actually." [On a scale of 1 to 10.] He said, "It's a 2, you're not in pain?" I said, "No, I've just told you, I told you I'm not in pain, I'm just uncomfortable, THAT'S ALL!"

IP#4

...one of the things that happened during the operation was that you're strapped, and not only are you under anaesthetic, but you're also immobilised. And somehow my arm must have been immobilised in a position that left me with a crook, and painful, muscle in my back. And so I was having physio on that, which was more painful than anything to do with the operation.

IP#5

I had an extremely sore back. Right in the small of my back. I just couldn't get comfy. I was trying to say, "My back's killing me." Because it was. That's the one thing I remember. At one stage I was really uncomfortable and I didn't realise I should have been shooting myself up with the morphine or whatever. At one stage, I thought, "God! I'm never going to get any." And they said, "Oh just give yourself some." And once I did that I was a bit better.

IP#12

Other participants experienced little or no pain. They attributed this lack of pain or even moments of euphoria to the morphine.

I think because of all the painkillers, I quite enjoyed Critical Care, because you're so floaty and not in pain. And I think probably the relief of being alive, and them saying: "Look, you've done so well. It really went well." And I mean I didn't want to leap up and "Yahooo!" but there was a certain sort of relief washing over me.

IP#3

I experienced absolutely no pain whatsoever. Absolutely nothing. No pain, other than the stitching pain, but those, those are always there. I thought the Morphine helped, but I think the Morphine sort of played with your mind a bit really, and I made sure I was pushing the button every five minutes, or whatever it was. Or fifteen minutes; I just made sure I was pushing the button. I felt absolutely no pain whatsoever, absolutely nothing.

IP#16

Time

One of the surprising issues to emerge from the participants was their preoccupation with the time. Knowing the time was really important for me as well. Because I'd had my spleen out I knew how frustrated I was that I couldn't talk, I was prepared this time. When I knew I had to have the transplant my sister prepared a little board for me and laminated it so it had all my key questions and comments like "Don't bump the bed", or "I'm cold", "I'm hot", "Can I have another blanket?", "Can I have another pillow", all those kind of things, and stuck it to me with a safety pin, so I could tap it. It made a noise, and the nurses would know I wanted to communicate (see Figure 1: Laminated ICU Card for Post-operative Communication, p. 15). So I'd go (tap tap tap) on the laminate, and the nurse would come over, and I was always pointing at "What time is it?" and they got really sick of it! I asked about every 15 minutes. I still don't quite know why. The only thing I can think of is because I couldn't tell if it was day or night. I wanted to know what the time was so I'd have an idea of when to expect my family, and when the Iloprost was next due as I couldn't trust the nurses.

When asked, other participants immediately raised not being able to tell the time as a problem for them when in the ward. They wanted to not only know whether it was day

or night (IP#6), but they were also concerned about times for treatment and family visits.

They [DCCM staff, when visiting post-transplant] said to me: “You always wanted to know the time.” I think I wanted to know when I was going to get out of there.

IP#2

And then I woke up, and I was in ICU. But I woke up thinking that it was still the same day, but it wasn't, we were in the evening, heading for the next day.

IP#14

When I came out of my operation, because I had the tube down my throat, I wanted to know two things: what was the time – because then I would know how long I'd been out for; and did they do it – because there was always a possibility for me that it wouldn't happen. And, of course, I couldn't ask them. And I kept trying to point to my arm, you know, but I didn't have much energy to point. And no one knew what I meant. I'd look around the room to try and see a clock and there, there wasn't one. But they were the two things that I was trying to find out.

IP#15

I was in Intensive Care for about five days. You couldn't tell if it was day or night ... I'd [ask]: “What time is it?”, “What day?”, “Are my family here?” You know, they were just sitting outside, and I'd always want them to come in and you'd wake up fifteen minutes later and you'd think you'd been asleep for a few hours!

IP#16

Post-operative Nursing Care

The fourth major theme arising from the literature recounted the patients' relationship with nursing staff. It was also a recurring theme in the interviews. Nursing care seemed to be quite a polarising issue, with many recipients extolling the virtues of their nurses and carers, and others experiencing distressingly poor quality care. Almost without exception in the interviews and survey responses there was praise for the liver transplant team, however the nurses in Intensive Care and some ward nurses were not

always as highly valued by recipients. The following quote from Kuhn is indicative of the feeling some recipients had when dealing with difficult nurses. [About the nurse] “I almost asked her what kind of transplant she had, to be such an authority on it, and to tell me that it was not going to be that bad” (Kuhn, 2008, p.87).

My experience with nursing care was sometimes good and sometimes distressing, especially with regard to the threat to remove my bell, some annoyingly squeaky shoes, and the feeling that I was being a problem patient due to the Iloprost treatment, but many of my memories of being back on the ward relate to things other than nursing care. For me, the first week back in the ward was very strange – because I was put on so many drugs so quickly, I tasted funny to myself so that when I swallowed or when I breathed, everything was just very metallic and tinny and odd, and I couldn’t escape it because it was me. It’s all the drugs in the system, mixing around until they get sorted out and accepted. So that’s strange. Then, at the same time, there is the sleep deprivation from avoiding the psychotic dreams and nightmares.

Once we manage to graduate from Intensive Care and get back to the ward, it becomes a challenge and a race to try to get rid of as many of the tubes in us as possible. A patient might start off with 14 tubes, and every time a tube is removed, it’s another victory, it’s another step forward. This is illustrated by the following quote from an interview:

But moving out of Intensive Care really said to me: “right we’ve progressed, we’re well down the track.” It was a huge leap. It felt like a massive leap. Every time they remove something you’d know that things were going really well.

IP#16

Then there are the things like being able to eat, drink, and talk once the tube is removed from the throat. Then we start doing a little bit of walking. I was still on oxygen, so I was on a six metre leash once I could walk, but I had to have the first shower with an oxygen tank, and all the “first” milestones. For me these included getting healthy colour back in my face; putting on a tremendous amount of weight quickly with the Prednisone; finding out that we can’t have plants in our rooms because of the fungal infection danger, and people turned up with plants to give me and I had to say “No, put them out in the hallway”; just getting used to the food – grated cheese on everything and ice-cream for breakfast, and the whole high protein situation, to try and re-build all the tissues that had been damaged. Then, they brought in my old liver, so that I could actually see it, and say goodbye to it, and see what a weird little thing it looked like. I found out for the first time that they removed my gall-bladder too, and I looked at the gall-bladder thinking “that’s really quite attractive; it’s like a greenstone pear.”

Participants remembered little achievements and accomplishments. They recalled various fears and painful experiences including medical procedures, however, some like IP#1 recalled the time as being fairly safe and comfortable in that she did not have to worry about day to day living tasks such as preparing meals. IP#2 recalled that only two days after the operation he walked about 35 metres pushing the little trolley with all the bits on it. “Ah, that was hard, but I did it.” He was particularly pleased with his achievement and the praise delivered by the nurse “...that’s good, you’ve just run a marathon.” The patients’ first walk is a huge achievement and they found the nurses’ encouragement in this area and other aspects of their recovery very important in being able to cope.

I thought that the doctors and most of the nurses were incredible. Like I did manage to find a nurse or two in the ICU who I just would have liked to have strangled, they were really horrible, and quite different

from the ones I struck the first time, and I knew that they weren't really doing what they should be.

I remember looking at my watch, and timing that I'd been trying to get this fruit container open for twenty minutes, just a fruit juice, trying to get the lid off it, and I was just too weak, basically, to get it off. But it still took me twenty minutes to give up, and call the nurse and ask them to do it.

I was still in the old hospital, which was pretty grotty. That was kind of scary, when they're telling you that you need to be on a safe diet, and there's paint peeling off the walls. You're thinking, "oh, I'm sure that's not good to have that," there was water coming in through the windows, and it's added stress that you don't need.

I don't think I ever thought I shouldn't have had it [the transplant], because mostly I did feel that it was going to be OK eventually. I suppose because I was so weak and tired, I didn't feel in a huge rush, it wasn't like I was chewing at the bit to be better. I, in some ways got to the point where I quite liked being in hospital, like I felt kind of safe there and it was, like I can understand what people say about becoming institutionalised; I'd be a perfect candidate. I just liked the fact that, you know, I hated the food but breakfast got brought round, and lunch got brought round, and you didn't have to do anything.

IP#1

One is that around that same stage, my daughter [name] had come home. And they'd sent some flowers up. Well, those flowers, I treated as a shrine. It is strange your emotional mix-up at the time, but those were the best flowers in the world, and doctors did use the term "shrine", my shrine there that I'd set up. Just out of total appreciation at the time.

IP#5

I actually tried to help myself and get up and go to the toilet and I never made it naturally. And I did a little bit – it was black – there's this little yellow and black thing on the floor. And the nurse came and she said, "WHAT'S THAT!" I sort of felt terrible. I said, "Oh, it's poo." I think that diarrhoea must be terribly common because my Mum spent an awful lot of time bed-panning me. It was constant. That's constant, terrible; yeah, that's the ultimate, when you can't do that, that is the ultimate, it's shame. You'd do anything to get up and stay clean.

But I could actually taste with my nose. And I'd be very, very hungry and I could taste with my nose. But when I went to put the food in my mouth, it didn't taste right at all. Cardboard. It was very bad.

I had to have Ensure though, yes. Because I couldn't eat. They had to put me on Ensure. Couldn't drink it. It tastes terrible.³⁸ I wouldn't drink it. They had to put it in another thing and down my nostrils and feed me. And then I negotiated with them the next time they were going to take it out and promised I would eat or drink. Which I struggled with, of course, but I forced myself to drink lots of Milo – and chocolate Primo and banana Primo. Anything but Ensure, really packed it back. I've never had an Ensure since, I've never had a Primo since. I've never had a milkshake since. It's put me right off.

IP#10

And being dirty and grimy, I didn't like that. It was when I had a shower a few days later and that was wonderful. Because my hair was all lank and I must have looked a, I mean I normally look not the best, but, then I must have looked gaunt, white, greasy, unshaven.

IP#12

Ten hours after I was back in the ward, I was up walking around. They came in to get me to sit up. But I stood there, I refused help, and then I suppose I would have walked probably [a few metres]. I walked over there, and walked back, unaided.

IP#13

For some patients just the move from the ICU to the ward improved their feeling of wellbeing and several interviewees spoke positively about their time in the ward.

But once I got into the ward, ah, that was different! They took all the tubes out, and I remember there was a Dutch nurse there, an older woman, like in her 50s or 60s or something, gee she was good. She really knew what she was doing.

IP#6

I never had any bad experience whatsoever. It was marvellous up there on the ward. Just brilliant. Staff and medical staff. I never had a problem at all. I couldn't speak highly enough of them.

IP#8

³⁸ Personal communication with the NZLTU May 2011. This response has been shared with the NZLTU dieticians.

Just being on the ward made me feel 100% better. I had my own room and had windows and people could come in and see me when they wanted. And I just felt so much better. Just from moving from ICU into the ward. It was just (snaps fingers) like a light had been turned on.

IP#15

Actually I was really, really pleased to get out of Intensive Care ... it was a huge leap. It felt like a massive leap. Every time they remove something you'd know that things were going really well. Pretty much after the operation the physio had come in and sat me up, and that was a great feeling.

Ron [Benjamin, social worker] had come in one morning and said: "You're going to love your first shower, you won't want to get out." And I actually didn't know what that meant, what he meant by that. I got into the shower, and I literally didn't want to get out. That very first shower was probably one of the most amazing experiences I've ever had!

IP#16

Other participants recalled their time in the ward in more negative even angry tones. Participants were anxious about their care, the sterility of their surroundings and cleanliness. IP#3 was concerned about the attitude of some nurses and the effect this had on her emotions and consequently her recovery. This was reinforced by IP#7 who had felt stressed "really scared and frightened, not feeling very well" when back in the ward. She also expressed serious concern that the "quality of care and nursing was pretty disgusting." She remembered lying on "mucky sheets", lack of help showering, medicinal concerns, general lack of cleanliness and lack of understanding about the operation. This was of concern to the participant because of the particular need for hygiene and sterility. She did develop an infection which was not attended to in time and needed to be drained.

I found that there were several nurses, who were particularly nice, and there were two or three who were right little bitches, and they couldn't have really cared less. There was one, really awful one, and that was incredibly important, I felt, because the good ones could just make you

feel so at ease and the other ones could make you feel so tense and a nuisance, and you didn't want to ring the bell.

IP#3

The first night back in the ward, I was really scared and frightened; not feeling very well and [spouse] had stayed with me until about 11 or 12 o'clock that night. And he left, and I got myself into quite a state, and I don't know for whatever reason, maybe delayed stress of the whole thing. And about 1 or 2 o'clock in the morning, they were trying to make me go to sleep, and I just said: "No, I want [spouse] back." And they were reluctant to ring him, because they knew he'd been up all night too and he was tired, and it was the only thing I wanted, him to come back. And they finally rang and got him back. I guess I got angry because they wouldn't listen to me, but, maybe they knew best. But once he'd come back, and had been with me for a while, I settled down again.

But the quality of care and nursing was pretty disgusting! But to break that down, starting at the start, going off to theatre and all of that was great, I mean the staff for that were fantastic, that was mostly the liver team coordinators that was great. Back into the ward, I recall, first of all, was that my bed was never really made. I remember lying on mucky sheets, and to the extent that my mother requested the sheets be changed.

I recall my first shower being left alone, to deal with that myself, and I recall there was no way I could dry myself, and I remember standing in the shower cubicle thinking: "How do I do this? I don't have the energy to move, I'm in agony." And I briefly remember getting myself back to my room by hanging on to the wall, sliding down the wall, basically, to get back to my room. I recall mum looking at my wound and noticing it quite pink and inflamed and realising that I had infection, asked them to change the dressings and they said: "No, they were too busy, they'd come back later." Consequently when I came out of hospital, I was back the next day, having drains, because I had infection. So I think that was to the quality of nursing, was not good.

The other thing that was a shock, was the food was disgusting. And after going through the support group and learning what I should eat and not eat, when I looked at the quality of food that was dished up to me in the ward, I couldn't believe they would do that. And I remember lying in bed looking up at the air conditioning grid up on the ceiling, and there were these long strings of dust and cobwebs hanging down; I remember thinking: "That's not very sterile when I'm supposed to be completely sterile, clean in this room" too. And the staff ... would come

in each morning and say: “Now, here’s your water, count how many glasses of water you drink, and take note of how many times you visit the bathroom, because of your kidney transplant.” And I remember saying: “I haven’t had a kidney transplant, I’ve had a liver transplant.” The ward is mixed renal and liver. And that was really frustrating and scary to think these nurses don’t even know what I’ve had done.³⁹

IP#7

Survey Responses on Time in Intensive Care and the Ward

A good nurse can make or break how you feel... On the whole they are pretty good, they just have too much of a workload.

SP#48

Section 5 of the survey focused on having the transplant, and time in hospital. It contained a selection of quotes from the 17 interviews, before Questions 11, 12, 13 and 14 were asked. Question 11 asked recipients to comment on their recollections of post-operative nightmares or delusions; Question 12 asked recipients about pain, Question 13 asked recipients about time and Question 14 asked recipients about being back in the ward.

Survey Responses on Nightmares and Delusions

In Question 11, survey recipients were provided with the statement “After the transplant we are started on a range of new medications, and some of us (including myself) had nightmares and/or delusions while others did not.” Survey recipients also were provided with some sample responses from the interviews and asked to indicate whether they had nightmares or delusions in Intensive Care and/or the ward. The follow-up asked about

³⁹ Personal communication with the NZLTU May 2011. As the number of liver transplants has increased in the unit, the NZLTU hopes this is no longer a typical experience for recipients.

the help they received as a result of any nightmares or delusions. A space was also provided for additional comments.

Again, using NVivo 8, each of the survey responses was coded, creating common themes. Out of the 49 survey responses, 22 responders commented on Question 10. Nearly a quarter of the participants responded that they had nightmares and a third had delusions. Of the responses about 40% of those that had nightmares or delusions were men and 60% were women.

I was embarrassed about my nightmares and delusions, as well as being really frightened of them. I didn't want to ask for help, as when I got unsolicited help it was from nurses whose reaction terrified me, threatening to take away my bell when I was screaming and didn't know I was screaming. I thought the wall was falling towards me and that I was falling out of bed. The doctors made me feel as if my sleep deprivation, from being too scared to sleep, was a psychological or mental issue.

Three examples of the hallucination effect provided by survey participants are recorded below.

I have so many memories, like a series of 'short stories'. I dreamed that I had died in several different ways. My memories are, and have been, frightening and disturbing throughout the experience. I had psychotherapy for a few years to deal with the flashbacks of these dreams, such as my skin being cut off. I'm still dealing with it now. And no one warned me about the nightmares and hallucinations. Out of all the things I have been through, those nightmares were and are the most frightening – more than anything else. It's nice to know I'm not alone. Thanks.

SP#6

It started with hallucinations that 'they' were trying to kill me to discredit the liver unit and the great job it was doing. I could not, in my

state of hallucination, trust any of the nurses etc, as they were all part of the plan. I kept asking for my wife to supervise what was being given to me.

SP#11

The morphine is dreadful – audio and visual hallucination, unfortunately a psychologist came in after my visitors were leaving, and I said I could hear them (they were talking in the corridor) so he promptly sedated me with something that made me feel like I was in jelly – when he came back I pleaded with him not to give me any more (totally unnecessary). I had paranoia – I thought the Devil was trying to get me. I felt another night like I was isolated from the staff. Then I thought I was Earth Mother sent to help women. That there would be world peace, a freighter I saw I thought was coming for a world peace convention. I could go on about all the fantasy I thought was real. Audio and visual illusions. The next time I had a procedure I asked for something else. I think patients should be given more information about the side effects.

SP#48

Other survey participants recorded examples of the delusions in the ward and some samples of these experiences are provided below illustrating the degree to which their trust, of the ward and carers, was undermined by the nightmares.

I got really paranoid about everyone, and thought everyone was trying to kill me and no one liked me at all, and the media was watching me. When I would try to answer questions, I couldn't express myself properly.

SP#5

It all felt so real. At first I did not know whether I was asleep, awake or mad, then later I feared going to sleep because of the weird dreams. I felt that nobody would believe me. That disappeared when I was taken back to the ward.

SP#13

My delusions were fairly benign, and I mostly knew they were delusions. I could hear people talking, or I thought people were in my room, when I was alone. I thought that I was pregnant, when I was having a scan, but realised as it was happening that it was a delusion.

SP#31

I also saw spiders climbing up the hospital chimney later in the ward, but that was okay.

SP#41

I do remember 'someone' (a man) hiding behind my room's door. I was also very emotional while in the ward, I cried a lot.

SP#37

My delusions were crazy. I wouldn't have listened. Yes the staff was helpful.

SP#49

Equal numbers of respondents wanted to ask (27%) or did not want (27%) to ask for help. Almost half did not comment in this section about asking for help. Sixteen percent did ask for help and 35% did not. Eighteen percent of respondents received help without asking for it.

I had one nightmare during the first night on the ward. My screaming brought a couple of nurses running, so I inadvertently asked for help and consoling. I had no sense of time.

SP#8

When I experienced this, my God Jesus is the one I turned to for help and He never let me be harmed.

SP#22

A number of respondents realised that it was the morphine that made them delusional or gave them nightmares. As a result some felt 'silly' describing their events to the nurses and this might have affected their willingness to ask for help.

I realised that it was due to the medications, possibly the morphine, as I had had hallucinations previously when on that. I wasn't too worried once I knew the cause, I just felt really silly after telling the nurses what I was seeing.

SP#36

The data from Question 11 (After the transplant we are started on a range of new medications, and some of had nightmares and/or delusions while others did not) is summarised in Table 14, p. 205.

Table 14: Question 11 Responses

	Yes	No	NA	Blank	?
(a) I had nightmares in Intensive Care and/or the Ward	12	33	0	4	0
(b) I had delusions in Intensive Care and/or the Ward	18	27	0	4	0
(c) I did not want to ask for help	13	13	1	22	0
(d) I asked for help	8	17	1	23	0
(e) I received help without asking	9	14	1	24	1

Survey Responses on Pain

In Question 12, survey recipients were asked to look “at your levels of pain pre-transplant and immediately post-transplant.” Again they were provided with some sample responses from the interviews and asked to indicate their levels of pain in Intensive Care and then in the ward. These indications (on a scale of 1-10) were compared to pain levels prior to transplant (one month before) and afterwards (one month and then three months after transplant). Of the 49 survey respondents, most (between 84% and 92%) responded to these questions.

Comments offered by recipients ranged from feeling intense pain to no pain at all due to the morphine or painkillers prescribed to the respondents.

I thought a truck trailer had run over me!!

SP#33

I was very uncomfortable and in pain post-op for two weeks.

SP#44

SP#45 identified with another participant’s comment that “I could put up with quite a bit of pain, but by Jove that was pain!” SP#24 described having “Back pain, not surgery

pain and pain from procedures.” And SP#25 “was never in any pain which surprised at the time.”

The following table summarises the data from Question 12 which looked at levels of pain pre-transplant and immediately post-transplant.

Table 15: Question 12 – Pain

	1	2	3	4	5	6	7	8	9	10	0
(a) Your level of pain 1 month before transplant	25	4	4	0	2	1	2	2	0	2	7
(b) Your level of pain in Intensive Care	13	6	5	5	3	3	3	1	0	3	7
(c) Your level of pain in the Ward	10	8	7	5	3	3	2	1	2	4	4
(d) Your level of pain 1 month after transplant	19	5	8	3	2	2	1	0	2	1	6
(e) Your level of pain 3 months after transplant	24	6	5	1	0	2	1	0	2	0	8

NOTE: The Zero column collects all non-responses as well as responses of no pain. Some are blank, or have a comment clearly showing they do not remember, or cannot put a figure on it.

Survey Responses on Time

I felt I wanted to know the time every 10 to 15 minutes. I didn't know, otherwise, when to expect to see medical staff, medical rounds, visitors, drugs that were time-sensitive, or to understand the passing of time in order to gauge when I might lose a tube or two. I found asking the time by trying to get the nurses' attention was difficult and seemed to frustrate them. Being intubated, it's difficult to explain why you want to know, and my handwriting was appalling! No one could read my attempts at writing which was also disconcerting.

Question 13 looked “at the concept of time after your transplant, while you were in Intensive Care.” Respondents were asked four questions: Did you want to know the time in Intensive Care?; were you told what the time was, enough to satisfy you?; could you differentiate between day and night? and were you able to see out a window? Respondents were provided with six different quotes about ‘time’ from the interview participants and asked to make comments. The responses were almost evenly split about whether patients wanted to know the time or not. Almost a quarter (22%) were not satisfied with just being given the time when they asked. Most (63%) were unable to differentiate between night and daytime. Almost the same number (70%) were unable to see out a window. The following table summarises their responses.

Table 16: Question 13 – Time

	Yes	No	NA	Blank	?	Yes & No
(a) Did you want to know the time in Intensive Care	23	20	1	4	1	0
(b) Were you told what the time was, enough to satisfy you?	26	12	1	6	3	1
(c) Could you differentiate between day and night?	11	31	1	5	1	0
(d) Were you able to see out a window?	8	35	1	4	1	0

One respondent (SP#8), considered that knowing the time was a “factor of being human” and another thought that knowing the time was an “attempt to orientate” themselves. Others commented that they didn’t know what the time was without qualifying whether that was an issue for them or not (SP#3). A sample of the comments is provided below and should be considered in conjunction with the survey table.

The time factor seemed very important on the one hand, but immaterial on the other. I think ‘knowing the time’ is a factor of being human, it grounds us and gives us focus. But really, days merged into nights and

the time wasn't so important. Usually I would ask the time when medications were given – it seemed a touchstone.

SP#8

I had lost all sense of time because I was in a room with lights on all the time, and I was drifting in and out of sleep. I remember wanting to know the date and time to get some sort of reference point.

SP#13

I had difficulty initially telling whether it was night or day, and keeping track of the days and time. I think it took about three days to become fully orientated.

SP#26

I think asking the time for me was an attempt to orientate myself. I think if I knew that I was going through another major operation I would make myself a chart, with the date and time etc. I would get visitors or the nurses to fill it out, so I could look at it every time I forgot the time, date etc.

SP#31

When I awoke I did not know the time, even whether it was day or night, and I had no window.

SP#3

While some patients wanted to know the time so as to judge when visitors or medication might be due, others were able to tell the time by the actual occurrence of the event.

I was in Intensive Care for six days, in a room in the middle so there were no windows and no clock that I could see. The lights were on all the time and I only knew night from day by the time of my visitors. My fiancé was working, so he came in the evening. My parents came during the day. A “room with a view would have nice for such a long stay.

SP#36

SP#12 “knew the difference between night and day and I had no complications at all” but others found it difficult to remember the time in Intensive Care and might have been unconscious. As SP#28 said “It was not a memorable place to be,” and as SP#11 answered “I was in Intensive Care for some days prior to transplant, as well as

afterwards. I lost consciousness in the ward and I cannot remember very much from that time, to the time of being back in the ward.” Although SP#49’s response was atypical with advising that she had “no time fixations as I had a watch with me” the patient could not tell the time and had to learn the skill again. “I could look at it, but it had no meaning.” However, SP#25’s comments were typical of a number of responses “I do not remember much about being in Intensive Care. “The first time I was really ‘with it’ was in the ward.”

Survey Responses on Returning to the Ward

Some nurses were fabulous, some not. During night duty one nurse had squeaky shoes which frustrated me terribly. My bowels were dysfunctional, I had diarrhoea for more than a week while in the ward. Some nurses made me feel it was my fault and didn’t realise, or want to realise, how embarrassed I was. Also in ward rounds doctors kept standing on my long oxygen tubing, which was long enough to allow me to get to the bathroom. This was a bit scary at times. Some medications were missed and I had to ring my bell to ask for them, for example the injection into the stomach. All the NZLTU team were totally awesome, especially Ed, Val, and Margaret.

Question 14 asked respondents to comment about how they felt in the ward after the transplant. Almost all (92% commented). The respondents’ comments covered three main areas: Physical discomfort/ embarrassment and a desire for independence, pleasure at having a shower, and nursing care. Sample comments are provided under these broad themes.

I was so ashamed of myself most of the time, because I would ring the bell thinking I needed to do a wee and the nurse would come to help me, and either I couldn’t go, or they would be too late and they would

have to change the bed and get me cleaned. For times I couldn't go, they would leave a bottle with me, and I was so doped up most of the time that I would spill it due to my tremor, but that is not their fault. They gave me excellent care!!

SP#5

I had some difficulty with bowel and bladder movements for two to three days and little appetite. The nurses were wonderful.

SP#26

I felt very weak. I couldn't believe how weak I was. I hated not being able to do things and having to ask for help.

SP#31

Yes, I remember like it was yesterday the operation seven years ago, lying in my own poo. I felt like a baby, although the nurses said don't worry. When they changed the sheets, I swore, spat and yelled abuse because the pain was so great.

SP#33

It was just draining. Also I remember having digestive problems (with the drugs), and getting to the toilet was a mission (getting myself there, there was no privacy), I would clean up. I remember dripping all over the floor (of course other patients were trying to get in), I cleaned it all up – luckily there was a cleaning product in there – then having to ring for another gown and I washed out the other one before putting it in the laundry. It was so demoralising. Hopefully you pick up your dignity before you go out the door. I would try to do as much for myself as possible as the nurses have so much to do.

SP#48

Many of the respondents were concerned about gaining independence and removing the reliance on staff for toileting and other needs.

After one day in my bed I wanted to go for a walk to the toilet but I was hooked up with a couple of catheters. I asked the nurses to remove them. They said it was too early for me to start walking, but I said I really wanted to go to the toilet by myself, and from then on there was no stopping me and my bottle on wheels.

SP#13

I was delighted when I was transferred from Intensive Care toward 7B. I could have normal meals, I could sit in a chair in front of a desk to do some writing. I was pleased with the spacious room with my own toilet. I could control the lighting easily and it was so quiet.

SP#9

On the third day I decided to walk to the end of the ward to look out over the park, but when I got to the window I couldn't focus, I don't know why. One night I got out of bed to go to the toilet and fell. I caught the bed handle against my side, and it really hurt. I had a bit of a crying fit. I was very fed up with myself.

SP#16

I set up a routine of breathing exercises and walking exercises. On the first day I was vomiting when eating food. I could go to the toilet and the shower with [spouse] easily. On the second day I was walking to the lifts to see people out. I felt a little guilty that my progress was so fast, and I used to change my rate of walking.

SP#41

Many of the respondents mentioned the delight at being able to have a shower. This simple event featured prominently in 15 responses. Samples are provided below.

I remember two part-time nurses coming in to shower me and do my bed and they were angels. Kindness goes a long way in these situations.

SP#8

I looked forward to sponge downs and the first full shower on the third day.

SP#26

The shower was wonderful; a lovely nurse helped dry me, and took me back to bed.

SP#33

I was in a single room with my own shower and bathroom, so it was like a five star hotel to me, apart from the surgery aspect!

SP#35

It was just great to have a shower for cleanliness reasons instead of for the easing of that dreadful itch.

SP#38

The third main theme that emerged from this question focused in the staff and nursing in particular. Apart from a minority number of negative experiences, most respondents expressed gratitude for their care.

Some of the respondents' comments are below.

I was asleep when they moved me back to my ward. I woke up to find that I was hooked up to a lot of gadgets on both sides of my bed. I thank the nurses from the bottom of my heart for taking care of me. They do their job at 100 per cent, both the day and night nurses.

SP#3

Initially I felt far less secure in the ward than in Intensive Care. The quality and attitude of the nurses varied hugely. Several were amazing and allowed me to feel safe. Two others only seemed interested in their own social lives and appeared disinterested to help me, though they did, but reluctantly it seemed. That was horrifying.

SP#8

All the nurses and staff were so nice and helpful. I was so happy to feel better every day. I was satisfied with the progress of my recovery and so were the doctors.

SP#9

I can't thank the nurses enough for looking after me, I had nothing to grumble about, they were very good to me. The only complaint was the room I was in was dark with no fresh air.

SP#14

For the first couple of days it was painful trying to get upright in bed, or out of bed, but I learned to get the nurses to help me, and found everything much easier. They did a fantastic job, so I tried not to call too often.

SP#18

In some ways it was good for me to be so helpless, and to have to ask for help. The nurses were mostly amazing.

SP#31

I can't think that I could stress enough just how good the nurses were on the ward.

SP#35

All the staff treated me with respect and nothing seemed to be of any trouble to them. I know at times I needed help, and the nurses were busy so I just had to wait my turn.

SP#38

I was in the old hospital ward and it was quite a walk to the showers. I'm very clean and independent; it was so exhausting, I remember

sitting in the shower room waiting for ages after ringing for the gown to be tied (if you were lucky to get one that tied) or help to get back to bed. It was just draining. Also I remember having digestive problems (with the drugs), and getting to the toilet was a mission (getting myself there, there was no privacy), I would clean up. I remember dripping all over the floor (of course other patients were trying to get in), I cleaned it all up – luckily there was a cleaning product in there – then having to ring for another gown and I washed out the other one before putting it in the laundry. It was so demoralising. Hopefully you pick up your dignity before you go out the door. I would try to do as much for myself as possible, as the nurses have so much to do. A good nurse can make or break how you feel I had a couple of trainee nurses that were a bit clueless. I had one I asked for a wash and she thought I wanted to get up for a walk... I sat freezing with just a small towel for an hour or so. I also had another one that was changing a dressing and then started pulling out tissue. On the whole they are pretty good, they just have too much of a workload.

SP#48

A total of 45 of a potential 49 respondents answered Question 14. The dominant themes that emerged from these questions focused on the respondents' desire to gain independence and dignity. Most suffered discomfort and pain but almost immediately following the transplant the overwhelming focus was on getting better and returning to 'well life' and being human again. SP#36 summed up the feeling by advising that she "begged to leave Intensive Care on the morning of the sixth day. I got to the ward and a room of my own, with windows. I felt so much better just by being on the ward. I felt Human again!"

Conclusion

My first thoughts were: “How dedicated they all are,” taking me bit by bit back to normal activity. Then how marvellous to be able to get out of bed in the morning, sit in the chair, and look out the window over the city and out over the harbour into the Hauraki Gulf.

SP#11

Most transplant patients did not enjoy their experience in the Intensive Care ward aside from the obvious relief of having come through the operation itself. The general comments focussed on distressing nightmares and delusions, some suffered pain and general discomfort. The patients then became determined to help themselves recover and perform ordinary daily tasks such as walking, toileting and showering on their own. This determination seemed to result from a desire to regain dignity as well as physical recovery.

The message emerging from the comments was that patients considered the return to “normality” as essential as the recovery itself. This is illustrated in the focus on time which one patient described as a “factor of being human” and another thought that knowing the time for me was an “attempt to orientate” themselves.

While most staff were praised for their concern and expertise, some respondents were reluctant to impose on the nurses for seemingly minor issues. However, it was these so called minor issues that respondents also identified as being of immense importance to

them at this time of the recovery. This is the last chapter that deals with recipients' experience in the ward following transplant.⁴⁰

Chapter Nine is about the mixture of emotions that recipients go through knowing that someone will die to provide the liver for their transplant. It looks at knowledge the recipients might have about their donor or donor family, the opportunities they have to communicate with this family, and how they come to terms, over the years, with the depth of their gratitude.

⁴⁰ Personal communication with the NZLTU May 2011. Patient observations, both negative and positive, presented in this chapter have been shared with staff in the unit. The observations, especially negative feelings experienced in the Intensive Care Unit (ICU), will inform educational resources for those awaiting transplant. The ICU management cannot be changed (drugs, noise, 24 hour lighting), neither can it be avoided after major surgery, however, the NZLTU has identified that they can better prepare patients for this experience. The medical and nursing staff noted that the positive feelings towards them (when the "delirium" associated with waking up after general anaesthesia has worn off) were very humbling for those who deliver this care.

Chapter Nine: Accepting the “Gift of Life”

I do feel that I somehow owe something to someone, but it is not a feeling I can adequately describe or even understand. I do some charity work – just to help deliver some meals on wheels – that sort of thing. I had never thought much about it before my transplant.

SP#35

Introduction

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.

Accepting a Donor Liver

Others have also struggled with accepting the concept of the gift of a donor liver, as shown in the two quotes below:

But I then realised it was between my life and death. They said: “It will probably take six months, on average, to get one.”

IP#3

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

IP#4

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.

IP#1

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 anymore, 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 anymore, 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."

IP#4

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

I had gone into a coma... my liver functions were very, 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. 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.

IP#10

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.

IP#5

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.

IP#7

Some recipients demonstrate 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.⁴¹

IP#6

Gratitude

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. The theme “Honour the donor” emerged, which 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, p. 330). My interviews have also shown that we, as recipients, do demonstrate an appreciation for the “gift of life,” however there are some differences to the research by Forsberg et al. 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 recipients wanting 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 10 years.

IP#11

⁴¹ Personal communication with the NZLTU May 2011. This has been another learning point for the NZLTU regarding the need for absolute anonymity with donor location at the time of the transplant.

...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.

IP#15

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.

IP#5

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.

IP#10

Experiencing organ donation through the gift of a liver may also awaken or change our experience of spirituality or thinking 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.

IP#10

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... even now, I don't propose, 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 anything else happens, it's because of the grace of God.

IP#5

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 been." But, kind of... on a daily basis you become more accepting, because it's there and it's working.

IP#1

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.

Gratitude expressed by survey participants is summarised in Table 17 below.

Table 17: Survey Participants’ Comments on Gratitude

	Yes	No	N/A	Blank	?	Yes & No
(a) Do you feel gratitude in relation to your liver transplant?	46	1	0	2	0	0
(b) Your own family?	45	1	0	3	0	0
(c) Your donor and donor family?	46	0	0	3	0	0
(d) The New Zealand Liver Transplant Unit?	46	0	0	3	0	0
(e) Organ Donation New Zealand?	44	1	0	3	1	0
(f) New Zealand society in general?	30	8	0	8	3	0
(g) Your employer?	14	15	8	12	0	0
(g) Other (<i>should have been (h)</i>)	15	2	0	32	0	0
(h) Do you feel a need to reciprocate in some way?	34	6	0	8	0	1
(i) Do you want the NZLTU to call on you to help others facing transplant?	35	6	0	5	3	0
(j) Do you believe the experience of our caregivers should be researched?	29	9	0	9	2	0

Survey participants, in the table above, indicated their gratitude to a number of “other” people and organisations than were provided as options in the survey. Examples of these are shown in the table below.

Table 18: Examples of “Other”

Welfare System	Novo Nordisk Diabetes Services	Closest Friends
Hospital staff	The Roche	Son-in-Law
GP	Parnell Cathedral	Caregivers
Social Worker	Bethli (research work)	My Jesus
Nurses and staff in the liver ward		Wife

Shifting Priorities

After our liver transplants, a number of us experienced a significant shift in our priorities. When Governor Casey returned to his position, he described major changes in his outlook and priorities:

On the day of my return to the Capitol, December 21, 1993 – six months and a week after the surgery – there were no foes to greet me, no stunned looks, no disappointed rivals. Everybody was happy. All pettiness, including my own, fell away in a general atmosphere of rejoicing.

I had reclaimed my powers as governor at 12:01 A.M. that morning.
(Casey, 1996, p. 171)

Then he wrote further:

I looked back on my whole life and career and medical ordeal. It all seemed to come together in a simple witness for the powerless. This, as best I could deliver it, would be my message: Guiding all political decisions should be an overriding, inviolable respect for our common humanity. No one forgotten. No one counted out. No one left behind.

For all our differences we are a family, the human family, and in families all are equally valuable, equally protected, loved, and cared for.

That would be the spirit of my campaign.

(Casey, 1996, p. 209)

Early indications from this research 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 comments 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...

IP#1

Little irritations may become less important; personally rush hour traffic in Auckland doesn't 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.

1P#7

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-centred way, I suppose. But now, it's not like that at all. Um, and I gravitate towards people that may have issues.

IP#10

Many I interviewed remember their liver transplant anniversary, and for some, it's a second birthday. Some 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*.

IP#4

Indeed, almost all recipients do commemorate this date (of transplant) and on special anniversaries (5 and 10 years), send cards to the NZLTU.⁴²

However, one male recipient likens the experience to a "blip" in life:

So that's why I say to people, if you're told you need an op, a major operation and you've, 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!

IP#6

Another sees 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.

IP#5

Feeling undeserving of a transplant has been commented on by male and female recipients. For some, there can be an added cultural dimension, as shown below:

⁴² Personal communication with the NZLTU May 2011.

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.

IP#16

Communication with Donor Families

After our liver transplants, the NZLTU, and in particular our donor coordinators, 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.

IP#16

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.

IP#6

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.

IP#3

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 me 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.

IP#8

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.

IP#1

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 a 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. [Be]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.

IP#15

Munson wrote, “perhaps they seldom write thank-you letters 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 endeavour. 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 19 below illustrates the communication between recipients and donor families for the 17 liver transplant recipients interviewed.

Table 19: Interview Participants on Communication with Donor

Interviewees	Male		Female		Total	
	As % of Male	As % of Female	As % of Male	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%
Sub-total	9	100%	8	100%	17	100%
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%
Sub-total	9	100%	8	100%	17	100%
Replied to donor family	0 ^a	0%	0	0%	0	0%

(^a Wants to reply, feels guilty for not replying)

By comparison survey participants responded as per Table 20, p. 229.

Table 20: Survey Participants on Communication with Donor

	Yes	No	N/A	Blank	?	Yes & No
(a) Have you written to your donor family?	37	11	0	1	0	0
(b) If you have not written to your donor family, have you tried to write but couldn't?	7	5	37	0	0	0
(c) Have you received a letter or card from your donor family?	11	35	0	2	1	0
(d) If you have received a letter from your donor family, have you replied to them?	6	7	34	2	0	0
(e) Do you see your new liver as a 'gift'?	49	0	0	0	0	0
(f) Do you see your new liver as a 'burden' or an 'obligation'?	6	33	0	6	1	3

Because I've never heard from my donor family, and because of time (nearly ten years) I don't think of the donor and family as much as I did to start with, say in the first two years. I do feel an obligation to the Liver Unit and society in general to care for the liver, and make good use of the extra time I've been given. It's a gift with no strings attached, but I've attached my own.

Many survey respondents commented on this sense of obligation as shown by the first quotes below, while some others were more pragmatic as shown by the last:

I do feel an unresolved obligation to the donor and that my very ordinary subsequent life has not justified it. But I know I will never win a Nobel prize and accept it as the incomprehensibility of fate.

SP#34

No, I haven't been able to write. I give myself enough to live up to. How do you say 'thank you' for a body part? It's not enough – will never be enough. As well I feel that I wish I could be more, do more, be smarter, do better? To me it's like I'm living for more than just myself – I'm living for all three of us. The two donors and myself. It's

kind of a burden, but I accept it. Like I said, how much more could I say to the families? I can't find the words, just a bit of survivor guilt.

SP#6

I have taken what might be seen as a selfish approach to this issue. I treat it as my liver and that's it. I was a donor also, at the time, so it could have gone either way. That's not to say that I don't appreciate every day what I have received. I often think the donor would just want me to live my life and feel no guilt.

SP#29

Like me, most survey respondents struggled to find words meaningful enough to express the overwhelming gratitude for the gift of life.

It took me around 200 hours on the computer to write the letter. It was one of the most difficult letters I've ever written. I tried to send money for flowers to be delivered with the letter, but because the donor came from Australia it was too difficult. That was a shame. I do feel that the liver isn't mine. It belongs to the donor, the NZLTU, my doctor, and me. There's a slight burden or obligation, but it's best to keep it in the background.

SP#41

Since it took me so long to write to my donor (two years after my transplant), I thought about them every day. A friend of mine helped me write a letter. I really didn't know what to say only Thank you so much for giving me the greatest gift of life for me and my family and friends. I feel sad they have not responded, maybe one day. I write every year.

SP#43

I wrote to the donor's family. I was not satisfied with what I wrote, but I felt that some acknowledgement had to be made. Even after ten years I would still like to meet the family.

SP#13

In contrast to this though, a few others were eager to write, and the quote below by SP#33 shows the impact possible from a reply from the donor family.

I could not wait to put pen to paper, and write a letter of my feelings to my donor family.

SP#38

Yes, I wrote as soon as I was allowed. We have written every couple of months, I know his first name. He fell off a ladder and landed on his head, he was brain dead when he got to hospital. They are working on it so that we can meet them, the family. He was very religious and didn't drink much. In a strange way it has made me more humble, I used to be a bad bugger. I think that had to do with having Hepatitis C from the age of 16, I am now 45.

SP#33

The lack of reply for most of us from our donor families leaves us wondering whether we chose to write about the things the family wanted to know.

I do wonder about the donor who died, who has kept me alive. In the letter to the donor family I often wonder whether I wrote the things they would like to know.

SP#25

This uncertainty is a large part of the problem with writing to our donor families. On the one hand we are overwhelmed with gratitude, and on the other, the donor family is overwhelmed with grief. It seems an unlikely chance that we will strike the right balance.

I wrote to my donor family about eight months after my transplant, but I got no reply, so I wrote again after two years. I received a reply thanking me for making the effort to thank them, but I was told they were still very upset over their loss (husband/father) so I just replied saying if they ever wanted to see me, I would be happy to oblige.

SP#18

I can only imagine that the grief of the donor's family was such that they didn't want to discuss my gratitude with them.

SP#47

I would like to let 'them' know just how honoured and grateful I am, but I would hate to think that I may upset them or hurt them in any way. I do not think it is my position or place to encroach on 'them' in any way, but I would be rapt to ever hear from 'them' that it was OK to say thanks, etc, etc.

SP#35

I tried to write to my donor's family, but I got very upset and I didn't want my emotion to add to their pain of losing a young son. Now I think it's too late to write, as it might bring the pain back for them. I feel guilty that I didn't write.

SP#16

Despite the difficulty in writing to donor families, survey respondents clearly held them in deep respect, and think about them at times known to be especially difficult, such as Christmas and anniversaries.

I think the donor and donor family are kind-hearted and generous people. They give hope and love to other people. They are respectable and honourable members of the community. I wish that I could live happily and survive as many years as I can, to show them that their donated organ really lives on and allows me to live for so many years. I am really grateful to them.

SP#9

I would like to meet the donor family some days, I think it's just curiosity. What sort of people are they? Why did they choose to donate? But I am really worried they wouldn't like me or would have preferred the liver to go to a different sort of person. I always reflect on my donor, and I say a special prayer at Christmas and on my anniversary. I still feel sad for the donor's family on these days.

SP#24

I sit in the Thanksgiving Service and I wonder if ‘my family’ is there. Am I sitting NEXT to them? I would like to meet ‘my family’, mainly so they can see I am living a normal healthy life, thanks to their loved one’s passing and gift of life. I would have been long dead without them. I usually write once a year on either the anniversary of the transplant or at Christmas, sometimes both.

SP#36

While some recipients would like to know the obvious details of their donor such as age, gender, or perhaps cause of death, some others would be happy just knowing where the donor was buried.

I have written many letters to my donor family, but I haven’t sent them. They never seem like enough. I would like to know where or if he is buried. It is very strange to have a dead man’s organ in my body. There is no set social ritual to deal with transplants.

SP#31

I would like to know who my donor is. I would like to know his name, and where he’s buried. If I knew where my donor was buried, on that day, for the rest of my life I would go there. And I’d sit there, from daylight to dark.

SP#45

Overall the feelings of survey recipients about their donor families can be summed up in the following quote:

After ten years I still think of my donor and family a lot. I have shared many happy occasions in this time and on those special days (21sts, weddings) and now three grandchildren, my donor and donor family are foremost in my mind. I always send them another special thanks in my mind. I will never forget.

SP#39

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 takes it, makes it a bit more distant. If I had a picture in my mind of whether it be 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.

IP#7

Table 21 (p. 234) shows how much factual information the seventeen recipients interviewed have of their donors. However, there is a lot more “gut feeling” about the donors and surmises 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 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 doesn't 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 21: Interview Participants on Knowledge of Donor

Gender	Age Range	Reason for death	Other
Male	30s	-	-
Male	50s	-	-
Male	Middle-aged	-	-

Gender	Age Range	Reason for death	Other
-	-	-	Australian
-	-	-	From Central Otago
-	-	-	Cause of death known
Male	20s	Motor accident	-
Female	Young	Accident	Sporty
<i>9 recipients knew nothing at all about their donor</i>			

By comparison survey participants responded as per Table 22, below.

Table 22: Survey Participants on Knowledge of Donor

	Yes	No	N/A	Blank	?	Yes & No	I know	Maybe
(a) Should the NZLTU offer consistent information to us about our donors?	21	21	0	5	1	0	0	1
(b) Are you happy with the amount of information you have about your donor?	31	13	0	3	0	2	0	0
(c) Do you want to know your donor's gender?	10	21	0	4	0	1	13	0
(d) Do you want to know if your donor came from New Zealand or Australia?	16	24	0	4	0	1	4	0
(e) Do you want to know your donor's age range?	14	20	0	4	0	2	9	0
(f) Do you want to know your donor's ethnicity?	14	30	0	3	0	2	0	0
(g) Do you want to know the reason for your donor's death?	15	25	0	4	0	1	4	0

Some recipients see one aspect of attending the Thanksgiving Service (annual in Auckland, biennial Wellington and Christchurch) 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?”

IP#15

Whenever I go to the gathering, every year, I’m always looking. I’m always looking, you know...

IP#4

However, other recipients 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.

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.

IP#2

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.”

IP#3

Survey respondents understood the reasons for anonymity between donor families and recipients, and to some extent willingly shared them, but running through the responses was a thread of mild curiosity about the donor, and often a strong desire to know something about them.

I don't have any problem with the [Liver Transplant] Unit keeping the information reasonably tight. I'm just curious about the donor's circumstances.

SP#44

I don't know anything about my donor. I would love to know the gender, the age and the reason for their death. And I would love to speak to the family.

SP#15

I am ambivalent about the amount of information, but I understand. The reason why the information is limited is to protect the privacy of both the donor family and the recipient. I know that my donor was male and in his thirties. That is all. In some ways it is enough. I have never known if he was an Australian or a New Zealanders, but I would like to know. I don't want to know how he died. If it was suicide or murder it would be very hard to deal with. I am more curious about who he left behind? Wife? Children?

SP#31

Personally, I imagined all sorts of scenarios. I tried to get to know my liver when I got it. Having no information is really frustrating. I wanted to make some kind of connection with it, to help in appreciating and caring for it. I don't want to talk to, or meet, the donor family as that could make me feel really guilty, especially if they didn't like me, or what I was doing with my life, but I'd like to know a bit of information about the donor.

It seems that there is some inconsistency with the amount of knowledge given to us about our donors, with some recipients, like me, knowing nothing about them, and others knowing a few details such as age range, or gender. Many survey respondents mentioned a desire for basic information to be available on request.

Everyone is different, but to be able to access details about your donor is a daunting choice to make. I do believe that it would be a good thing to have the choice to find out this information if you want.

SP#35

I think that if you want to know details, rather than names, this information should be available – but not straight after transplant. I am not sure how long the recipient should wait, but your brain is so scrambled with drugs and the enormity of it all immediately post-transplant, that I think we would cope better with the information at a later date.

SP#24

I know New Zealand has a ‘no’ policy when it comes to knowing your donor, but surely we should be able to get the chance to find out basic details such as sex, first name, age. I think I know the sex and age of my donor through a family member knowing someone who attended the funeral (etc) around the date of my transplant. The co-ordinators should also be able to use their discretion.

SP#37

For most of us the desire for some information about our donor is not idle curiosity, but rather a mechanism by which we may be able to identify with the donor’s family.

I would like to know more about my donor and her family. I would like to meet them. I find it hard when I write a note to them each year, starting it off ‘To my donor’s family’. A name would be much nicer. I write each year to let them know I am still around and that their daughter’s liver is still doing her proud!

I would also like to know if ‘my family’ were happy receiving my letters. I haven’t had one returned, so presumably they are, but if I

knew definitely that they wanted to hear from me, I might write more, tell them more etc, or write more often.

SP#36

To my delight not long after I wrote to the donor's family I received a letter explaining all about their loved one and would eventually like to meet with me. The meeting came about three years later. It was an emotional experience. After nearly eight years we still communicate and are one big happy family!!!

SP#42

Ultimately though, survey responses showed that specific knowledge of the donor, while desirable, was unimportant in the greater scheme of things:

Curiosity is a natural thing, but in the long term none of [those things] are necessary. The donor gave and I am privileged to be the one accepting. Who he or she was is irrelevant, it's the thoughtful act of giving that is important.

SP#11

I would like to know the answer to all those questions [age, gender, etc] but I know that they are irrelevant in the sense that the donor liver was considered suitable, and was successful. Perhaps knowing little or nothing is really the best way.

SP#13

I seem to have less curiosity than most people. I don't know why. It doesn't seem important as to what gender, ethnicity, etc my donor was. I suppose the only thing which would concern me would be to know that he or she was a healthy person who didn't abuse his or her body.

SP#8

As time passes it is less of an issue, although I did want a few answers at the beginning. I know nothing, except suspicions. I was told it was an excellent liver. Is anything more important?

SP#32

It might be pertinent to ask the question as to whether the immense gratitude expressed by recipients towards the transplant team would be seen if this study had been conducted in a country where medical care is not provided by the state, such as the USA where patients pay insurance premiums, and suspicions exist that lower policies provide inferior cover, or Asia where all care is privately funded and hence only available to the wealthy.

Many of the observations made in this chapter highlight an issue ignored by transplant programmes and donor procurement organisations that not providing any donor information depersonalises the transplant process and that transplant differs from other major surgery because of the need for the mental acceptance of the organ from another human being.

Chapter Ten: Findings and Recommendations

I thought they were waking me up to say: “Wake up, we’re going to start the transplant, the operation.” When I’d woken up I didn’t actually know that it was all over, it was all done. Because the nurses woke me up, and I was struggling to say something to them, and they [said]: “Do you need a pen?” So went and got a pen and paper and told me to write. I couldn’t write! So I was in shock because my hands were not writing, so I struggled to write, and they were all of course running around wondering what I was trying to communicate and thinking I was in pain or something. And all I was writing was “thank you.” And I gave it to them. That’s all I wanted to say: “Thank you.”

IP#16

This research highlights similarities and differences within a group of people that have a shared experience at one level and a unique experience at another level. Recipients come to the transplant experience from a variety of medical backgrounds. They may present with co-morbidities, 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 of 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, and even in the ICU. Some may have days or weeks to live and know it, others may have months or longer to live under excellent medical management.

The findings of this research, reflected the findings to some degree of the European study of the socio-economic determinants of health-related quality of life for children and young people in that they started to show a possible trend towards psychological wellbeing issues (including moods and emotions) more than economic wellbeing issues dominating recipients’ wellbeing.

The “nothing about us without us”⁴³ research approach had enormous benefits. Other recipients knew my history. In an interview setting we had instant rapport and trust, a shared language, a common experience and a connection through the medical and surgical staff and resources we all benefited from.

Significance of the Research Findings

This is the first major international research of the wellbeing of liver transplant recipients, focused on the expertise of their experience. It fills a gap long recognised in international literature reviewed in this thesis. Integral to this research and of on-going benefit to the transplant research community has been the development of a comprehensive new survey tool for the assessment of recipients’ wellbeing (see Appendix 15, p. 316). This can be used or adapted by others, as illustrated in the section Recommendations for Further Research (p. 246).

As previously noted, the survey has many advantages over the generic QOL measurements in that it is designed specifically to collect information on topics specific to liver transplantation. It should be noted that this tool needs to be validated in other populations of adults, deceased donor transplant recipients and then trialled in different populations, such as live donor transplant recipients.

While this research is conducted from the patient-recipient standpoint, it is rigorous and scholarly. The substantive literature review which highlighted this “gap” in international

⁴³ This phrase is a powerful political slogan and motto of the international disability rights movement and is attributed to James Charlton, author of the book *Nothing about Us without Us: Disability Oppression and Empowerment* (Charlton, 2000). It is also an important principle of the phenomenological approach undertaken in this study.

literature, is appended (see Appendix 19 on CD Data Disk) for others who will research in this area and may add to the recipient voices who might find the hitherto spaces of silence. From first becoming unwell, the thesis describes the impact of the communication point in the patients' transition to being told they need a transplant. Two key concepts arise: the denial of the illness and its seriousness by the recipients; and the mode and delivery of information from medical practitioners to New Zealanders becoming unwell. Some key recommendations follow.

The external significance I hope will be widespread. The significance for the liver transplant recipients who participate in this research should include an acknowledgement or validation of their experiences. They should be able to recognise their experience and experiences of their 'fellow travellers' in the research, and hopefully it will add something to their lives. The significance for those liver transplant recipients not eligible for inclusion as participants in this research, for example post-2005 recipients, may be similar. The research and its presentation in summary through pamphlets, to future liver transplant recipients and their families may assist these New Zealanders in coping with thinking about liver transplantation in their personal family context.

The research will hopefully have a significant impact on strategic and operational policies as well as on processes. It may be able to provide an evidence base for process and policy changes in both the Ministry of Health and Ministry of Social Development. It may also be able to influence changes within other agencies that have a connection to liver transplant recipients, whatever these turn out to be. The research may also prove of value to agencies such as Organ Donation New Zealand, who may find experiences and

concepts that are exposed through reflection on the donor, organ donation and the donor family useful in their work.

Recommendations from the Research

1. The NZLTU team (physicians, surgeons, coordinators and social workers) need to better understand the gaps in information available for patients undergoing assessment. Many liver transplant recipients stated that whilst on the waiting list, they felt scared and less informed because they were poorly informed about all aspects of liver transplantation. There is therefore a need for the Liver Transplant Unit team to design the assessment based on the probability that patients are more scared. It is important to realise that there is a large unmet need in the current written material that patients and their caregivers receive prior to assessment.

Specific issues that patients struggle with include the following:

- (i) the assessment procedure, including:
 - a. the decision making process (chances of being listed);
 - b. what constituted contraindications to listing;
 - c. what happened if a patient is not considered suitable for transplantation – reassessment at a later date, option of an independent second opinion (including review by NZLTAG), expected survival and access to palliative care.
- (ii) the waiting list period:
 - a. the expected waiting time
 - b. how patients are prioritised – first-come first-served, or other system;

- c. what was allowed whilst waiting with respect to driving, employment, physical activity, travel from home;
 - d. the risk of being removed from the waiting list because of disease progression;
 - e. new strategies to reduce this risk including live donor liver transplantation.
- (iii)** the transplant procedure including:
- a. what to do when phoned i.e. what to bring to hospital;
 - b. chance of not going ahead (unsuitable donor).
- (iv)** the Intensive Care stay:
- a. nightmares;
 - b. waking up.
- (v)** the ward stay;
- (vi)** the discharge home/transplant house:
- a. what to eat;
 - b. when to drive;
 - c. when caregiver can leave.
- (vii)** the later post-transplant period:
- a. if/when does physical fitness ever return to normal, or are the effects of malnutrition from liver failure irreversible?
 - b. if/when does cognitive functioning (memory, intelligence) return to normal or are the effects of chronic encephalopathy irreversible?
 - c. if/when does quality of life ever return to normal?
 - d. if/when to resume work;
 - e. if/when will fertility returns (male and female);

- f. if/when pregnancy will be possible and the associated risks for both baby and mother.

It would be important for liver transplant recipients to be involved in producing the next version of the Liver Transplant Handbook so that they can address specific fears that they experienced themselves during the transplant process (from the time of assessment, through to late post-transplant). It would also be helpful if a handbook summarising this research be provided both as a freely available education resource for all potential transplant candidates prior to assessment and as recommended reading for all members of the Liver Transplant team.

2. Offer transplant recipients the opportunity to obtain consistent limited information about their donor if they wish it, including the donor's age and gender, and allow the recipient to contact the donor family to express gratitude for receiving this "gift of life" and provide them with the recipient's progress following transplantation.
3. Harness the gratitude recipients feel, in promoting organ donation or other related activities, as 69.3% of survey participants felt a need to reciprocate in some way for their second chance at life.

Recommendations for Further Research

1. Similar phenomenological research into the lived experience of caregivers and family members of patients with liver disease that leads to transplantation. This research should be undertaken by a caregiver who has lived this experience and should address many of the same issues described above. This research should also

lead to the preparation of a separate resource handbook for caregivers of future potential liver transplant candidates.

2. Similar phenomenological research into the lived experience of paediatric liver transplant recipients. There are specific issues which relate to paediatric transplantation. Chronic childhood illness, before and after transplantation, may severely disrupt physical, emotional and educational development with lifelong consequences for both the patient and his/her family. Specific issues include the following:
 - a. an apparent “deferring” of their experience to the parents’ experience;
 - b. the emotional connection to the paediatric medical team and a “resistance” to moving to adult maintenance care;
 - c. integrating back into the school system with traumatic effects of being “held back,” experiences of bullying;
 - d. use of the transplant/sickness as an excuse to get out of disliked activities;
 - e. resisting peer pressure to drink alcohol, take drugs;
 - f. perception of not being “normal” in a work context, although not acknowledging any barriers to living a “normal” life.

There appear to still be some common areas between paediatric and adult recipients, including gratitude, thankfulness and appreciation for the donor and their family. However, the paediatric experience appears to be quite different from that of an adult recipient. Adult recipients are likely to remember some, if not all, of the time leading up to the listing for transplant, the transplant process itself (i.e. going to theatre, waking up in the DCCM), and the recovery time post-transplant, although a recipient’s memories may be affected by whether they were in a coma or suffered hepatic encephalopathy

during that time. Adult recipients may be able to compare their experience of pre-transplant life and post-transplant life, where paediatric recipients may not have clear memories of life before the liver transplant.

There may also be a wider array of reasons for adult transplantation, including some reasons that may be seen as “lifestyle” reasons, not probably within the experience of paediatric recipients. These could include alcohol use or abuse, and drug use.

3. Phenomenological research into the lived experience of recipients of a live-donor liver transplantation, including the relationship to the donor before and after the operation, feelings of guilt, gratitude, need to succeed for the donor.

Living donors in liver transplantation (LDLT) tend to be family members of the recipient, which brings in a very different dynamic to that of accepting a “gift of life” from a stranger. LDLT has been available through the NZLTU since 2002. During the late 1990s, international experience with live donor liver transplantation increased rapidly and important technical and donor safety issues began to be addressed. After extensive discussion the NZLTU developed a detailed protocol for LDLT and approval was granted by the Auckland Regional Ethics Committee to introduce the procedure in 2001. The first LDLT was undertaken in August 2002 (McCall, Johnston, et al. 2009, p. 25) and since then, there have been a total of 35 live donor liver transplants.

Most (80%) were performed in paediatric transplant candidates and therefore many of the issues related to paediatric transplantation pertain to this.

4. Phenomenological research into the lived experience of live donors. Most will be close family members of the recipient of a live-donor liver, the donor is usually parent but often uncle, aunt, or grandparent. The relationship between the donor and recipient will be entirely different for an adult recipient of a live-donor liver where the donor is usually the spouse, but occasionally sibling or child. If the indication for live donation is acute liver failure, the emergency nature of the transplant assessment and procedure may also influence the decision to donate and indeed the outcome for the recipient.
5. Phenomenological research into the lived experience of a patient who undergoes liver transplantation in North America focusing on how the experience of a North American liver transplant candidate will differ from that lived by a New Zealand transplant candidate, including transplantation in a privately funded health system and impact of not having insurance, listing in a large organ procurement organisation, multicentre listing, travelling to different regions for extra regional listing, impact of organ listing, prioritisation and allocation using the MELD system.
6. Phenomenological research into the lived experience of a patient who undergoes liver transplantation in an Asian country, to evaluate the impact of different cultures and religions on the acceptance of organ from either a deceased donor or live-donor, from a donor from a separate ethnicity, gender, cast, or religion. This should also highlight the issues faced in many Asian countries, such as Pakistan and India, where the entire procedure must be privately funded thereby limiting access to transplantation to only the very wealthy.

7. Phenomenological research into the lived experience of a New Zealand Maori who undergoes liver transplantation in New Zealand, comparing to that of a non-Maori. This should explore the impact of Maori cultural beliefs on the acceptance of organ from either a deceased donor or live-donor, either Maori or non-Maori. The current attitudes of the greater Maori community towards organ donation, both deceased and live, could also be studied.

8. Phenomenological research into the lived experience of a patient who undergoes liver transplantation through “transplant tourism” i.e. when the privately funded patient has travelled to a foreign country (such as China or India) to receive a deceased or live-donor organ. Specific issues to be explored include:
 - a. sub-standard surgical techniques, post-operative care and long-term follow-up;
 - b. poor selection of candidates, whereby accepted contra-indications to listing (advanced cancer) are waived for privately funded patients;
 - c. prioritisation of privately funded patients above other patients on the waiting list;
 - d. poor selection of donors, include risk of severe rejection from mismatching and risk of transmission of blood-borne infections (HBV, HCV and HIV);
 - e. exploitation of paid live donors;
 - f. harvesting organs from executed prisoners;
 - g. risk of inability to access ongoing medical care when transplant recipient returns to country of origin after recovery from the transplant.

9. Phenomenological research into current attitudes towards xeno-transplantation. This should encompass acceptance of liver transplant candidates and their caregivers of

xeno-transplantation when interviewed both before and after successful deceased donor liver transplantation. This is still experimental but may become a future means to address the growing gap between supply and demand for liver transplantation. Issues to be addressed in these interviews could include the following:

- a. informed consent for research protocols (should this include patients who are not currently deemed suitable for deceased donor transplantation?);
- b. need for widespread public consultation before governments grant regulatory approval for inclusion of human subjects in studies conducted by commercial companies;
- c. safety concerns regarding animal tissue donation – impact of different hepatic physiology on organ function, risk of transmission of porcine infections including retroviruses;
- d. animal rights concerns re killing animals to harvest organs or genetically modifying animals to reduce risk of rejection;
- e. religious concerns from Islamic communities about receiving porcine tissue.

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Abbreviations

AUTEC	Auckland University of Technology Ethics Committee
BP	Blood pressure
CD	Compact Disk
DCCM	Department of Critical Care Medicine
GP	General Practitioner
IP	Interview participant
LDLT	Living Donor in Living Transplant(ation)
NZLTAG	New Zealand Liver Transplant Advisory Group
NZLTU	New Zealand Liver Transplant Unit
OLT/OLT	Orthotopic Liver Transplant
RSA	Returned Services Association
SP	Survey participant
Tx	Transplant
WHO	World Health Organisation

Appendices

Appendix 1 Ethics Application

**Auckland University of Technology Ethics Committee
(AUTEC)**

EA1

APPLICATION FOR ETHICS APPROVAL **FOR RESEARCH PROJECTS**



Please read the notes at the end of the form before submitting this application.

A. General Information**A.1. Project Title**

If you will be using a different title in documents to that being used as your working title, please provide both, clearly indicating which title will be used for what purpose.

The social and economic wellbeing outcomes for New Zealand liver transplant recipients, transplanted for their first transplant between January 1998 and December 2005, focussing on the lived experience of liver transplantation.

A.2. Applicant Name and Qualifications

When the researcher is a student (including staff who are AUT students), the applicant is the principal supervisor. When the researcher is an AUT staff member undertaking research as part of employment or a staff member undertaking research as part of an external qualification, the applicant is the researcher. Staff should refer to Section 11.4 of Applying for Ethics Approval: Guidelines and Procedures to check requirements for ethics approval where they are studying at another institution.

Professor Marilyn Waring

Qualifications: Ph.D.

A.3. Applicant's School/Department/Academic Group/Centre

The Institute of Public Policy, AUT.

A.4. Applicant's Faculty

Health and Environmental Sciences, AUT.

A.5. Student Details

Please complete this section only if the research is being undertaken by a student as part of an AUT qualification.

A.5.1. Student Name(s):

Bethly Vivienne Wainwright, known as Bethli.

A.5.2. Student ID Number(s):

9715501

A.5.3. Completed Qualification(s):

Bachelor of Arts (Auckland University)

Diploma of Librarianship (post-grad) (Victoria University of Wellington)

Graduate Diploma of Business (Information Systems) (Auckland University)

A.5.4. E-mail address:

ptoli@ihug.co.nz (home) or betwai83@aut.ac.nz (AUT student) or bethli.wainwright002@msd.govt.nz (work).

A.5.5. School/Department/Academic Group/Centre

The Institute of Public Policy, AUT.

A.5.6. Faculty

Health and Environmental Sciences, AUT.

A.5.7. Name of the qualification for which this research is being undertaken:

Master of Philosophy.

The student's supervisor is applying for upgrading this thesis to Ph.D. status at the completion of the post-graduate Qualitative Research Methods paper.

A.5.8. Research Output

Please state whether your research will result in a thesis or dissertation or a research paper or is part of coursework requirements.

Thesis.

A.6. Details of Other Researchers or Investigators

Please complete this section only if other researchers, investigators or organisations are involved in this project. Please also specify the role any other researcher(s), investigator(s) or organisation(s) will have in the research.

A.6.1. Individual Researcher(s) or Investigator(s)

Please provide the name of each researcher or investigator and the institution in which they research.

Not applicable.

A.6.2. Research or Investigator Organisations

Please provide the name of each organisation and the city in which the organisation is located.

Not applicable.

A. 7. Are you applying concurrently to another ethics committee?

If your answer is yes, please provide full details, including the meeting date, and attach copies of the full application and approval letter if it has been approved.

No.

A.8. Declaration

The information supplied is, to the best of my knowledge and belief, accurate. I have read the current Guidelines, published by the Auckland University of Technology Ethics Committee, and clearly understand my obligations and the rights of the participant, particularly with regard to informed consent.

Signature of Applicant

Date

(In the case of student applications the signature must be that of the Supervisor)

Signature of Student

Date

(If the research is a student project, both the signature of the Supervisor, as the applicant, and the student are required)

A.9. Authorising Signature

Signature of Head

Name of Faculty/Programme/School/Centre

Date

B. General Project Information

B.1. Project Duration

B.1.1. Approximate Start Date of Primary Data Collection

This research project is going to be undertaken in two phases. These phases are:

PHASE 1: Focus group and qualitative interviews.

PHASE 2: Qualitative survey

I hope to undertake Phase 1 in 2008 and 2009. I hope to have the qualitative survey tool developed in 2009 for Phase 2 implementation in 2009.

B.1.2. Approximate Finish Date of Complete Project

I hope to have the research project completed, written up, and thesis submitted by 2011.

B.2. Are funds being obtained specifically for this project?

If your answer is yes, then you must complete section G of this Application Form.

No.

B.3. Types of persons participating as participants

Please indicate clearly every one of the following categories that applies to those participating in your research.

B.3.1. Researcher's students

No.

No other students of Professor Marilyn Waring are involved in this research.

Bethly Wainwright is not a tutor or lecturer at AUT and has no students.

B.3.2. Adults (20 years and above)

All participants in this research project, whether participating in the focus group and/or the qualitative interviews and/or the qualitative survey will be 20 years of age or older at 1 January 2009.

B.3.3. Legal minors (16 to 20 years old)

All legal minors are excluded from this research project. No research participants will be under the age of 20 at 1 January 2009.

B.3.4. Legal minors (under 16 years old)

All legal minors are excluded from this research project. No research participants will be under the age of 20 at 1 January 2009.

B.3.5. Members of vulnerable groups

e.g. persons with impairments, limited understanding, etc. If your answer is yes, please provide a full description.

The research group is recipients of liver transplants. It is possible that liver transplant recipients view themselves as members of a vulnerable group. This may be because of the experience they have gone through (including probably facing death), the lifestyle changes they may be asked to make, the medication they are on, or other reasons. Bethly Wainwright, as transplant recipient #62, is personally aware of at least two other transplant recipients who have other significant health issues, which these recipients *may* self-assess as making them members of vulnerable groups. However, these two individuals may also see themselves as "ordinary New Zealanders." Until the eligible recipient group is contacted (once the Ethics approval is achieved), any self-assessed vulnerabilities will remain unknown.

B.3.6. Hospital patients

Bethly Wainwright does not expect that eligible participants will currently be in-patients within a hospital, however this cannot be excluded.

From time to time some liver transplant recipients may be hospitalised, and they will be able to choose whether they wish to disengage from the research, or postpone their participation (when timeframes permit).

All patients will be out-patients of the New Zealand Liver Transplant Unit (NZLTU) as post-transplant liver transplant recipients of this unit.

B.3.7. Prisoners

It is unlikely, but not impossible, that a liver transplant recipient, eligible for this research project, is a current prisoner. However, until Ethics approval is achieved and eligible liver transplant recipients are contacted, this remote possibility cannot be excluded.

B.4. Does this research involve use of human remains, tissue or body fluids which does not require submission to a Regional Ethics Committee?

e.g. finger pricks, urine samples, etc. (please refer to section 13 of the AUTEK Guidelines). If your answer is yes, please provide full details of all arrangements, including details of agreements for treatment, etc.

No.

B.5. Does this research involve potentially hazardous substances?

e.g. radioactive materials (please refer to section 15 of the AUTEK Guidelines). If your answer is yes, please provide full details.

No.

B.6. Research Instruments**B.6.1. Does the research include the use of a written or electronic questionnaire or survey?**

If your answer is yes, please attach to this application form a copy of the questionnaire or survey.

Yes. Phase 2 of this research project will see the development of a qualitative survey tool for use by all eligible liver transplant recipients.

The qualitative survey tool will be developed once the focus group and qualitative interview data has been gathered and analysed. The key concepts from the focus group and interviews will be used to develop the survey.

Key to the success of the qualitative survey tool is that the survey reflects the priority concepts identified by liver transplant recipients. As a liver transplant recipient, Bethly Wainwright may believe that these concepts may include guilt, fear, safety and gratitude, however until the focus group and qualitative interview data is collected and analysed, the priority concepts await discovery.

The proposed research process for Phase 1 is:

- Literature review on all literature relating to the recipients perspective, experiences, in the wider context of qualitative literature on transplantation, organ donation, wellbeing.
- Focus group meetings brainstorming key concepts for recipients around their experience of liver transplantation. This could cover their lived experience pre-transplant, during the transplant experience (hospitalisation) and will cover their post-transplant experience. The focus group would be comprise six to eight liver transplant recipients.

- Qualitative interviews with 10% of the eligible liver transplant recipients.
- Development of qualitative survey tool by Bethly Wainwright.
- Piloting of qualitative survey tool with focus group for feedback and changes.

Enter Phase 2, and implement the qualitative survey tool.

B.6.2. Does the research involve the use of focus groups or interviews?

If the answer is yes, please indicate how the data will be recorded (e.g. audiotape, videotape, note-taking). When interviews or focus groups are being recorded, you will need to make sure there is provision for explicit consent on the Consent Form and attach to this Application Form examples of indicative questions or the full interview or focus group schedule.

Yes.

The focus group is expected to be held using video-conferencing technology, i.e. the Kiwi Advanced Research and Education Network (KAREN), using the AUT Access Grid.

Bethly Wainwright has spoken with Calum MacLeod, IT Strategy Manager at AUT for KAREN and the Access Grid, who advises that it is possible to record KAREN sessions, but these can only be played back on a computer, with special software.

It is expected that the KAREN process (including recording) will be trialled in a dummy run, to see if it works well. Any focus group will also have a note taker present, to ensure the content is captured. If the video conferencing recording is not sufficient or suitable when trialled, then an audio-tape process will be investigated, and if a trial is successful, used.

For liver transplant recipients invited to participate in the focus group and in the qualitative interviews, consent forms will be sent. The process around the consent forms will be:

- Focus group members will be selected by Bethly Wainwright and the New Zealand Liver Transplant Unit. Bethly already has well-developed relationships of trust with eligible liver transplant recipients (urban/rural, male/female, Pakeha/Pasifika), who can support her in the focus group. To ensure that the focus group clearly represents the demographic profile of liver transplant recipients, the New Zealand Liver Transplant Unit will additionally send the information sheet and consent form for the focus group to two liver transplant recipients, one Asian and one Maori, as well. [The New Zealand Liver Transplant Unit will send the information sheet and consent form to all focus group prospective participants].
- Qualitative interview participants will be randomly selected by the New Zealand Liver Transplant Unit, ensuring a good mix of gender, ethnicity, age and geographic location. These participants are expected, in general, to not be known by Bethly Wainwright. Qualitative interviews will be face-to-face, and the liver transplant recipients being interviewed can identify a location of their choice for the one-to-one interviews. Bethly will personally finance air fares and vehicle costs to meet the recipients in their preferred location.

B.6.3. Does the research involve the use of observation?

If the answer is 'Yes', please attach to this application a copy of the observation protocol that will be used.

The research does not formally use observation. However, Bethly Wainwright, as a liver transplant recipient (#62, from August 2000), has built up a body of personal knowledge of life as a liver transplant recipient through her personal networks.

In addition, Bethly Wainwright has been running a liver transplant support website for over seven years (www.livers.org.nz) and gets approached by liver transplant recipients to upload information on the site on their behalf.

An observation protocol has not been developed.

B.6.4. Does the research involve the use of other research instruments such as performance tests?

If the answer is yes, please attach to this application a copy of the protocols for the instruments and the instruments that will be used to record results.

No.

B.6.5. Who will be transcribing or recording the data?

If someone other than the researcher will be transcribing the interview or focus group records or taking the notes, you need to provide a confidentiality agreement with this Application Form.

Phase 1: Focus group – Bethly Wainwright will hire a professional note taker to transcribe the KAREN access grid content, as she will be facilitating the focus group and will be unable to take notes at the same time.

A confidentiality agreement is attached to this application.

Phase 1: Qualitative interviews – Bethly Wainwright hopes to transcribe this data herself. If it physically becomes impossible (while still working full-time), a professional transcriber will be hired on an 'as needed' basis.

A confidentiality agreement is attached to this application.

Phase 2: Qualitative surveys – survey responses should not require transcribing. The analysis process will be undertaken by Bethly Wainwright. The qualitative survey is anonymous. Minimal demographic data will be asked for. This should allow free and frank disclosure of the liver transplant recipients' lived experiences, including controversial areas such as alcohol consumption (not recommended).

B.7. How does the design and practice of this research implement each of the three principles of the Treaty of Waitangi (Partnership, Participation and Protection) in the relationships between the researcher and other participants?

Please refer to Section 2.5 of AUTEK's Applying for Ethics Approval: Guidelines and Procedures (accessible in the Ethics Knowledge Base online via <http://www.aut.ac.nz/about/ethics>) and to the relevant Frequently Asked Questions section in the Ethics Knowledge Base.

The focus of this research project is about 'our' experiences, 'us' being liver transplant recipients in New Zealand. As Bethly is a liver transplant recipient, this research is a partnership project between peers. "By us, for us." As a recipient, Bethly is also very protective of, and understanding of, liver transplant recipients. She will do everything she can to ensure that the anonymity of the survey participants is maintained and that the confidentiality of the focus group and qualitative interview group is successful.

Partnership

Key to the development of the survey tool is the participation of liver transplant recipients, and in particular, a Maori representative, in both the focus group and the qualitative interview group. Only with a strong recipient voice in Phase 1, will Phase 2 (the qualitative survey tool) be effective. This whole research project is an example of partnership in action within a peer grouping.

The research will not be looking at the specific health outcomes. The wellbeing outcomes are part of the subjective experience and world view of each liver transplant recipient. There may be Maori recipients who view this phenomenon within a Maori world view, and other Maori recipients who may not. The researcher aims to ensure that each recipient is empowered to tell their own story, within their own cultural context, with a focus on equality of 'power' within the recipient researcher/recipient participant relationship.

The research project has a focus on reciprocity, in that the findings should be of value to all participants, and will be made available to all participants. The researcher, Bethly, will be striving to act openly, honestly and in good faith, at all times with the participants, as this is a group of her peers. The expertise lies with the recipients, who are participants, and this is of critical importance to ensure the research and research findings are validated, supported and endorsed by the participants.

Participation

It is important that all eligible recipients (i.e. those non-paediatric patients transplanted between January 1998 and December 2005, who received a liver from a deceased donor, who are alive in 2009) are able to participate in this research if they wish. This includes any Maori recipients. Bethly hopes for a high participant involvement rate. Although this research project is not "*by Maori, for Maori*", Bethly hopes for their participation, as the experiences of Maori going through liver transplantation, and their view of their wellbeing, will be of value to other Maori awaiting transplant or with liver disease and the fear/promise of the need for a transplant in their future.

Already, in the preliminary information consultation, it is apparent that cultural and religious beliefs will have a significant role within this research. The safe participation of all eligible liver transplant recipients of any race or creed is a priority.

Protection

A key aspect of protecting all eligible liver transplant recipient participants is to ensure that they are well informed of the research project, give their voluntary consent to participate, and know that they can withdraw from the research project at any time up to final data analysis.

The researcher, Bethly, will be constantly striving to ensure that participants / potential participants do not feel coerced into participating, do not feel that any deceit or lack of transparency has occurred, and do not get harmed in any way. Hopefully, participation in the research project will be positive and informative.

B.8. Does this research target Maori participants?

This research does not target Maori participants exclusively, however Maori are actively included in the research cohort as Maori are recipients of liver transplants.

The most recent information from the New Zealand Liver Transplant Unit is that there have been 325 liver transplant recipients to date, of whom **54**, or **17%**, are Maori. As there are a disproportionate number of Maori needing liver transplants (17%), compared to their proportion of the New Zealand population (14.6% identify as Maori in Census 2006), it is important that the New Zealand Liver Transplant Unit ensures that **20%** of the information sheets and consent forms for the qualitative interview are sent to Maori recipients.

The Annual Reports of the New Zealand Liver Transplant Unit for the years 1998 to 2005 have already been supplied to the researcher by the head of the New Zealand Liver Transplant Unit, Professor Munn. Although the data (except for 1998) is only in bar graph form, the ethnic diversity of the recipient group is clearly indicated, apart from 1999, which did not include this information in the body of the report.

The table below shows the rough data indications by the ethnic breakdowns used by the New Zealand Liver Transplant Unit. The largest numbers of recipients are in the category of European/Caucasian (fluctuating between approximately 58% and 74% of recipients during this study period).

	European	Maori	Asian	Middle Eastern	Polynesian	Other
1998	8	2	1	1	1	
1999	<i>not available</i>					
	Caucasian	Maori	Asian	Middle Eastern	Pacific Islander	Other
2000	approx 73%	approx 2%	approx 9%		approx 11%	Approx 2%
2001	approx 58%	approx 17%	approx 8%		approx 14%	
2002	approx 74%	approx 11%	approx 7%		approx 8%	
	European	Maori	Asian	Middle Eastern	Pacific Islander	Other
2003	70%	approx 12%	approx 4%		approx 11%	
2004	approx 62%	approx 14%	approx 6%		approx 9%	
2005	approx 69%	approx 9%	approx 9%		approx 6%	

When the focus group membership is selected, and when the New Zealand Liver Transplant Unit selects eligible recipients to receive the qualitative interview consent form, representation should cover:

- Gender (male, female)
- Ethnicity (Maori, Pasifika, NZ European, Asian)
- Locale (rural, urban)
- Geography (North Island, South Island)

B.8.1. If 'Yes', what consultation has been undertaken when designing the research?

Please identify the group(s) with whom consultation has occurred and provide evidence of their support and any impact this consultation had on the design of the research. Researchers are advised to read the Health Research Council's Guidelines for researchers on health research involving Maori, available via the Ethics Knowledge Base.

Limited consultation has been informally undertaken. Bethly Wainwright has talked (phone, face-to-face) with eligible liver transplant recipients personally known to her (met during their joint times in hospital), and received feedback and endorsement

for this research. She has also communicated by e-mail with recipients already known to her.

The New Zealand Liver Transplant Unit celebrated its 10th anniversary with a lunch for all liver transplant recipients (at the Green Lane Novotel) on Friday 4th April. Bethly Wainwright was able to utilise this opportunity to have further one-to-one conversations with recipients that she knew, and new acquaintances, to assess the support and need for this research to be undertaken.

One eligible recipient and new acquaintance she spoke with was Maori. This recipient had had a very traditional Marae upbringing, through their grandparents. This recipient explained the conflict and stress that they faced when told a liver transplant was required. This went against their culture and traditional upbringing. The decision to proceed with the transplant was based on the feedback from their children, and their Christian faith.

B.9. Does this research target participants of particular cultures or social groups?

Please refer to Section 2.5 of AUTEK's Applying for Ethics Approval: Guidelines and Procedures (accessible in the Ethics Knowledge Base online via <http://www.aut.ac.nz/about/ethics>) and to the relevant Frequently Asked Questions section in the Ethics Knowledge Base.

No. This research targets recipients of a service – liver transplantation – irrespective of their ethnicity, socio-economic status, self-classified social grouping or spiritual belief system or any other similar determinants.

This research excludes:

- Paediatric liver transplant recipients.
- Liver Transplant recipients who are younger than 20 years of age at 1 January 2009.
- Live Liver Donor liver transplant recipients.
- Recipients who are unable to communicate in English.
- Recipients who received a liver from a deceased donor, and who are deceased at the time of the survey (that is, the survey will not be provided to their caregiver or next-of-kin).

NOTE: It may be that a finding from this research is that liver transplant recipients view themselves as a unique social group; however that is not currently known.

B.9.1. If 'Yes' please identify which cultures or social groups are being targeted and how their cultures or social groups are being considered in the research design.

No specific cultures or social groups are targeted in this research project, unless the findings of the research show that liver transplant recipients uniformly self-select as being members of a particular culture or social group.

B.9.2. If your answer to B.9 was 'Yes', what consultation has occurred with these cultures or social groups in the design of the research?

Please identify the group(s) with whom consultation has occurred and provide evidence of their support and any impact this consultation had on the design of the research.

Bethly Wainwright has talked to, and e-mailed, a number of liver transplant recipients, to gauge their reaction to this research project and their support for it. Without exception, fellow liver transplant recipients are supportive of this research project.

B.10. Is there a need for translation or interpreting?

If your answer is 'Yes', please provide copies of any translations with this application and any Confidentiality Agreement required for translators or interpreters.

The New Zealand Liver Transplant Unit has advised Bethly Wainwright that about 5% of their liver transplant recipients do not speak English. They advise that this group is mainly Asian, and is made up of Indians, Chinese and south east Asians.

Including these recipients would require the use of interpreters for the qualitative interview, and translation of the consent forms, information sheet, and later the qualitative survey and the research findings. For budget reasons and time constraints, Bethly Wainwright is choosing to exclude non-English speaking participants from this research project.

As approximately 95% of the recipients will be English speaking, this should adequately represent this group of liver transplant recipients.

New Zealand has three official languages and if recipients prefer to use an official language other than English, the researcher will work with the Auckland University of Technology as to the most appropriate way to source translation services for either Te Reo Maori, or sign language interpreters. The researcher is aware that there are few sign language interpreters who sign in Te Reo Maori. If this is required it may impact on the timeline and the personal finances of the researcher.

C. Project Details

Please describe the project details in language which is, as far as possible, free from jargon and comprehensible to lay people.

C.1. Aim of project:

Please explain the broad scope and purpose of the project and state concisely how the type of information being sought will achieve the project's aims. Please give the specific hypothesis(es), if any, to be tested.

The aim of the project is:

- To find out the most important social and economic wellbeing indicators and concepts for New Zealand liver transplant recipients.
- To report on the social and economic wellbeing trends for liver transplant recipients in New Zealand, from the start of the New Zealand Liver Transplant Unit in 1998, to 31 December 2005.
- To understand what the lived experience of liver transplantation is, for New Zealand liver transplant recipients.
- To provide local trend data to New Zealanders listed for transplant or New Zealanders with liver disease, in order to reduce potential stress and anxiety to potential recipients, by providing recipient-driven information.

The aim of the research is to ensure that the recipient 'voice' is heard, and can provide value to the current liver transplant recipients who will participate in the research project, the New Zealand Liver Transplant Unit, New Zealanders with liver disease and their families and friends, and also officials charged with development of people-centric policy.

C.2. Why are you proposing this research?

(ie what are its potential benefits to participants, researcher, wider community, etc?)

As a liver transplant recipient, Bethly's personal experience is that one does not necessarily go through life prepared for a major life event or phenomenon such as transplantation. For many she has met, and for her, a transplant can come as a sudden shock.

When faced with a transplant, one tends to also be faced with death. Grappling with the concept of a transplant, the death of the donor, one's own mortality, often severe illness and sometimes reduced cognitive ability, the immediate and longer term situation can leave the potential recipient and their family reeling with questions and few answers.

The purpose of this research is to be able to utilise the collective experience and expertise in being liver transplant recipients, for the benefit of future liver transplant recipients, their caregivers and families. This should also provide data trends and qualitative data that will benefit:

- The New Zealand Liver Transplant Unit
- The Ministry of Health
- The Ministry of Social Development (note that most if not all eligible recipients will have been (and may still be) on Sickness or Invalid's Benefit).

Throughout this research the 'voice' will be that of recipients. Two examples from published recipient 'stories' in the "Our Stories" section of the website www.livers.org.nz illustrate this perspective:

(1) *"Liver transplantation was mentioned as an end alternative but knowing nothing of recent developments it sounded too horrendous to contemplate. If successful, what life quality would I have? Maybe I could have a transplant and live with a drugged feeling? My ignorance almost cost me my life."* **Pam's Story, April 2001.** http://www.livers.org.nz/Our_Stories/Pams_Story.htm

(2) *"During my episodes in the ward I have befriended an art teacher, a fashion manufacturer, a heavy-booted bikie, a Maori elder, a lawyer, a school girl, a former Olympian rower. Oh, and that's right, a nurse who had never before entered hospital as "a horizontal." We all knew the despair of being skeletal of limb, bloated, yellow, itchy skinned and messy minded, fearful for our lives and utterly exhausted. We knew the anxiety of going into the Martian space ship, the relief of landing, and the magnificent highs and drum-beat lows of the recovery process. We knew the wonders of morphine, the significance of every tube penetrating our bodies, and the elation of having them removed, one at a time, over the ensuing days. We followed each other's progress with a vested interest and celebrated each other's steps towards our new lives."* **My Accidental Family**, by Lyn Loates.

(First published in ***North & South*** magazine, May 2005). Reprinted with permission on http://www.livers.org.nz/Our_Stories/Lyns_Story.htm

C.3. Background:

Please provide sufficient information, including relevant references, to place the project in perspective and to allow the project's significance to be assessed. Where appropriate, provide one or two references to the applicant's (or supervisor's) own published work in the relevant field.

Bethly's preliminary mini-literature review (for the purpose of the application) indicated that a recipient driven approach to researching and reporting on the social and economic wellbeing outcomes, and the lived experience, of liver transplant recipients has not been undertaken as yet.

There is English-language literature on various aspects relating to the quality of life of liver transplant recipients from a number of countries. A Danish study (Aadahl, 2002, p252) used the SF-36 tool also used by Bielby in New Zealand. The Danish study, in

relation to anxiety and depression scores that were low, noted “*Liver Transplant recipients may relate their assessment to the OLT [orthotopic liver transplantation], and their perception of these concepts may differ from that of the general population. Having survived a lethal disease may markedly change the experience of anxiety*” (Aadahl, 2002, p257). A key point in the Danish study is their comment that “*the prevalence and severity of specific symptoms and problems after OLT may not have been sufficiently covered by generic questionnaires used in this study*” (Aadahl, 2002, p258.) This could be seen as providing some support for a recipient-driven survey tool that addresses wider social and economic wellbeing issues post orthotopic liver transplantation.

A United States study on fatigue post orthotopic liver transplantation indicated that “*In the majority of reports, however, the average HRQL [Health Related Quality of Life] for a group of LT [Liver Transplant] recipients (both short- and long-term) is still reduced when compared to age- and sex-matched general population data*” (Talwalkar, 2006, p899.) This assists in justifying my choice to base the survey on the subjective view of wellbeing pre-transplant, during transplant and post-transplant of each in-scope recipient. This emphasises the importance of the lived experience of each eligible liver transplant recipient. The general population’s experience is outside the range of experiences held by orthotopic liver transplant recipients. The self-awareness and self-ranking of each orthotopic liver transplant recipient within the scope of a recipient-developed survey tool will provide the experiential richness of data on social and economic wellbeing outcomes that is desired from this research project.

A Swiss study, also using the SF-36 tool, noted that “*liver patients remained below the norms in most of the SF-36 subscales. Social functioning in all three organ groups [lung, liver, allogeneic bone marrow] was reduced before as well as after the transplant*” (Goetzmann, 2006, p281.)

A Canadian study acknowledged that “*there is a growing recognition within the field that survival is not the only yardstick by which to measure treatment effectiveness. Improved quality of life is necessary in order to justify the personal and societal costs associated with this most invasive of surgical procedures*” (Littlefield, 1996, p36S.) This recipient-driven approach to research should reflect the ‘reality’ of life post-transplant in our own subjective context.

Some aspects explored in international literature may be used for some comparisons with the New Zealand results. For example, a Dutch study found that “*women were more severely fatigued than men and that older recipients were more severely fatigued than younger recipients*” (van den Berg-Emons, 2006, p928.) It will be interesting to see whether survey questions on fatigue in New Zealand recipients have a similar result.

The New Zealand study found that “*Transplant recipients are likely to perceive their quality of life more positively than the general population because of the striking contrast between terminal illness before transplantation and better functioning following transplantation, thus accounting for a positive perception of functioning*” (Bielby, 2003, original pagination not available, pages 5 and 6 of .PDF.)

C.4. Procedure:

C.4.1. Explain the philosophical and/or methodological approach taken to obtaining information and/or testing the hypothesis(es).

This research project has two components: the experience of the researcher (liver transplant recipient #62) and the experience of the liver transplant recipients eligible for the research project.

Two methodological approaches will be taken.

(1) Bethly will use an auto-ethnographic approach to ensure her experience is included in the research.

(2) Bethly will use a phenomenological approach to capture the lived experiences of the liver transplant recipients eligible for this research project. This means focussing on the 'things themselves' or the actual experiences. This approach will be based on the philosophy of Heidegger as it is applied in current qualitative health research.

C.4.2. State in practical terms what research procedures or methods will be used.

The research project will be triangulated in terms of methods by approaching the concept of 'what is the lived experience of liver transplantation for New Zealanders transplanted between 1998 and 2006 who received a liver from a deceased donor' by using three methods to obtain data:

- A small, purposively selected focus group – the data will be used in such a way that all participants identities are kept **confidential**.
- A proportion of the total eligible liver transplant recipients (10%) to be selected for qualitative interviews by the New Zealand Liver Transplant Unit – the data will be used in such a way that all participants' identities are kept **confidential**.
- A qualitative survey to be provided to all eligible liver transplant recipients, where the data is **anonymous**.

C.4.3. State how information will be gathered and processed.

Phase 1A: Focus group

Depending on the success of video-recording on the access grid to the KAREN system, the focus group will either be video-recorded or audio-recorded (if either of these is technically successful at testing stage).

In the event that the technology is dubious, a note taker will be hired to take notes at any meeting of the focus group. (Consent form attached).

Phase 1B: Qualitative interviews

Bethly Wainwright will visit the interview candidate at a venue and location of their choice, whether this is Kaitaia or Invercargill. Bethly will attempt to transcribe all the interview data herself, unless it becomes physically impossible due to either health or full-time work commitments, in which case she will hire a transcriber. (Consent form attached).

Phase 2: Qualitative survey

The qualitative survey will be sent out to all eligible liver transplant recipients. It will ask for minimal demographic data. This data will probably be:

- Gender (male or female)

- Geographic location (North Island or South Island)
- Lifestyle (urban or rural)
- Age band at time of survey (20-35, 36-50, 51-64, 65+)
- Ethnicity (New Zealand European/Pakeha, Maori, Pasifika, Asian, Other)

This should allow for a contextual situating of the lived experiences, when analysed.

All the information will be carefully read to highlight concepts and patterns. As Phase 1 influences Phase 2, the data from the qualitative survey will be read and analysed in the context of the knowledge already gained from Phase 1.

The data will be written and condensed, analysed and reduced to its essence, using a personal computer and probably Microsoft Word and Microsoft Excel.

C.4.4. State how your data will be analysed.

“Phenomenological analysis seeks to grasp and elucidate the meaning, structure, and essence of the lived experience of a phenomenon for a person or group of people” (Patton, 2002, page 482).

Initially the data will be inventoried to ensure that all data from the focus group, qualitative interviews, and surveys is available for analysis.

Inductive analysis will be the approach taken. The data will be thematically coded, and the content of the themes analysed. The thematic coding will include pattern recognition: searching for recurrent words, themes and practices. Once this has been completed, the thematic coding will be interpreted, to attempt to reveal the essence of the phenomenon.

C.4.5. Provide the statistical or methodological justification for this.

This is the approach taken within phenomenological research and is justified by the literature. Van Manen wrote that *“Making something of a text or of a lived experience by interpreting its meaning is more accurately a process of insightful invention, discovery or disclosure – grasping and formulating a thematic understanding is not a rule-bound process but a free act of “seeing” meaning”* (1990, page 79).

Bethly is prioritising the real life experiences of the liver transplant recipient participants, and for this reason wishes to retain the authenticity and texture of these experiences through this phenomenological approach.

C.5. References

Please include the references for your responses to this section in the standard format used in your discipline.

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D. Participants

D.1. Who are the participants?

The participants are all eligible, living, liver transplant recipients transplanted for their first liver transplant in the years 1998 to 2005, who are not live liver donation recipients, nor paediatric liver transplant recipients. All liver transplant recipients should be resident in New Zealand at the time of the survey or contactable by the New Zealand Liver Transplant Unit by mail (for the consent form to reach them). All those eligible recipients who participate in the focus group and/or in the interview must be resident in New Zealand during this period. An eligible recipient may be overseas and still complete the qualitative survey, if the New Zealand Liver Transplant Unit has a mailing address for the consent form.

It is expected that the majority of eligible recipients will have had their liver transplant at the New Zealand Liver Transplant Unit in Auckland. There may be one or more recipients who received their liver transplant overseas during 1998 – 2005 and are now resident in New Zealand and are out-patients of the New Zealand Liver Transplant Unit. These recipients will also be included if their first transplant was between 1998 – 2005.

Recipients re-transplanted between 1998 and 2005 for a first transplant received prior to 1998 are excluded as the technology and immuno-suppression medications and other drug therapies are not comparable.

All participants will be 20 years of age or older at 1 January 2009.

D.1.1. What criteria are to be used in recruiting the participants?

The participants will be out-patients of the New Zealand Liver Transplant Unit.

- They will have received their first donor liver in the period 1998-2005.
- They will be 20 years of age or older at 1 January 2009.
- They will be alive.
- They will have received a liver from a deceased donor.
- They will be able to communicate in an official language of New Zealand.
- They will be resident in New Zealand at the time of the focus group and interviews. For the survey, they will be easily contactable by post. (NOTE: Bethly has personal knowledge of one recipient, who in the future may spend one to two years in the United Kingdom. Including this person may profile a positive example of the ability to travel and reside overseas.)

D.1.2. What criteria are to be used for selecting participants from those recruited?

All eligible liver transplant recipient participants who have been recruited through the consent form process will be selected for the qualitative survey.

The focus group will be purposively selected by Bethly to provide long-term support for her in this research project as well as key informant data.

Eligible liver transplant recipients will be selected for interview through a selection process by the New Zealand Liver Transplant Unit that ensures a good gender, ethnicity, age and geographic location mix. Approximately 10-15 interview consent forms (with pre-stamped, self-addressed envelopes and a letter of invitation) will be provided to the New Zealand Liver Transplant Unit by Bethli Wainwright.

D.1.3. Are there any potential participants who will be excluded?

If your answer is yes, please detail the criteria for exclusion.

Yes. The following potential participants are excluded:

- Liver transplant recipients who received a lobe from a live liver donor.
- Liver transplant recipients who had their first liver transplant prior to 1998 or subsequent to 2005.
- Liver transplant recipients who are dead. That is, their caregiver / next- of-kin will not be asked to complete the survey for them.
- Liver transplant recipients who are aged 19 years or under at 1 January 2009.
- Liver transplant recipients selected for interview, who are not resident in New Zealand at the time of the interview.
- Liver transplant recipients who cannot communicate in an official language of New Zealand.

- Liver transplant recipients who are mentally impaired to the extent that completion of the survey is not possible. (Assessed by caregiver or recipient at the time the consent form is sent).
- Any liver transplant recipient who has a contagious illness and wishes to be interviewed will only be interviewed if the New Zealand Liver Transplant Unit approves a process that keeps the health of the recipient-researcher safe. A face-to-face interview may be declined by Bethly in this type of situation.

D.2. Are there any potential conflicts of interest or possible coercive influences in the professional, social, or cultural relationships between the researcher and the participants (e.g. dependent relationships such as teacher/student; parent/child; employer/employee; pastor/congregation etc.)?

The relationship between Bethly and the participants is that of recipient-researcher and recipient-participants. The researcher is transplant #62 from August 2000, and is a member of the eligible liver transplant recipient group.

Some participants will already know Bethly from previous liver transplant support groups (run by the New Zealand Liver Transplant Unit), Bethly's newsletter "*Hepatic Happenings*" (written and distributed to liver transplant recipients for approximately one year, while she was recuperating from her transplant and not yet re-engaged in the labour market). In addition, the researcher (with fellow liver transplant recipient #27, now deceased) has a 'public service' website at www.livers.org.nz which is easily found through a Google search on liver transplants in New Zealand, and receives a regular amount of e-mail traffic.

The researcher is currently employed in the regional office of Work and Income, a service delivery unit of the Ministry of Social Development. As this research is not being done on behalf of Work and Income, it will be important to be completely neutral in relation to any and all negative feedback on Work and Income products and services.

There is no conflict of interest or coercive issues between the researcher and the participants.

D.2.1. If your answer was 'Yes', please identify the nature of the relationships concerned and provide full information about the processes being incorporated into the research design to mitigate any adverse affects that may arise from them.

The issue of Bethly's employment with Work and Income, an agency that may not be viewed positively by all liver transplant recipients, will be made clear in the information sheet. It will be stressed that this is private research.

D.3. How many participants will be selected?

There will be approximately 100-150 participants. This is based on the knowledge that the New Zealand Liver Transplant Unit has of the potential number of eligible recipients.

Phase 1: Focus group (6 to 8 participants)

Phase 1: Qualitative interviews (approximately 10-15 participants)

Phase 2: Qualitative survey (approximately 100-150 participants)

D.3.1. What is the reason for selecting this number?

From analysing the data in the New Zealand Liver Transplant Unit's Annual Reports between 1998 and 2005 (the study period), there were 249 transplants, some of which were re-transplants.

Taking into consideration the exclusion criteria and feedback from the New Zealand Liver Transplant Unit, Bethly expects that there will be between 100 and 150 eligible liver transplant recipients. Until consent forms are sent out and received back, the exact number of eligible participants will remain unknown.

Reasons for Liver Transplantation in the New Zealand Liver Transplant Unit between 1998 and 2005

(NOTE: number of transplants does not equal number of patients as multiple transplants for some patients)

Condition	
Alcoholic liver disease <i>w/out viral hepatitis</i> (ALD)	18
Alpha-1 antitrypsin deficiency	5
Amanita poisoning	1
Amyloidosis	1
Autoimmune hepatitis (AIH)	4
Biliary atresia	15
Budd-chiari syndrome	6
Cryptogenic	14
Drug	1
Haemochromotosis	4
Hepatic artery thrombosis (HAT)	2
Hepatitis B virus related (HBV)	59
Hepatitis C virus related <i>with or w/out alcohol</i> (HCV)	58
Kaposi's sarcoma	1
Non A/B hepatitis	9
Non alcoholic steatohepatitis	4
Other causes (acute)	5
Other causes (chronic)	9
Primary Biliary cirrhosis (PBC)	10
Primary non-function	1
Primary sclerosing cholangitis (PSC)	14
Rejection (post Tx)	4
Sarcoidosis	1
Systemic sclerosis (SSc)	1
Wilson's disease	2
TOTAL	249

D.3.2. Provide a statistical justification where applicable, if you have not already provided one in C.4 5. above.

Please see the table (above) that shows the number of transplants (249) in this study period.

D.3.3. Is there a control group?

If your answer is yes, please describe and state how many are in the control group.

There is no control group, as the research focuses on the lived experiences of liver transplantation and the self-assessed wellbeing of liver transplant recipients using recipient developed indicators.

D.4. Describe in detail the recruitment methods to be used.

If you will be recruiting by advertisement or email, please attach a copy to this Application Form

Phase 1: Focus Group

The focus group is made up of eligible recipients personally known to the recipient researcher. Currently, through Bethly's personal network, there are 'expressions of interest' to be part of the focus group from:

- Urban Pasifika male (North Island)
- Urban European female (North Island)
- Rural European male (South Island)
- Urban European male (South Island)
- Urban Maori female (North Island)

The New Zealand Liver Transplant Unit will be asked to forward the information sheet and a consent form to the purposively selected eligible recipients (who are within reasonable proximity of a university in order to access the KAREN video-conferencing). In addition, the New Zealand Liver Transplant Unit will be asked to select one Maori and one Asian recipient to join the focus group.

The focus group also acts as a 'sounding board' and support group to the recipient researcher.

Phase 1: Qualitative interviews

Eligible liver transplant recipient participants will be selected for interview through a selection process undertaken by the New Zealand Liver Transplant Unit. This will ensure that there is a good gender, ethnic, age and geographic location mix. This will include ensuring that 20% of the selected recipients for the qualitative interviews are Maori.

The information sheet and consent form will be posted to 10% of the eligible liver transplant recipients, along with a pre-stamped and a self-addressed envelope. This will ensure that the consent form is returned to Bethly, c/- the Institute of Public Policy at AUT.

Phase 2: Qualitative survey

An information sheet (attached) introduces the research. The New Zealand Liver Transplant Unit will be asked to mail the information sheet along with a consent form, to all eligible liver transplant recipients, transplanted between 1998 and 2005. This will exclude live liver donor liver transplant recipients, paediatric liver transplant recipients, recipients unable to communicate in an official language of New Zealand, and deceased recipients.

The consent form will be accompanied by a pre-paid, self-addressed envelope, addressed to the researcher c/- Auckland University of Technology.

All signed consent forms will be filed by the researcher and stored securely at the Auckland University of Technology.

The consent form will include an option to tick for an e-mail update on the research.

D.5. How will information about the project be given to participants?

(e.g. in writing, verbally). A copy of information to be given to prospective participants is to be attached to this Application Form. If written information is to be provided to participants, you are advised to use the Information Sheet exemplar.

Please see the attached information sheet.

The consent forms allow for participants to receive e-mail updates.

D.6. Will the participants have difficulty giving informed consent on their own behalf?

Consider physical or mental condition, age, language, legal status, or other barriers. If the answer is yes, please provide full details.

Bethly does not expect this.

If a participant is in a condition where they cannot give their own informed consent, they would probably not be able to undertake the survey, participate in the focus group or take part in an interview, and would therefore be excluded due to incapacity.

D.6.1. If participants are not competent to give fully informed consent, who will consent on their behalf?

If the participant cannot give fully informed consent, they would be excluded from the research. Consent on their behalf would not be sought.

D.6.2. Will these participants be asked to provide assent to participation?

If the answer is yes, please attach a copy of the assent form which will be used. Please note that assent is not the same as consent (please refer to the Glossary in Appendix A of the AUTECH Guidelines and Procedures.

No.

D.7. Will consent of participants be gained in writing?

If the answer is yes, please attach a copy of the Consent Form which will be used. If the answer is No, please provide the reasons for this.

Yes. Please see the attached consent forms.

D.8. Will the participants remain anonymous to the researcher?

Please note that anonymity and confidentiality are different. If the answer is yes, please state how, otherwise, if the answer is no, please describe how participant privacy issues and confidentiality of information will be preserved.

Focus group participants will be known to Bethly and fellow focus group members as we will jointly video-conference together.

Qualitative interview participants will be known to Bethly as she will conduct interviews face-to-face in a one-to-one situation and venue of the participant's choice.

Qualitative survey participants will remain anonymous to the researcher. Limited demographic data will probably identify:

- Gender (male or female)
- Geographic location (North Island or South Island)
- Lifestyle (urban or rural)
- Age band at time of survey (20-35, 36-50, 51-64, 65+)
- Ethnicity (New Zealand European/Pakeha, Maori, Pasifika, Asian, Other)

D.9. In the final report will there be any possibility that individuals or groups could be identified?

If the answer is yes, please explain how and why this will happen.

If an interview participant requests to be identified using their liver transplant recipient number (e.g. mine is #62), then they would be identifiable to anyone who knows what their number is, for example, the New Zealand Liver Transplant Unit, their immediate family, their friends, if they have disclosed this number.

All survey recipients will be anonymous, unless something in their response identifies them to the New Zealand Liver Transplant Unit or to medical staff or fellow recipients who may have been in Auckland Hospital at that time. This is not expected to occur.

Any case studies will be carefully assessed to see if identifying information (such as the reason for transplant, or the date of transplant) has been included. When identifying information of this nature has been included, the case study will be discussed with the recipient (if it came from an interview) to gain permission to edit this information out, and if it came from a survey, the researcher will attempt to edit the information out without destroying the recipient's narrative. This is particularly important when the reason for transplantation may be limited to only 1 or 2 recipients. For example, I am one of two Wilson's disease participants.

The individual most likely to be identified in this research project is Bethly Wainwright.

D.10. Will feedback or findings be disseminated to participants (individuals or groups)?

If the answer is yes, please explain how this will occur and ensure that this information is included in the Information Sheet.

Yes.

Some form of written report (synopsis) with key findings will be provided to all participants. In addition, the consent form allows for e-mail progress reports to be provided during the course of the research project.

The findings may also be able to be made available to liver transplant recipients who were not eligible for the research project, for their information if they are interested.

In addition, the findings from this study will be presented and published in a peer-reviewed journal.

A final outcome would be for key findings to be made available in pamphlet, brochure or booklet form to new patients of the New Zealand Liver Transplant Unit who may face a liver transplant in their future.

D.11. Will the findings of this study be of particular interest to specific cultures or social groups?

If your answer is 'Yes', please identify how the findings will be made available to them.

The findings should be of particular interest to:

- All New Zealanders with liver disease.

- All New Zealanders listed for a liver transplant.
- All New Zealanders who have already had a liver transplant.
- Caregivers, family members and friends of New Zealanders with liver disease, or listed for transplant, or liver transplant recipients.
- The New Zealand Liver Transplant Unit.
- The Ministry of Health.
- The Ministry of Social Development.
- Social Workers.

The findings may also be of interest to New Zealanders who have had other transplants, such as lung transplant recipients, heart transplant recipients and kidney transplant recipients.

E. Other Project Details

E.1. Where will the project be conducted?

Please provide the name/s of the Institution/s, town/s, city or cities, region or country that best answers this question.

Auckland University of Technology (AUT) at Northcote, Auckland.

My home, 197 Glengarry Road, Glen Eden, Waitakere 0602, Auckland.

The interview venue of their choice for participants who are selected for one-to-one qualitative interviews.

E.2. Who is in charge of data collection?

Bethly Wainwright.

E.3. Who will interact with the participants?

Bethly Wainwright.

The New Zealand Liver Transplant Unit (sending out the envelopes containing the consent forms with the information sheets).

E.4. What ethical risks are involved for participants in the proposed research?

Please consider the possibility of moral, physical, psychological or emotional risks to participants, including issues of confidentiality and privacy. Researchers are urged to consider this issue from the perspective of the participants, and not only from the perspective of someone familiar with the subject matter and research practices involved.

There could be a psychological and/or emotional risk to participants, as liver transplantation can be a very traumatic process.

The qualitative interview and/or the qualitative survey may well require some 'reliving' of past traumatic experiences, which could be emotional for participants.

E.4.1. Are the participants likely to experience any discomfort, embarrassment (physical, psychological, social) or incapacity as a result of the research's procedures?

Participants should not experience any physical or social discomfort or embarrassment. As noted above, reliving their lived experiences may have psychological implications.

There should be no incapacity (physical, psychological or social) as a result of this research project.

E.4.2. If there are risks, please identify their probability and describe how they will be mitigated.

Please describe how these will be minimised or mitigated (e.g. participants do not need to answer a question that they find embarrassing or they may terminate an interview or there may be a qualified counsellor present in the interview or

the findings will be reported in a way that ensures that participants cannot be individually identified, etc.) Possible risks and their mitigation should be fully described in the Information Sheets for participants.

By being clear as to the purpose of the research project and the way the results from the research should assist other New Zealanders who will face that same trauma in their future.

By stressing the voluntary nature of participation. A participant can choose to stop the interview, leave the focus group or not complete the survey.

By stressing that it's OK to take a long time to complete the survey.

By stressing that a no-response to one or more areas is fine.

E.4.3. If the participants are likely to experience any discomfort, embarrassment, or incapacity, what provision for counselling has been made, either with AUT Counselling (who also provide an online service) or with other counselling professionals (this is to be at no charge to the participants)?

Please refer to section 2.3 of AUTEK's Applying for Ethics Approval: Guidelines and Procedures in the Ethics Knowledge Base. If the answer is No, please explain the arrangements which have been made to have qualified personnel available to deal with unexpected adverse physical or psychological consequences?

All liver transplant recipients are able to contact the social worker in the New Zealand Liver Transplant Unit. They will already know the social worker from their time at Auckland City Hospital when they received their transplanted liver.

Bethly will also have the contact details for the New Zealand Liver Transplant Unit's social worker with her at all times.

E.5. What risks are involved for the researcher(s) in the proposed project (such as physical, social, psychological, or safety risks)?

If this project will involve interviewing participants in private homes, undertaking research overseas, or going into similarly vulnerable situations, then a Researcher Safety protocol should be designed and appended to this application.

There may be a minimal risk in the qualitative research stage, when the interview is held in a venue of the participant's choosing. This will be mitigated by ensuring that Bethly's supervisor and family know where she is, when she should start the interview, and approximately when the interview should conclude.

A psychological risk to Bethly may be an 'overloading' of experiences with which she can identify and empathise, with her requirement to listen and understand but not 'drown' in the experiences. Mitigating this will be the timing and pacing of the interviews, and regular supervision.

E.6. Will there be any other physical hazards introduced to AUT staff and/or students through the duration of this project?

If the answer is yes, please provide details of management controls which will be in place to either eliminate or minimise harm from these hazards (e.g. a hazardous substance management plan).

No.

E.7. Is deception of participants involved at any stage of the research?

If the answer is yes, please provide full details of and rationale for the deception. Please refer to Section 2.4 of AUTEK's Applying for Ethics Approval: Guidelines and Procedures when considering this question.

No.

E.8. How much time will participants have to give to the project?

Participants are divided into three groups:

- Phase 1: Focus group participants (also pilot the survey and are full survey participants) – 20 hours

- Phase 1: Qualitative interview participants (also full survey participants) – 6 hours
- Phase 2: Survey participants – 3 hours (includes survey time and follow-up time)

If an interview or survey participant has a case study to illustrate a particular concept or indicator, then this may add another 1-2 hours time for the drafting, editing and checking of the case study.

E.9. Will any information on the participants be obtained from third parties?

If the answer is yes, please provide full details. This includes use of third parties, such as employers, in recruitment.

This is not expected. The New Zealand Liver Transplant Unit Annual Reports provide generalised data, which do not identify specific recipients.

Demographic and personal information will only be sought from each liver transplant recipient who has given consent.

E.10. Will any identifiable information on the participants be given to third parties?

If the answer is Yes, please provide full details.

No.

Identifiable information (focus group and qualitative interviews) will be restricted to Bethly Wainwright and her two supervisors.

The information from the qualitative survey is anonymous.

A copy of the thesis will be provided to the New Zealand Liver Transplant Unit.

E.11. Provide details of any payment, gift or koha and, where applicable, level of payment to be made to participants.

Please refer to Section 2.1 of the AUTECH's Applying for Ethics Approval: Guidelines and Procedures and Appendix A of that document for AUTECH's policy on Payment and Koha, especially in relation to recruitment.

No koha or gift or payment will be provided to the recipient participants.

It is possible that a packet of biscuits may be supplied by the researcher to the focus group each time we meet.

For the qualitative interviews, if it is morning or afternoon tea time, Bethly may provide biscuits or muffins for herself and the interview participant.

F. Data and Consent Forms

F.1. Who will have access to the data?

The researcher, Bethly Wainwright.

The chief supervisor, Professor Marilyn Waring, AUT.

The second supervisor, Dr Ed Gane, Associate Professor of Medicine, Auckland City Hospital, will not have direct access to the data but will be involved in conversations about the data.

F.2. Are there plans for future use of the data beyond those already described?

The applicant's attention is drawn to the requirements of the Privacy Act 1993 (see Appendix I). If there are future plans for the use of the data, then this needs to be explained in the Information Sheets for participants.

It cannot be predicted, but the findings of the research may point to the usefulness of further work in the future.

Bethly Wainwright would hope to be able to provide a book and/or written pamphlets, based on this research that would provide direct information to New Zealanders with liver disease who may face liver transplantation in their future.

F.3. Where will the data be stored once the analysis is complete?

Please provide the exact storage location. AUTEK normally requires that the data be stored securely on AUT premises in a location separate from the consent forms. If you are proposing an alternative arrangement, please explain why.

AC312, Auckland University of Technology.

F.4. For how long will the data be stored after completion of analysis?

AUTEK normally requires that the data be stored securely for six years. If you are proposing an alternative arrangement, please explain why.

The AUT postgraduate handbook 2007 states that "Health information must be stored for ten years" (Page 80). This data will be stored for 10 years.

F.5. Will the data be destroyed?

If the answer is yes, please describe how the destruction will be effected. If the answer is no, please provide the reason for this.

Yes. The data will be kept for 10 years at AUT and then destroyed. Paper data will be shredded, and then put in the confidential document destruction. Electronic data (tapes) will be wiped and destroyed through confidential destruction services.

F.6. Who will have access to the Consent Forms?

The researcher, Bethly Wainwright.

The chief supervisor, Professor Marilyn Waring, AUT.

F.7. Where will the completed Consent Forms be stored?

Please provide the exact storage location. AUTEK normally requires that the Consent Forms be stored securely on AUT premises in a location separate from the data. If you are proposing an alternative arrangement, please explain why.

AC314, Auckland University of Technology.

F.8. For how long will the completed Consent Forms be stored?

AUTEK normally requires that the Consent Forms be stored securely for six years. If you are proposing an alternative arrangement, please explain why.

The consent forms will be stored for 10 years.

F.9. Will the Consent Forms be destroyed?

If the answer is yes, please describe how the destruction will be effected. If the answer is no, please provide the reason for this.

At the end of 10 years, the consent forms will be shredded, and then put in the confidential document destruction.

G. Material Resources

G.1. Has an application for financial support for this project been (or will be) made to a source external to AUT or is a source external to AUT providing (or will provide) financial support for this project?

No. Bethly is funding the costs of this research project herself.

Bethly has applied for one of the new AUT Laptop scholarships. She does not know yet if she is successful.

G.1.1. If the answer to G.1 was 'yes', please provide the name of the source, the amount of financial support involved, and clearly explain how the funder/s are involved in the design and management of the research.

Bethly has applied for one of the new AUT Laptop scholarships. She does not know the value of this scholarship, nor whether she will be successful in gaining one.

If Bethly gains an AUT Laptop scholarship it will not impact on the design or the management of this research project.

G.2. Has the application been (or will it be) submitted to an AUT Faculty Research Grants Committee or other AUT funding entity?

If the answer is yes, please provide details.

No.

G.2.1. If the answer to G.2 was 'yes', please provide the name of the source, the amount of financial support involved, and clearly explain how the funder/s are involved in the design and management of the research.

Not applicable.

G.3. Is funding already available, or is it awaiting decision?

Please provide full details.

The Institute of Public Policy makes a small amount of funding available to students for reimbursement of directly thesis related expenditure.

G.4. Please provide full details about the financial interest, if any, in the outcome of the project of the researchers, investigators or research organisations mentioned in Part A of this application.

Bethly Wainwright is doing this research at her own expense. The research should be of interest and value to a number of individuals (current and future recipients and their caregivers) and agencies (New Zealand Liver Transplant Unit, Ministry of Health etc). The individuals and agencies that may find this of interest are not financially investing in this research project.

In the future, once the research project has concluded and the findings are clear, it may be necessary to consider obtaining funding in order to publish suitable brochures for future liver transplant recipients. This will be discussed with the New Zealand Liver Transplant Unit at that time.

H. Other Information

Have you ever made any other related applications?

If the answer is yes, please provide the AUTEK application / approval number(s)

No.

I. Checklist

Please ensure all applicable sections of this form have been completed and all appropriate documentation is attached as incomplete applications will not be considered by AUTEK.

Section A	General Information Completed	
	Signatures/Declaration Completed	
Section B	Project General Information Completed	
Section C	Project Details Completed	
Section D	Participant Details Completed	
Section E	Other Project Details Completed	

Section F	Data & Consent Forms Details Completed	<input type="checkbox"/>
Section G	Material Resources Completed	<input type="checkbox"/>
Section H	Other Information Completed	<input type="checkbox"/>

Spelling and Grammar Check (please note that a high standard of spelling and grammar is required in documents that are issued with AUTECH approval)

Attached Documents (where applicable)

Participant Information Sheet(s)	<input type="checkbox"/>
Consent Form(s)	<input type="checkbox"/>
Questionnaire(s)	<input type="checkbox"/>
Indicative Questions for Interviews or Focus Groups	<input type="checkbox"/>
Observation Protocols	<input type="checkbox"/>
Recording Protocols for Tests	<input type="checkbox"/>
Advertisement(s)	<input type="checkbox"/>
Hazardous Substance Management Plan	<input type="checkbox"/>
Any Confidentiality Agreement(s)	<input type="checkbox"/>
Other Documentation	<input type="checkbox"/>

Before submitting this application, please note the following:

- ❖ *If you think that your research may be of low ethical risk, use the EA8RA self assessment form to make sure that this is the correct form for your application;*
- ❖ *Incomplete or incorrectly formatted applications will not be considered by AUTECH;*
- ❖ *Please check online for the most recent version of this form before submitting your application;*
- ❖ *Please do not alter the formatting of this form or delete any sections. If a particular question is not applicable to your research, please state that as your response to that question;*

This form needs to be submitted, along with all associated documents as follows:

- ❖ *In printed form;*
- ❖ *With the required signatures in sections A.8 and A.9;*
- ❖ *Single sided;*
- ❖ *Using clips rather than staples;*
- ❖ *By 4 pm on the agenda closing date at:*

*The AUTECH Secretariat
Room WO201, WO Building
56 Wakefield Street, City Campus.*

- ❖ *The Internal Mail Code is D-89. If sending applications by Internal Mail, please ensure that they are posted at least two days earlier to allow for any delay that may occur.*

Appendix 2 Participant Information Sheet

Participant Information Sheet



Date Information Sheet Produced:

28 April 2008

Project Title

The social and economic wellbeing outcomes for New Zealand liver transplant recipients, transplanted for their first transplant between January 1998 and December 2005, focussing on the lived experience of liver transplantation.

An Invitation

My name is Bethli Wainwright, liver transplant recipient #62 (August, 2000) and I would like to invite you to participate in my research project on our wellbeing outcomes as liver transplant recipients in New Zealand.

My research is in two phases. Phase 1 is working with a small focus group of 6 to 8 liver transplant recipients to brainstorm what was/is most important to us pre-transplant, during the transplant and post-transplant. The second part of phase 1 is to have one-to-one interviews with 10% (about 20) liver transplant recipients who were transplanted between 1998 and 2005. These interviews are an opportunity for you to tell the story of your experience.

Phase 2 is to take key concepts and knowledge gained from phase 1 to develop a survey. This survey will then be made available to liver transplant recipients who were transplanted between 1998 and 2005. Two groups are excluded, those who received a transplant from a live liver donor and those who received a transplant as a child and are still under the age of 20 at 1 January 2009. This is because you may be too easily identified in the research, and your situation was slightly different. If you are part of this group, you are still welcome to the findings and can sign up for e-mail updates.

Your participation is completely voluntary. If you do wish to participate, then change your mind, that's fine. If you do not wish to participate, but would like to see any results from the research, that is also fine.

This research is co-supervised by Dr. Ed Gane, Hepatologist at the New Zealand Liver Transplant Unit. The chief supervisor is Dr. Marilyn Waring of the Institute of Public Policy, Auckland University of Technology.

What is the purpose of this research?

This research is being undertaken primarily to be able to provide information to future liver transplant recipients and their families and friends. As a liver transplant recipient, I remember the questions I had when faced for the first time with the thought of a liver transplant. As recipients, we are the experts in understanding what our futures post-transplant have been, and continue to be.

The end product of the research will be a Thesis. Additionally, I hope to have some really useful, succinct data that can be made available in pamphlet or booklet form for

New Zealanders with liver disease, already under the care of the New Zealand Liver Transplant Unit. I would also like to consider the possibility of making the findings of the research available in a book form, if there is a publisher who is interested in this.

I believe that there could be potential for an article (or two) on this research in the New Zealand Medical Journal, possibly in association with the New Zealand Liver Transplant Unit. There may also be potential for a conference paper.

This research should also be of benefit to the Ministry of Health and the Ministry of Social Development in terms of policy development and review.

At the conclusion of this research, if I am successful academically, I should receive a Master of Philosophy qualification from the Auckland University of Technology. *On 24 February 2009 my research was upgraded to a Doctor of Philosophy research project.*

How was I chosen for this invitation?

You have been invited to participate in this research as you received your liver transplant in the period 1998-2005, you are currently resident in New Zealand, and you are 20 years of age or older at 1 January 2009. In addition, you received a cadaveric liver, not a lobe from a live liver donor.

What will happen in this research?

In this research you may be asked to participate in one, two or three activities. Six to eight of you will be invited to be part of the focus group. The members of the focus group will still be invited to complete the survey. In addition, 10% of you will be invited to have one-to-one interviews where you talk about your experience of liver transplantation. You will still be invited to complete the survey, and it may be that one or more of you are part of the focus group too.

The focus group will meet by video-conference in University centres, as it is the KAREN (Kiwi Advanced Research and Education Network) system that will be used.

Interviews will be face-to-face, in your town and at a venue of your choice.

Once I have the key concepts from the focus group and from the interviews, I will develop the survey and pilot this initially with the focus group.

Once the surveys have been returned to me, I will analyse the three sets of data for key findings, write these up, and make them available to you.

What are the discomforts and risks?

You may find reliving the transplant experience could become emotional. If you wish to withdraw from the research, that's fine. In addition, there will be a lengthy period of time in which you can complete the survey.

How will these discomforts and risks be alleviated?

The Social Worker at the New Zealand Liver Transplant Unit is fully aware of this research project and you can contact him if you wish for some support or debriefing.

What are the benefits?

One key benefit will be that you will receive the findings on what it's been like for us, the group transplanted in the first eight years of the New Zealand Liver Transplant Unit.

In addition, you know that your experience is contributing towards a source of really helpful information for future liver transplant recipients like you and me.

And finally, the voice of liver transplant recipients will be able to be acknowledged when policy is developed in this field. You will have the satisfaction of knowing that your experience may help make the future better for many New Zealanders with liver disease.

How will my privacy be protected?

The survey is completely anonymous. Very general demographic data will be requested (gender, North Island or South Island type questions) which cannot identify you. If you are selected for an interview, your data will be kept confidential, but the researcher will know who you are.

If you are part of the focus group, you will be known to the researcher and to the limited number of recipients in the focus group (6 to 8).

Your consent form and your data will be held securely within the Auckland University of Technology with very restricted access. (Accessed by myself, my chief Supervisor Dr. Marilyn Waring, and if I need to hire a typist, the typist who will be subject to a strict confidentiality agreement).

I am currently employed by Work and Income, Ministry of Social Development. I want to stress that this research is not for Work and Income. I am not part of 'front line'. I cannot access any information contained within any databases that have client information or benefit information. My role within Work and Income is to manage the Family Violence Intervention Programme and to be a relationship manager with local government in the area of social development under the Local Government Act 2002 and the Act's focus on community outcomes. If you read my story⁴⁴ you will note that my agent's dealings with Work and Income during my transplant were difficult. Having been on the Invalid's Benefit, I am an advocate for change within this organisation.

What are the costs of participating in this research?

If you choose to participate in the survey, the cost to you will be the time taken to complete the survey. For those of you randomly selected for interview there will be the additional 1 to 2 hours for the interview, and any follow-up phone call(s) that the researcher may need to make if anything requires clarification. It should not be more than a couple of hours in total. Focus group participants will be asked to contribute time for the focus group meetings and then participate in the survey.

What opportunity do I have to consider this invitation?

You have 6 weeks to consider this invitation. If you wish to discuss this research with me, while you consider whether you wish to participate or not, please don't hesitate to contact me by mail at AUT. I will do my best to answer all your questions!

Bethli Wainwright
c/- Dr. Marilyn Waring
Institute of Public Policy
Auckland University of Technology
Private Bag 92006
AUCKLAND 1142

How do I agree to participate in this research?

If you wish to participate in this research, please complete the enclosed consent form(s) and return it to me in the self-addressed, pre-paid envelope provided.

⁴⁴ See http://www.livers.org.nz/Our_Stories/Bethli/Bethli.htm

Will I receive feedback on the results of this research?

You will receive a copy of the research findings. In addition, the consent form gives you the option for regular research project update e-mails if you wish. The research findings will either be posted (on DVD) or e-mailed to you, depending on your preferred method of receipt.

What do I do if I have concerns about this research?

Any concerns regarding the nature of this project should be notified in the first instance to the Project Supervisor,

Dr. Marilyn Waring, marilyn.waring@aut.ac.nz or phone (09) 921-9999 ext 9661.

Concerns regarding the conduct of the research should be notified to the Executive Secretary, AUTEK,

Madeline Banda, madeline.banda@aut.ac.nz, 921-9999 ext 8044.

Whom do I contact for further information about this research?

Researcher Contact Details:

Bethli Wainwright
c/- Dr. Marilyn Waring
Institute of Public Policy
Auckland University of Technology
Private Bag 92006
AUCKLAND 1142

Project Supervisor Contact Details:

Dr. Marilyn Waring
Professor of Public Policy
Institute of Public Policy
Auckland University of Technology
Private Bag 92006
AUCKLAND 1142

Approved by the Auckland University of Technology Ethics Committee on 25 June 2008, AUTEK Reference number 08/81.

Appendix 3 Interview Consent Form

Interview Consent Form



Project title: *The social and economic wellbeing outcomes for New Zealand liver transplant recipients, transplanted for their first transplant between January 1998 and December 2005, focussing on the lived experience of liver transplantation.*

Project Supervisor: *Dr. Marilyn Waring*

Researcher: *Bethli Wainwright*

- I have read and understood the information provided about this research project in the Information Sheet dated 28 April 2008.
- I have had an opportunity to ask questions and to have them answered.
- I understand that notes will be taken during the interviews and that they will also be audio-taped and transcribed.
- I understand that I may withdraw myself or any information that I have provided for this project at any time prior to completion of data collection, without being disadvantaged in any way.
- If I withdraw, I understand that all relevant information including tapes and transcripts, or parts thereof, will be destroyed.
- I agree to take part in this research.
- I wish to receive a copy of the report from the research (please tick one): Yes No
- I wish to receive periodic e-mail updates on this research project (please tick one): Yes No

Participant's signature:.....

Participant's name:

Participant's Contact Details (if appropriate):

.....

E-mail (for updates only) :.....

Date:

Approved by the Auckland University of Technology Ethics Committee on 25 June 2008 AUTEK Reference number 08/81.

Note: The Participant should retain a copy of this form.

Appendix 4 Focus Group Consent Form

Focus Group Consent Form



Project title: The social and economic wellbeing outcomes for New Zealand liver transplant recipients, transplanted for their first transplant between January 1998 and December 2005, focussing on the lived experience of liver transplantation.

Project Supervisor: Dr. Marilyn Waring

Researcher: Bethli Wainwright

- I have read and understood the information provided about this research project in the Information Sheet dated 28 April 2008.
- I have had an opportunity to ask questions and to have them answered.
- I understand that identity of my fellow participants and our discussions in the focus group is confidential to the group and I agree to keep this information confidential.
- I understand that notes will be taken during the focus group and that it will also be video or audio-taped and transcribed.
- I understand that I may withdraw myself or any information that I have provided for this project at any time prior to completion of data collection, without being disadvantaged in any way.
- If I withdraw, I understand that while it may not be possible to destroy all records of the focus group discussion of which I was part, the relevant information about myself including tapes and transcripts, or parts thereof, will not be used.
- I agree to take part in this research.
- I wish to receive a copy of the report from the research (please tick one): Yes No
- I wish to receive periodic e-mail updates on this research project (please tick one): Yes No

Participant's signature:.....

Participant's name:

Participant's Contact Details (if appropriate):

.....

E-mail (for updates only) :.....

Date:

Approved by the Auckland University of Technology Ethics Committee on 25 June 2008 AUTEK Reference number 08/81.

Note: The Participant should retain a copy of this form.

Appendix 5 Confidentiality Agreement

Confidentiality Agreement



For someone typing data, e.g. notes of interviews.

Project title: The social and economic wellbeing outcomes for New Zealand liver transplant recipients, transplanted for their first transplant between January 1998 and December 2005, focussing on the lived experience of liver transplantation.

Project Supervisor: Dr. Marilyn Waring

Researcher: Bethli Wainwright



- I understand that all the material I will be asked to type is confidential.
- I understand that the contents of the notes or recordings can only be discussed with the researchers.
- I will not keep any copies of the transcripts nor allow third parties access to them.

Typist's signature:.....

Typist's name:

Typist's Contact Details (if appropriate):

.....
.....
.....

Date:

Approved by the Auckland University of Technology Ethics Committee on 25 June 2008 AUTEK Reference number 08/81.

Appendix 6 Ethics Approval



MEMORANDUM

Auckland University of Technology Ethics Committee (AUTEC)

To: Marilyn Waring
 From: **Madeline Banda** Executive Secretary, AUTEC
 Date: 23 May 2008
 Subject: Ethics Application Number 08/81 **The social and economic wellbeing outcomes for New Zealand liver transplant recipients, transplanted for their first transplant between January 1998 and December 2005, focussing on the lived experience of liver transplantation.**

Dear Marilyn

I am pleased to advise that the Auckland University of Technology Ethics Committee (AUTEC) approved your ethics application at their meeting on 12 May 2008, subject to the following conditions:

1. Clarification of how the focus groups can be conducted effectively through KAREN, who will be organising access to the network for the participants, and who will be paying for its use;
2. Provision of the indicative questions for the focus groups and for the interviews;
3. Provision of a researcher safety protocol for use when visiting participants in their homes;
4. Use of a consistent spelling of the researcher's name throughout the documentation being given to participants;
5. Amendment of the Information Sheet as follows:
 - a. Removal of the second sentence in the fourth paragraph of the section titled 'An Invitation';
 - b. Alteration of 'can' in the last sentence of the last paragraph of the section titled 'What are the benefits?' to 'may';
6. Completion of the last of the three bullet points in the Confidentiality Agreement.

This approval is for the focus group and qualitative interviews only. Other stages will need to be approved separately before the data collection associated with them is undertaken.

I request that you provide the Ethics Coordinator with a written response to the points raised in these conditions at your earliest convenience, indicating either how you have satisfied these points or proposing an alternative approach. AUTEC also requires written evidence of any altered documents, such as Information Sheets, surveys etc. Once this response and its supporting written evidence has been received and confirmed as satisfying the Committee's points, you will be notified of the full approval of your ethics application.

When approval has been given subject to conditions, full approval is not effective until *all* the concerns expressed in the conditions have been met to the satisfaction of the Committee. Data collection may not commence until full approval has been confirmed. Should these conditions not be satisfactorily met within six months, your application may be closed and you will need to submit a new application should you wish to continue with this research project.

When communicating with us about this application, we ask that you use the application number and study title to enable us to provide you with prompt service. Should you have any further enquiries regarding this matter, you are welcome to contact Charles Grinter, Ethics Coordinator, by email at charles.grinter@aut.ac.nz or by telephone on 921 9999 at extension 8860.

Yours sincerely

A handwritten signature in black ink, appearing to read 'M. Banda'.

Madeline Banda
Executive Secretary
Auckland University of Technology Ethics Committee

Cc: Bethly Vivienne Wainwright ptoli@ihug.co.nz, bethli.wainwright002@msd.govt.nz

Appendix 7 *Response to Ethics Committee*



MEMORANDUM

Institute of Public Policy

To: Charles Grinter, Ethics Coordinator
 From: Marilyn Waring, Professor, Institute of Public Policy
 Date: 8 June 2008
 Subject: Ethics Application Number 08/81 **The social and economic wellbeing outcomes for New Zealand liver transplant recipients, transplanted for their first transplant between January 1998 and December 2005, focussing on the lived experience of liver transplantation.**

Dear Charles

Thank you for your approval of the ethics application subject to the six conditions below. I understand that stage 2 of the research (the qualitative survey) requires separate ethics approval and that this approval is for stage 1, the focus group and qualitative interviews.

1. Clarification of how the focus groups can be conducted effectively through KAREN, who will be organising access to the network for the participants, and who will be paying for its use;
2. Provision of the indicative questions for the focus groups and for the interviews;
3. Provision of a researcher safety protocol for use when visiting participants in their homes;
4. Use of a consistent spelling of the researcher's name throughout the documentation being given to participants;
5. Amendment of the Information Sheet as follows:
 - a. Removal of the second sentence in the fourth paragraph of the section titled 'An Invitation';
 - b. Alteration of 'can' in the last sentence of the last paragraph of the section titled 'What are the benefits?' to 'may';
6. Completion of the last of the three bullet points in the Confidentiality Agreement.

This memo addresses the six conditions that are required to be met.

Yours sincerely

Marilyn Waring
Professor
Institute of Public Policy
AUT University

Cc: Bethly Vivienne Wainwright ptoli@ihug.co.nz, bethli.wainwright002@msd.govt.nz

Appendix 8 KAREN Focus Group

I have viewed the KAREN video conferencing suite (Room WO211, level 2, WO Building – the Oracle Tower). Living Au, the KAREN technician, demonstrated to me the way the video conferencing works, the data capture methods (video and audio) that can be used to ensure the content of the focus group is available for transcription, the costs and the turnaround time. Living Au's contact details are:

Email: living.au@aut.ac.nz

Phone: (09) 921-9999 x8367.

KAREN has its own website at <http://www.karen.net.nz/home/>.

The KAREN video conferencing suite at AUT is easy to find when given clear directions. There is pay and display parking available on Wakefield Street for focus group members and in the adjacent side street (St Paul Street) there are disabled car park spaces as well.

The KAREN table layout in Auckland is a $\frac{3}{4}$ square shape, facing three screens, which can have single or multiple destinations showing. The picture and sound quality are excellent. There are two external microphones in the AUT suite. I and four liver transplant recipients will comfortably fit in the room; it has capacity for more than double that number.

The KAREN video conferencing suite is available for use at no charge during normal AUT business hours. This is:

⇒ Term time – 7am to 7pm

⇒ Holidays – 7am to 5pm

Outside of these hours, the cost is \$75.00 per hour, for a minimum of 3 hours. Living Au was unable to state whether this was inclusive or exclusive of GST. There is a further \$50.00 fee for the conversion of the sound file to a format (.wav) that can be emailed to the researcher for transcription. Costs are payable in advance, using Internal Charge Dockets (ICDs). I will access these from the Institute of Public Policy.

I have emailed Canterbury University (colin.mcmurtrie@canterbury.ac.nz) to ask what their hours of operation and costs are. Colin was one of three technical contacts noted on the web page <http://www.bluefern.canterbury.ac.nz/karen/> that has some general information about KAREN at Canterbury University. Living Au is also following up with his counterparts at Canterbury University to find out the costs, minimum amount of time required to book, availability of technicians on weekends, too.

For the purpose of this research project, I will be video-conferencing between AUT University and Canterbury University. This will involve having the majority of the focus group (four liver transplant recipients and myself) in Auckland, and the balance (three liver transplant recipients) in Christchurch.

There would be between two and three focus group sessions in 2008, two in 2009, and one to two sessions in 2010 and 2011. In between focus group sessions, I will send regular e-mails to keep the focus group members updated on the progress of the research.

The expectation is that the focus group would meet after working hours. It is expected that all members of the focus group would be employed, either part- of full-time. My aim is to minimise the disruption that being a member of the focus group might cause, especially when it comes to employment.

Once final Ethics Approval has been obtained, my first action, when the members of the focus group are in place, will be to contact them to determine the time that best suits them for focus group meetings. This may be Saturday mornings, or after work in the evenings. Either way, it is anticipated that there will be some costs involved. The costs will be met either from the Institute of Public Policy or by me privately. The important consideration is to minimise the disruption to the focus group members.

If the focus group meets in the evening, I have discussed having food and beverages in the room with Living Au. I can supply nibbles (such as cheese and crackers) and bottles of water, as long as any debris is removed afterwards, and no liquid is allowed near either of the sensitive, expensive Austrian microphones. I assume this will be similar at Canterbury University, and although I am unable to supply the nibbles and water, I will ensure that the focus group members in Canterbury know what is, and is not, permissible, before the first focus group meeting.

I will follow the following process:

1. Contact the focus group members to determine whether evenings or weekends suit them better.
2. Contact Living Au at AUT with two or three tentative dates and times to get these dates pencil booked for the focus group (at least 4 weeks before the first date) – Living Au liases with Canterbury University.
3. Contact the focus group members with the pencil booked dates.
4. Book the date the majority prefer.
5. Send detailed instructions (parking, room location) to the focus group members at least one week prior. Include details of what food and beverages will be supplied in Auckland, and what can be brought in to the room in Canterbury. Check whether anyone would like Bethli to reimburse any parking costs. Check whether there are babysitting costs they would like reimbursed.
6. Bethli will arrive at the Auckland venue well in advance of the start time, to ensure everything is ready, and to set up a backup digital voice recorder in case the KAREN voice recording technology fails (not expected).

Appendix 9 Indicative Questions – Focus Group and Interviews

Based on the data in the Development of Indicative Questions (next page), my own experience, and the preliminary literature review, my indicative questions for the focus group and qualitative interviews are:

1. Do you remember how you felt when you first found out you had a liver problem?
2. Do you remember how you felt when you were told you *might* need a liver transplant?
3. Can you tell me how you felt when you were listed for transplant?

Possible follow-up questions...

What was it like waiting for the call?

Did you think about the potential donor?

Did you think about dying?

How do you think your life changed?

Were you stressed? (about money, the future, dying, your family, the transplant process...)

4. During your transplant / hospital experience, how did you feel?

Possible follow-up questions...

Were you scared?

Did you have people to support you?

Do you remember how you felt in the Department of Critical Care Medicine?

Do you remember how you felt when you were first back on the Ward?

5. How did you feel when you were allowed to leave the hospital, either for Domain Lodge/Transplant House/other accommodation or your own home?

Possible follow-up questions...

How did you feel in terms of independence and dependence?

Do you remember your emotions at this time?

What kind of life were you living?

Did you feel supported?

Who / what were your main forms of support?

6. When you think of your first three to six months post-transplant, how would you describe your life?

Possible follow-up questions...

What pre-transplant activities were you doing again? (working, driving, socialising)

What was your financial situation? (able to work, accessing income support, supported by family)

How did you view your health?

What about family relationships?

7. How would you describe your life today?

For the focus group members, the first two questions will be sent as “thought provokers” a couple of days prior to the first focus group meeting. By giving focus group members an “aid” or “cue” to think about in advance, they will be able to reflect on their experiences and come to the focus group prepared for these topics to be discussed.

Appendix 10 Development of Indicative Questions

The following two data sources have contributed to the development of indicative questions (previous page) for both the focus group and the qualitative interview.

Table 23: Recipient Concepts in Relation to Wellbeing

These questions were taken from “Our Stories” on <http://www.livers.org.nz>

<p><u>PHYSICAL WELLBEING</u></p> <ul style="list-style-type: none"> • Exhaustion (physical and mental) • Fatigue • Sleeplessness • Lack of strength and mobility • Pain 	<p><u>SELF PERCEPTION</u></p> <ul style="list-style-type: none"> • Loneliness (isolation) • Uniqueness • Personal concepts of health • Justice
<p><u>AUTONOMY</u></p> <ul style="list-style-type: none"> • Dignity • Inhibited • Loss of independence (dependence on others) 	<p><u>FAMILY RELATIONS AND HOME LIFE</u></p> <ul style="list-style-type: none"> • Stress in family relationships • Stress in intimate relationships • Tension
<p><u>MOODS AND EMOTIONS</u></p> <ul style="list-style-type: none"> • Appreciation • Jubilation • Positivity (attitude) • Fear • Institutionalization (where the hospital bed provides the feeling of safety). • Scared (night of the call) • Trepidation (re testing donor liver for viability for transplant) • Anticipation • Boredom (forced inactivity) • Waiting 	<p><u>PSYCHOLOGICAL WELLBEING</u></p> <ul style="list-style-type: none"> • Blame (in respect of the genetic transfer of diseases) • Self-contempt (re weekend road wrecks) • Denial (of seriousness, of past transplant) • Drug reaction – irrationality and fear • Upset (recipients or waiting list patients who do not survive) • Spirituality (also in relation to ‘donor presence’)
<p><u>FINANCIAL RESOURCES</u></p> <ul style="list-style-type: none"> • Disclosure (to employers? How to move into the future) 	<p><u>PEERS AND SOCIAL SUPPORT</u></p> <ul style="list-style-type: none"> • Denial (by family and/or friends)

I grouped the concepts available in “Our Stories” (<http://www.livers.org.nz>) by the quality of life dimensions used in the European study of the socio-economic determinants of health-rated quality of life for children and young people (von Rueden et al., 2006).

Table 24: Sample Questions

These were provided by a Liver Transplant Recipient by email – 2 June 2008

<p><u>FINDING OUT YOU NEEDED A TRANSPLANT</u></p> <ul style="list-style-type: none"> • What did you feel when you were told you needed a liver transplant to survive? • Were you told how the transplant happens? • What supports did you need? • Were you offered supports? 	<p><u>FINANCIAL RESOURCES</u></p> <ul style="list-style-type: none"> • Were you employed at the time of diagnosis? • Did you have to resign from your job? • Were you financially able to stop work and carry on life as normal – i.e. were you able to maintain a mortgage etc?
<p><u>AWAY FROM HOME</u></p> <ul style="list-style-type: none"> • Do you live in Auckland? • How long did you have to be away from your home town? • Did that mean being without family for a period of time? 	<p><u>STAYING IN HOSPITAL</u></p> <ul style="list-style-type: none"> • How was your time in hospital? • How was the nursing care? • Were all your needs met? • Was the hospital area you were in clean?
<p><u>SUPPORT DURING THIS EXPERIENCE</u></p> <ul style="list-style-type: none"> • Did you have a support group? • Were you introduced to other liver transplant patients? • Did you see the Social Worker from the New Zealand Liver Transplant Unit? • Were your questions answered? • Did you get enough support from the Transplant Coordinators? • Were you advised about income support / benefits? • Did you know about the long-term consequences of being out of work for so long? 	<p><u>FAMILY AND INTIMATE RELATIONSHIPS</u></p> <ul style="list-style-type: none"> • Do you have a partner? • If you were in a relationship at the time of the liver transplant – has that survived? • How is your life affected now? • Is life the same socially? • Is life better health-wise?
<p><u>THE DONOR AND DONOR FAMILY</u></p> <ul style="list-style-type: none"> • Do you know anything about your donor? • Do you wish you knew something? • Have you written a letter or sent a card to your donor family? • Have you had a reply? 	<p><u>POST-TRANSPLANT FOLLOW-UP</u></p> <ul style="list-style-type: none"> • What is your experience of the follow-up? • How long has it been since your liver transplant? • Do you have to research out for yourself information on liver transplantation and your particular medical reason for transplantation?

Appendix 11 *Researcher Safety Protocols*

The Researcher Safety Protocol for home visits is based on personal advice given by the chief supervisor, and recommendations made by Paterson, Gregory and Thorne in “A Protocol for Researcher Safety” (1999).

The research and advice suggested that there were four aspects to a Researcher Safety Protocol. These were an assessment of the situation the researcher expects to go into, looking at preventative strategies to ensure the safety of the researcher, how to identify a threat and how to respond appropriately, and what follow-up action might be required.

For the purposes of this research, the following assumptions have been made:

- The New Zealand Liver Transplant Unit would not consciously select a recipient for interview who was known to be dangerous.
- The recipients would fully aware that they were known to the New Zealand Liver Transplant Unit, and if anything went wrong (threats, danger, violence), they would be easily identified to the New Zealand Police.
- The recipients would fully aware that they were being interviewed by a fellow recipient.

Situation Assessment

- When I contact the recipient (by phone) to be interviewed, I will ask the recipient to name the venue where they wish to be interviewed. I will ask for details about this venue. If it is their home, I will ask for clear instructions on how to get there, who else will be in the house, I will stress the privacy of the interview, ask about dogs and other pets on site, and assess the suitability and safety of this setting. If it is not the recipient’s own home, a more thorough questioning around the venue and geographic area will take place.
- I will explicitly state that both my supervisors have information on where and when the interview will take place. If there is any seemingly negative reaction to this by the recipient, further conversations will take place to assess whether this interview is safe to undertake.

Preventative Strategies

- I will “drive by” addresses in the Auckland region once, to assess the geographic environment. For addresses outside of Auckland, I will conduct internet searches on media stories that might have occurred in these streets or roads or suburbs, to assess general safety.
- Both my supervisors will have a list of the recipients being interviewed and the address the interview is taking place at.
- I will send a text message to my chief supervisor, Dr Marilyn Waring, immediately prior to entering the interview venue, and a further text message to Dr Waring as soon as the interview was completed.
- I have a code word established with my chief supervisor, in the event of potential danger. I will have my chief supervisor’s cell phone number on speed dial, and also the 111 emergency number.
- If Dr Waring has not received a text message within four hours of the first text message indicating entry to the interview venue, she will contact the New Zealand Police, after first trying my cellphone.

Threat Identification and Response

- I will use my gut feeling, and observation, to assess whether an interview situation is safe or not.
- If an interview candidate is obviously intoxicated or under the influence of prescription or recreational drugs, I will not enter, or I will immediately exit the interview venue.
- The kitchen will not be accepted as a desirable location for the interview unless in exceptional circumstances.
- Rooms which have an exit to the outside world will a priority for interviews.
- If there are weapons on display, an external door would provide a strategic exit.
- The presence of other people within the venue who might be under the influence of alcohol and drugs would require a rescheduling or cancellation of the interview.

Follow-up

- Any threat or use of force will be immediately reported to the New Zealand Police.
- Any feeling of potential risk or vulnerability will be de-briefed with my chief supervisor as soon as possible.

As this is a small community, where many of the recipients know or know of others, with email and phone contact continuing post-hospitalisation, I do not expect this community to be inherently dangerous to interview. All liver transplant recipients are strongly advised/instructed not to drink or use alcohol in their futures, nor indulge in recreational drug use. It will be highly unlikely that liver transplant recipients who did not follow this advice, would indulge in either activity before or during interviews.

Appendix 12 Final Ethics Approval



MEMORANDUM

Auckland University of Technology Ethics Committee (AUTEC)

To: Marilyn Waring
 From: **Madeline Banda** Executive Secretary, AUTEC
 Date: 30 June 2008
 Subject: Ethics Application Number 08/81 **The social and economic wellbeing outcomes for New Zealand liver transplant recipients, transplanted for their first transplant between January 1998 and December 2005, focussing on the lived experience of liver transplantation.**

Dear Marilyn

Thank you for providing written evidence as requested. I am pleased to advise that it satisfies the points raised by the Auckland University of Technology Ethics Committee (AUTEC) at their meeting on 12 May 2008 and that on 25 June 2008 I approved your ethics application. This delegated approval is made in accordance with section 5.3.2.3 of AUTEC's *Applying for Ethics Approval: Guidelines and Procedures* and is subject to endorsement at AUTEC's meeting on 14 July 2008.

Your ethics application is approved for a period of three years until 25 June 2011.

This approval is for the focus group and qualitative interviews only. Other stages will need to be approved separately before the data collection associated with them is undertaken.

I advise that as part of the ethics approval process, you are required to submit the following to AUTEC:

- A brief annual progress report using form EA2, which is available online through <http://www.aut.ac.nz/about/ethics>. When necessary this form may also be used to request an extension of the approval at least one month prior to its expiry on 25 June 2011;
- A brief report on the status of the project using form EA3, which is available online through <http://www.aut.ac.nz/about/ethics>. This report is to be submitted either when the approval expires on 25 June 2011 or on completion of the project, whichever comes sooner;

It is a condition of approval that AUTEC is notified of any adverse events or if the research does not commence. AUTEC approval needs to be sought for any alteration to the research, including any alteration of or addition to any documents that are provided to participants. You are reminded that, as applicant, you are responsible for ensuring that research undertaken under this approval occurs within the parameters outlined in the approved application.

Please note that AUTEC grants ethical approval only. If you require management approval from an institution or organisation for your research, then you will need to make the arrangements necessary to obtain this.

When communicating with us about this application, we ask that you use the application number and study title to enable us to provide you with prompt service. Should you have any further enquiries regarding this matter, you are welcome to contact Charles Grinter, Ethics Coordinator, by email at charles.grinter@aut.ac.nz or by telephone on 921 9999 at extension 8860.

On behalf of the AUTEC and myself, I wish you success with your research and look forward to reading about it in your reports.

Yours sincerely

A handwritten signature in black ink, appearing to read 'M. Banda', with a stylized flourish at the end.

Madeline Banda
Executive Secretary
Auckland University of Technology Ethics Committee

Cc: Bethly Vivienne Wainwright ptoli@ihug.co.nz, bethli.wainwright002@msd.govt.nz

Appendix 13 Ethics Approval for Survey

MEMORANDUM

Auckland University of Technology Ethics Committee (AUTEC)

To: Marilyn Waring
From: **Madeline Banda** Executive Secretary, AUTEC
Date: 25 May 2010
Subject: Ethics Application Number 08/81 **The social and economic wellbeing outcomes for New Zealand liver transplant recipients, transplanted for their first transplant between January 1998 and December 2005, focussing on the lived experience of liver transplantation.**

Dear Marilyn

At their meeting on 10 May 2010, the Auckland University of Technology Ethics Committee (AUTEC) received the report on your ethics application. AUTEC noted your report and asked me to thank you.

When communicating with us about this application, we ask that you use the application number and study title to enable us to provide you with prompt service. Should you have any further enquiries regarding this matter, you are welcome to contact Charles Grinter, Ethics Coordinator, by email at ethics@aut.ac.nz or by telephone on 921 9999 at extension 8860.

On behalf of AUTEC and myself, I congratulate you on your research and look forward to reading more about it in future reports.

Yours sincerely

A handwritten signature in black ink, appearing to read 'Madeline Banda'.

Madeline Banda
Executive Secretary
Auckland University of Technology Ethics Committee

Cc: Bethly Vivienne Wainwright ptoli@ihug.co.nz, bethli.wainwright002@msd.govt.nz



MEMORANDUM

Auckland University of Technology Ethics Committee (AUTEC)

To: Marilyn Waring
 From: **Madeline Banda** Executive Secretary, AUTEC
 Date: 14 June 2010
 Subject: Ethics Application Number 08/81 **The social and economic wellbeing outcomes for New Zealand liver transplant recipients, transplanted for their first transplant between January 1998 and December 2005, focussing on the lived experience of liver transplantation.**

Dear Marilyn

I am pleased to advise that the Chair of AUTEC and I have approved the second stage of your ethics application. This delegated approval is made in accordance with section 5.3.2 of AUTEC's *Applying for Ethics Approval: Guidelines and Procedures* and is subject to endorsement at AUTEC's meeting on 12 July 2010.

I remind you that as part of the ethics approval process, you are required to submit the following to AUTEC:

- A brief annual progress report using form EA2, which is available online through <http://www.aut.ac.nz/research/research-ethics>. When necessary this form may also be used to request an extension of the approval at least one month prior to its expiry on 25 June 2011;
- A brief report on the status of the project using form EA3, which is available online through <http://www.aut.ac.nz/research/research-ethics>. This report is to be submitted either when the approval expires on 25 June 2011 or on completion of the project, whichever comes sooner;

It is a condition of approval that AUTEC is notified of any adverse events or if the research does not commence. AUTEC approval needs to be sought for any alteration to the research, including any alteration of or addition to any documents that are provided to participants. You are reminded that, as applicant, you are responsible for ensuring that research undertaken under this approval occurs within the parameters outlined in the approved application.

Please note that AUTEC grants ethical approval only. If you require management approval from an institution or organisation for your research, then you will need to make the arrangements necessary to obtain this. Also, if your research is undertaken within a jurisdiction outside New Zealand, you will need to make the arrangements necessary to meet the legal and ethical requirements that apply within that jurisdiction.

When communicating with us about this application, we ask that you use the application number and study title to enable us to provide you with prompt service. Should you have any further enquiries regarding this matter, you are welcome to contact Charles Grinter, Ethics Coordinator, by email at ethics@aut.ac.nz or by telephone on 921 9999 at extension 8860.

On behalf of the AUTEC and myself, I wish you success with your research and look forward to reading about it in your reports.

Yours sincerely



Madeline Banda
Executive Secretary
Auckland University of Technology Ethics Committee

Cc: Bethly Vivienne Wainwright ptoli@ihug.co.nz, bethli.wainwright002@msd.govt.nz

Appendix 14 Survey Consent Form

Survey Consent Form



Project title: The social and economic wellbeing outcomes for New Zealand liver transplant recipients, transplanted for their first transplant between January 1998 and December 2005, focussing on the lived experience of liver transplantation.

Project Supervisor: Dr. Marilyn Waring

Researcher: Bethli Wainwright

- I have read and understood the information provided about this research project in the Information Sheet dated 28 April 2008.
- I have had an opportunity to ask questions and to have them answered.
- I understand that I may withdraw myself or any information that I have provided for this project at any time prior to completion of data collection, without being disadvantaged in any way.
- If I withdraw, I understand that all relevant information including the survey will be destroyed.
- I agree to take part in this research.
- I wish to receive a copy of the report from the research (please tick one): Yes No
- I wish to receive periodic e-mail updates on this research project (please tick one): Yes No

Participant's signature:.....

Participant's name:

Participant's Contact Details (if appropriate):

.....

E-mail (for updates only) :.....

Date:

Approved by the Auckland University of Technology Ethics Committee on 25 June 2008 AUTEK Reference number 08/81.

Note: The Participant should retain a copy of this form.

Appendix 15 *Research Survey*



Research Survey

The Lived Experience of Liver

An anonymous voluntary survey of liver transplant recipients, by liver transplant recipient Bethli Wainwright (transplanted August 2000), for a doctor of philosophy degree at AUT University, supervised by Professor Marilyn Waring (AUT University) and Associate Professor Ed Gane (Auckland University).

This survey is anonymous

This is an anonymous voluntary survey of liver transplant recipients in New Zealand. In order to ensure that all responses are anonymous, the following steps have been taken:

- Only Associate Professor Ed Gane and Liver Transplant Coordinator Val Honeyman know which liver transplant recipients have been sent a copy of this survey. They do not see the survey responses. Val very kindly addressed all the envelopes and posted these out - a huge task!
- Surveys are sent out in envelopes with the New Zealand Liver Transplant Unit's return address on it (for *return to sender*, if not able to be delivered). Therefore only the New Zealand Liver Transplant Unit will know which surveys were undeliverable.
- The **Survey Consent Form** (for participants who would like a copy of the final thesis, or a summary of the findings) is sent back in a separate stamped, self-addressed envelope to Professor Marilyn Waring at AUT, to collect for the researcher.
- The **Survey** is sent back to the researcher in a separate stamped, self-addressed envelope, again to Professor Waring at AUT, to hold for the researcher.
- If a recipient wishes to complete this survey on a computer using Microsoft Word, Professor Marilyn Waring's personal assistant, Suzanne McIntyre, can e-mail a copy on request. The recipient can return this to Suzanne McIntyre (suzanne.mcintyre@aut.ac.nz), who will remove all personal information (e.g. name and e-mail address) from it before forwarding it to the researcher.
- Only basic demographic data is asked for, to enable the researcher to look for patterns and groupings.

SURVEY DATE - 1 JULY 2010

RESPONSES DUE - 1 SEPTEMBER 2010

Eligibility to participate in this survey

Associate Professor Ed Gane has applied the researcher's eligibility criteria to the database of liver transplant recipients, who have received transplants through the New Zealand Liver Transplant Unit, since it commenced its work in New Zealand in 1998. This has determined which recipients the New Zealand Liver Transplant Unit posted a copy of this survey to. If you have received a copy of this survey, you should meet the following criteria:

- ✓ you received your liver transplant between 1998 and 2005;
- ✓ you received a donor liver from a deceased donor (not a living donor);
- ✓ you received your liver transplant at the age of 20 years or older.

You do not have to be currently living in New Zealand to complete this survey if the above criteria are met. If the New Zealand Liver Transplant Unit has overseas contact details for you and you receive this survey, you are welcome to complete it.

There is no requirement to participate

Although the New Zealand Liver Transplant Unit has posted this to you, on behalf of the researcher, please be aware that there is no requirement to participate. Your participation is voluntary. If you do not wish to participate this will not alter any aspect of your treatment or care. The researcher would like to thank you in advance for considering whether to participate, and, although appreciating all responses, fully understands that some of you may not wish to re-visit your transplant journey.

If receiving this survey, itself, has made you feel uncomfortable and/or reminded you of events you would rather forget, you are welcome to contact the New Zealand Liver Transplant Unit's two Social Workers. Contact details are:

Ron Benjamin

 021-835-604 &  ronb@adhb.govt.nz

Cindy Penny

 021-849-375 &  cindyp@adhb.govt.nz

Introduction

This survey has 9 sections and 32 questions. There are a number of **quotes** from fellow liver transplant recipients to read. You will need about 25 minutes to read the survey and about 25 minutes to complete it. If you wish to keep a copy of the survey, you are welcome to photocopy it.

Section 1 – Demographics

Section 2 – Caregiver support

Section 3 – Being unwell

Section 4 – Listed for transplant

Section 5 – Having the transplant and time in hospital

Section 6 – First three months after the transplant

Section 7 – Life today

Section 8 – The donor

Section 9 – Community

Section 1 – Demographics

This section only captures enough information to allow the researcher to explore potential groupings, such as similarities or differences within the transplant experience according to geography, gender, age grouping etc. It is not enough to identify any recipient.

Question 1

Using the same classifications as *Census 2006* (Statistics New Zealand), please tick the ethnicity you most closely associate to.

(a) European	<input checked="" type="checkbox"/>
(b) Māori	<input type="checkbox"/>
(c) Pacific Peoples	<input type="checkbox"/>
(d) Asian	<input type="checkbox"/>
(e) Middle Eastern / Latin American / African	<input type="checkbox"/>
(f) Other Ethnicity	<input type="checkbox"/>

See <http://www.stats.govt.nz/Census/2006CensusHomePage/QuickStats/quickstats-about-a-subject/culture-and-identity/ethnic-groups-in-new-zealand.aspx> (retrieved 14 March 2010).

Question 2

Please tick the age band you were in, at the time of your liver transplant.

	<input checked="" type="checkbox"/>
(a) 20 to 29 years of age	
(b) 30 to 39 years of age	
(c) 40 to 49 years of age	
(d) 50 to 64 years of age	
(e) 65+ years of age	

Question 3

Please tick your gender.

	<input checked="" type="checkbox"/>
(a) Male	
(b) Female	

Question 4

Please tick the most appropriate description of your geographic environment at the time immediately prior to your liver transplant. That is to say, if you were normally resident outside of Auckland prior to transplant, and had to stay in an Auckland motel for example, once you were listed for transplant, this is asking for your geographic area before you were in the Auckland motel, or Transplant House etc.

	<input checked="" type="checkbox"/>
(a) Auckland (from Orewa to Pukekohe)	
(b) North Island – urban (e.g. Rotorua, Wellington)	
(c) North Island – rural (e.g. Waikato, East Coast)	
(d) South Island – urban (e.g. Christchurch, Dunedin)	
(e) South Island – rural (e.g. Canterbury, Southland)	
(f) Islands (Great Barrier Island, Waiheke Island, Chatham Islands, Stewart Island)	
(g) Other (e.g. Australia, Samoa)	

Section 2 – Caregiver support

This section asks for brief details on the caregiver support you received during your transplant.

Question 5

All of us have to have people caring for us during our transplant journey. Some of us had a number of caregivers, others had a primary caregiver who shouldered most of this work. Please tick the categories of people who provided most of your caregiver support.

	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>
	3 months before your transplant	During your transplant	3 months after your transplant
(a) Spouse or partner			
(b) Mother			
(c) Father			
(d) Other family member			
(e) Friend			
(f) Work colleague			
(g) Other			

Question 6

Was your main caregiver...

(If you had more than one main caregiver, e.g. different on week-ends to week-days, please use "A", "B", "C" to differentiate between caregivers.)

	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>
	3 months before your transplant	During your transplant	3 months after your transplant
(a) Working full-time			
(b) Working part-time			
(c) Self-employed			
(d) Retired			
(e) Required to give up work (resigned OR took leave)			
(f) Receiving income support from WINZ			

Section 3 – Being unwell

This section asks you to read liver transplant recipients statements about being unwell and write about your own experience. The following quotes are taken from interviews with seventeen liver transplant recipients from Auckland to Invercargill undertaken between late 2008 and early 2010.

Statements from liver transplant recipients

“I sort of wouldn’t acknowledge that I was ill, my wife kept saying to me: “There’s something wrong with you, you’re yellow, you’re tired.” All the rest of it.” (Male)

“I just felt ill, it was just a feeling that it wasn’t getting any better.” (Female)

“I see a specialist again and he says: “Oh, yes. ...we suspect you might have this” ...And I thought: “Oh I wonder what this is?...Do I want to look it up?” ...I went to the public library...I pick up this book and look it up and it says: “This is nearly always fatal.” Fatal. Liver disease. I thought: “Oh @#%\$.” ...And so I didn’t want to read about it from then on.” (Male)

[Liver cancer]”...shocked and stunned. ...I wasn’t unwell, so that was probably the biggest shock.” (Female)

“I actually could feel myself going weak, probably eighteen months before it got to the yellow jaundice stage. And ah, ‘cause I’ve always been a thick head, and I was: “Oh, I can work it off!”...they [colleagues] said: “You’ve got yellow eyes, your skin’s yellow, you’re in big trouble...” And they told me straight out: “Get to a doctor!”...so I went to the doctor, and the doctor took one look at me and he said: “You’ve got liver problems.”” (Male)

“I thought I was just really run down and depressed.” (Female)

“...for about a month before that I was feeling really really unwell...I just thought I was going through a phase. ...I went to the doctor’s, and I said: “I’m not feeling too good.” And he said: “Go and have a blood test.” ...Got the blood test the following day...he called me and said: “You need to get to the hospital immediately.”” (Male)

“I kept complaining that I was unwell and they gave me all the tests under the sun...I did go to the hospital one day for a check up and there was a doctor there...And he said to me: “Well, you’ve got liver trouble and one day you’ll have to, um, it might get so bad that you’ll just die.” ...And that was a real shock...” (Female)

“...one morning I came down for breakfast, and both [spouse] and my sister said: “you look B’ awful!” I said: “I feel alright!” And my sister, who’d been trained as a nurse, said: “Well, you’re not.”” (Male)

“I don’t think I really realised that I was as sick as I was until they started talking about liver transplants. I’d been putting on a bit of weight, I thought, around my waist ... But then one weekend, I just blew up! ... And I was so itchy...so I went to the doctor...she thought it might have been sort of a bit of gas or something...” (Female)

Question 7

What do you remember of first becoming unwell?

Please use extra paper if you need to.

Section 4 – Listed for transplant

This section looks at employment pre-transplant, life while waiting for the ‘call’ and how we felt once called for transplant.

Question 8

This question looks at how we may have changed or stopped employment as we became unwell.

Statements from liver transplant recipients

“I think I’m going to be well enough this week, or I think I’m not going to [be], you know,... just teaching one class a couple of hours a week, because of my whole energy kind of, allotment, for that week. I was really, really sick by then. But I didn’t think I was.” (Female)

“I was still a full-time employee but I was only working four hours a day.” (Female)

“I went, still carried on working for a couple of months after they diagnosed me.” (Male)

“I’d go down to Wellington every month for two or three days. Get up at 5 in the morning, drive to the airport. When I think about it, I don’t know how I did it.” (Female)

“I worked right up until the day before each of the attempts to transplant.” (Female)

Please tick your employment status in the three categories below, prior to your liver transplant.

	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>
	1 year before your transplant	6 months before your transplant	1 month before your transplant
(a) Working full-time			
(b) Working part-time			
(c) Self-employed (full-time hours)			
(d) Self-employed (part-time hours)			
(e) Sick leave or other financial support from employer			
(f) Income support from WINZ			
(g) Retired			
(h) Other			

Your response:

Please use extra paper if you need to.

Question 9

How did you feel once you were listed for a liver transplant and were on the waiting list?

Statements from liver transplant recipients

“...when I did think about being on the wait, you know, just – there were times when I thought: “Oh, God, am I waiting around for someone to die.” Kind of thing...my brain sort of says, um, you know: “They were going to die anyway, at least something good has come of their death.”” (Female)

“...my sister’s brother-in-law, he was number [xx]. So I sort of knew about it. And when I found out that I had to have the liver, I went and talked to him, and he sort of talked me through what would happen...” (Male)

“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.” (Female)

“I met a guy who...had his in Brisbane, ...so I rang him up, and ah, I spoke with him, and he said to me, he says: “Come around, come around” he said. “We’ll have a cup of tea, cup of coffee, and we’ll talk about it.” And the more he talked to me, the easier it got.” (Male)

Your response:

Please use extra paper if you need to.

Question 10

How did you feel once you were called to hospital to have your liver transplant surgery?

Statements from liver transplant recipients

“I thought I might die on the operating table...I think that’s one of the reasons why I had to believe it was really unreal, like I definitely felt that way the night that I was in hospital – waiting when I’d been called in.” (Female)

“As they wheeled me into the theatre on the trolley there was a photograph on the wall of a Pacific island, white sand, coconut trees, and when I saw that, I thought: “It’s going to be good.”” (Male)

“... Steve [Munn] had already told me they’d never lost anyone on the operating table. Which was the main concern at that point...the look on my daughters’ faces will forever haunt me, I’ve just never seen the fear.” (Female)

“...they were in at quarter to six, woke me up, ...so the family come in, and...I said to my family: “If anything goes wrong, you are not to blame the hospital.” I said: “You hear that?”” (Male)

“I still thought, I mean I honestly thought as they were wheeling me to the operating theatre, like when I was in the elevator, I still thought they were going to realise they’d made a mistake.” (Female)

Your response:

Please use extra paper if you need to.

Section 5 – Having the transplant and time in hospital

This section is about your recollections in Intensive Care and the Ward after your transplant.

Question 11

After the transplant we are started on a range of new medications, and some of us (including myself) had nightmares and/or delusions while others did not.

Statements from liver transplant recipients

“I was on this bed, in the fishmonger’s room...I was calling out, and nobody came...then I saw this nurse coming through...and she said: “What’s the matter?” And I went to explain, and I couldn’t explain it, I...went from the irrational hallucination and felt like a stupid fool that I was in this fishmonger’s room. Scary at the time.” (Male)

“...after my transplant, when I was in the ward, I called the nurses in one night and I said: “Look! The skin’s all peeling off my legs.” And I went like that on my leg. I said: “Look at it!” And I looked at the nurses and I could tell, just by the way they were looking at me, that it wasn’t happening...that I was just imagining it.” (Female)

“I dreamt this big fat Russian nurse came in...and she said: “We’re going to give you, we’ve got to” do something to me. And they cut me in half. And the top half, and they sliced me like a bacon slicer, you know, virtually in pieces, and then they put me all back together. But they got me mixed up with the woman next door, and I finished up with a woman’s bod, oh, God, it was terrible.” (Male)

“I had a spray of flowers ...and there was this little mouse that kept running around amongst them – and everything. And I could see this little mouse. But, of course, it wasn’t there at all.” (Female)

“I had one really vivid bizarre dream...it involved the Everley Brothers, Al Qaeda, it was just out of this world.” (Male)

“I remember asking the nurse who was playing the ukulele...it was just the monitoring system that was there, beeping...I remember asking one of the nurses why she was hiding her cigarettes underneath my bed...and she said to me: “No, no, I do smoke but I wasn’t hiding anything under the bed.”” (Male)

Part 1: please note below if you had nightmares or delusions.

	Please write Yes or No
(a) I had nightmares in Intensive Care and/or the Ward	<input type="checkbox"/>
(b) I had delusions in Intensive Care and/or the Ward	<input type="checkbox"/>

If you answered Yes to either or both of the above boxes, please answer Part 2.

Part 2: Did you want help in managing or coping with your nightmares and/or delusions?

For example: *My first week back in Ward 7B I watched TV all night (with the sound off) while listening to the radio on my headphones, in order to prevent myself falling asleep and having repetitions of the nightmares.*

	Please write Yes or No
(c) I did not want to ask for help	<input type="checkbox"/>
(d) I asked for help	<input type="checkbox"/>
(e) I received help without asking	<input type="checkbox"/>

Your response:

Please use extra paper if you need to.

Question 12

This question looks at your levels of pain pre-transplant and immediately post-transplant.

Statements from liver transplant recipients

“...at one stage I was really uncomfortable and I didn’t realize I should have been shooting meself up with the morphine or whatever...at one stage, I thought: “God! I’m never gonna get any. And they said: “Oh just give yourself some.” And once I did that I was a bit better.” (Male)

“Dying doesn’t hurt, you know. You’re just like: “Oh God.” What did I say that for, ‘cause they’re just feeling sorry for themselves and I’m going: “It’s alright. It doesn’t hurt!” It’s not painful. It’s simple. They don’t know though, do they? They don’t know what we know.” (Female)

“I could put up with quite a bit of pain, but by Jove that was pain!” (Male)

“...it’s not the shock of the transplant, by having that, or the pain or anything like that. ‘Cause I can’t remember any pain. I think it’s learning to walk again and getting out and doing things.” (Female)

“I was getting better, and the pain was starting to go away, and that, and I’d say within prob’ly eight, nine days, it was gone. Pain was gone...” (Male)

“...It was like I’d been run over by a truck, just belted by a truck in the front. And I think for me it was just that physical whole thing of getting my energy back, getting through the pain.” (Female)

“...you feel as if you’ve been run over by 24 trains and a couple of big buses, don’t you!” (Male)

“...he says: “Are you feeling OK today?” And I said: “Yeah.” I said: “I feel like someone’s hit me on the head with a hammer that’s all!”“ (Female)

“...you know what a transplant’s like, it’s um, it was uncomfortable.” (Male)

“...I think because of all the painkillers, the Critical, I quite enjoyed Critical Care, because you’re so floaty and not in pain...[move to the ward] and then the pain started, and then the, mirages and the, all of that stuff. And I do remember having a couple of really really bad nights. Just couldn’t get comfortable and the pain was intense...” (Female)

“I didn’t feel much pain. Not even with the operation. It was very uncomfortable for a while, but not hugely painful.” (Male)

“I was terrified of death, because you know what it was? The pain. Having a painful death...death was very scary for me. It was only because of the pain. If I didn’t have the pain I think I would have accepted death.” (Female)

“...I said: “the only thing that’s worrying me.” I says: “I’m really uncomfortable.” I had no, no pain. Even when all the um the drugs I felt noth[ing], I just said: “Look, I’m just really uncomfortable.” And they kept saying: “But ‘uncomfortable’, what does that mean?” And I said...: “it’s about a 2 actually.” He said: “It’s a 2, you’re not in pain?” I said: “No, I’ve just told you, I told you I’m not in pain, I’m just uncomfortable, THAT’S ALL!”“ (Female)

“...for me the biggest thing was pain, I was in agony. And the next thing I remember about staff and everything else, was this Occupational Therapist wanted to get me up, and get me walking. Get me to the gym. And I was in so much pain! I was really in pain, I just, and whether that was because I wasn’t sick before, so suddenly I’ve had this massive cut, and I was in agony.” (Female)

	<input checked="" type="checkbox"/>									
	1	2	3	4	5	6	7	8	9	10
1= very low pain, 10=extreme pain. The same pain scale as in hospital										
(a) Your level of pain 1 month before transplant										
(b) Your level of pain in Intensive Care										
(c) Your level of pain in the Ward										
(d) Your level of pain 1 month after transplant										
(e) Your level of pain 3 months after transplant										

Question 13

This question looks at the concept of time after your transplant, while you were in Intensive Care.

Statements from liver transplant recipients

“I woke up thinking that it was still the same day, but it wasn’t, it had, we were going in to the ev-, we were in the evening, heading for the next day.” (Female)

[Intensive Care – return visit] *“They said to me: “You always wanted to know the time.” And they said: “That’s the clock that you kept wanting to know the time.”*” (Male)

“...when I came out of my op, ‘cause I had the tube down my throat, all I wanted to know [was] two things: what was the time – because then I would know how long I’d been out for; and did they do it – because there was always a possibility for me that it wouldn’t happen. And, of course, I couldn’t ask them. And I kept trying to point to my arm, but I didn’t have much energy to point. You know? And no one knew what I meant. I’d look around the room to try and see a clock and there wasn’t one. But that was the two things that I was trying to find out.” (Female)

“Because I was sick and tired of this pipe down my throat, you know. They said: “Oh, no, you’re going to be here for another 12 hours or 18 hours.” You know. But as I said I couldn’t remember, I can remember lying on my back looking at the ceiling and the nurse either side of me and looking at the clock, and I can’t remember going from there in the lift up to the Ward.” (Male)

“Cause I was in the room where there was no windows at all. And like for six days I was in that room. I thought they could have moved me to one that had windows in...Lights on all the time. Lights on all the time.” (Female)

“But the time that I was in there, I think it was five days, I’m not sure. Did, didn’t mean anything, you know, one, it runs between being awake and asleep...I didn’t know whether it was night or day or what it was.” (Male)

Please write
Yes or No

(a) Did you want to know the time in Intensive Care?	
(b) Were you told what the time was, enough to satisfy you?	
(c) Could you differentiate between day and night?	
(d) Were you able to see out a window?	

Your response:

to the wall, sliding down the wall, basically, to get back to my room. And I sat on the bed and called the nurse...I was sopping wet, with my dressing gown on top, still sopping wet. And they ended up, then, agreeing to help dry me. To get me back into bed. So every morning from then on, for the next few mornings, [spouse] came in and helped me to shower, or Mum, because I couldn't do it." (Female)

Your response:

Please use extra paper if you need to.

Section 6 – First three months after the transplant

This section asks about what it was like to go home after your transplant, and becoming independent again.

Question 15

Did you find it hard to return to your own home after your liver transplant?

Statements from liver transplant recipients

“There were times when I thought I’d never get to...live in my own house...I kind of in some ways got to the point where I quite liked being in hospital, like I felt kind of safe there...I can understand what people say about becoming institutionalized...” (Auckland recipient)

“...I wasn’t nervous about going home...I walked into our bedroom to go to bed, and I looked around and I said to [spouse]: “You’ve had the bedroom painted.” And [spouse] said: “No, I haven’t.” And I said: “Well it’s brighter.” Everything looked different...” (Auckland recipient)

“...he [Dr Ed Gane] said. “Go home for the half a day, come back, and the next day you’re going home”...I said: “But can I come back?...if something happens?”...I was living on the edge...” (Auckland recipient)

“...I had food, I had security here, but I didn’t have the security if you know what I mean. I was absolutely petrified, to stay here [home] alone.” (Auckland recipient)

“...it was ah, a little bit frightening, probably for, for the first, ah, 200kms out of Auckland, but then I thought to myself: “Well, I’m going home, I’m still alive. Go out and @\$%& enjoy it!””* (North Island recipient)

“...we were supposed to stay there [motel] for like three months...I got Ed to let me go after about six weeks...I said to him: “I just want to go home...and be on my own. Not with [caregiver] with me.”” (North Island recipient)

“...I’d been up there for three months after the op, so I came home on Election day ‘99. I was, we were ready to come home.” (North Island recipient)

“They [NZLTU] said I could come home one day...then they called me over, and no...you can’t go home yet. I was terribly disappointed...I came back from the hospital...and I burst into tears...” (South Island recipient)

“They made me stay three months. I was dying to get home.” (South Island recipient)

	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>
	Too early	The right time	Too late
(a) Do you believe you returned to your own home...			

Your response:

Please use extra paper if you need to.

Question 16

Driving is something that can provide us with independence again, after our transplant. Please tick the box in relation to driving.

“...that was a break-through, the day I drove by myself.” (Female)

	☑	☑	☑	☑
	In the first 3 months after transplant	3-6 months after transplant	7-12 months after transplant	Do not drive
(a) When did you start driving?				

Question 17

This question asks you to reflect on how people treated you in the first three months after the transplant. Were they overly protective or did they facilitate you regaining independence at your own pace?

Statements from liver transplant recipients

“My parents, they handled it really, really well. But ever since they worry about me, all the time. They never stop – worry, worry, worry...” “You shouldn’t be doing this and you shouldn’t be doing that. You can’t go to work. And, you work too hard.” (Female)

“...got back to full-time [work] and they found it hard to give me, you know, like, I needed more from them, sort of work wise...I had an issue with them...one set of people were always getting the extra jobs that would advance their careers and stuff like that...I actually talked to my manager about it and she said: “Oh well, you know, it’s hard for us to realize that you’re well now.” You know? And like she said: “Oh we’ve probably been treating you a little bit different because you’ve been sick.” And I said to her: “Well, I’m not sick anymore. I’m normal. I’m quite healthy.” And it took them a little while to realize that.” (Female)

“I’m very grateful to my [spouse], my [child], and my sister-in-law, and the two kids, well. When I went home, Gawd they were getting all over me like a blue-ass fly, you know? And I hate that.” (Male)

“...[spouse] come home: “What are you doing?” “I’m just sweeping a little bit here.” “No, don’t do that, go inside and sit down. Don’t do anything.” It was a sense, when I felt that I could do things for us as a family again, I felt I belonged.” (Female)

“...I was well now, you know...I wasn’t the same as I was before I had it.” (Female)

“...my GP’s a lot more cautious than the liver doctors are, like she doesn’t really even still like me going to see her...being with the other patients there.” (Female)

Please write
Yes or No

(a) Did you feel that you were being overly protected or sheltered by people helping you?	
(b) If you started working towards the end of the first three months after your transplant, do you feel your employer treated you differently to other employees?	
(c) Did you feel you had the level of independence and responsibility you wanted?	
(d) Did you feel that people saw you as ‘sick’ while you were recovering from your transplant?	
(e) Did you feel that your local GP treated you the same as other patients?	

Section 7 – Life today

This section asks you to comment on your everyday life now. It looks at medication, alcohol, travel, employment, prejudice and so on.

Question 18

Here are comments from liver transplant recipients on taking medications after our transplants. Please read these statements and tick the boxes that reflect your own experience.

Statements from liver transplant recipients

“I still haven’t had any problems. Nothing...all my blood tests are okay. I’m just on the medication...But the medication plays up with my hair...My hair’s terrible...And I’m conscious of it, you know.” (Female)

“...every now and then I’ll get a bad headache. And that’s just the Tac [Tacrolimus], I think.” (Male)

“...my Tac’s quite, seems to be quite stable. And my Warfarin...I’ve been on it for so long now, you know, I sort of self-medicate...I’ll go and have a blood test and I’ll get the results. And I’ll look at it and I think: “Oh, it’s a little bit low. I’ll just up my dose.”” (Female)

“The one thing with Sirolimus with me, is that it’s playing around with my bone density...But they say that could be age, as well as the medication.” (Male)

“...I have actually forgotten. Like, yeah, on the odd occasion. Mainly on the weekend. You know, ‘cause like, at work, I have it set in my calendar...” (Female)

“...the drugs didn’t worry me in general terms.” (Male)

“...I had a great fear that I might forget my medication. I remember saying to [Liver Transplant Co-ordinator]: “I don’t know how I’m going to do this.” You know, because at the beginning, of course, there were screeds of pills, and you had your yellow card.” (Female)

“...there’s different results of medication and it’s not necessarily the Tac that I’m on, but some of them maybe, I get a scratchy part of my hair there...Things like that, on your skin.” (Male)

“...sometimes I have strange feelings about the drugs, you know, I mean I know Tac has a, it can cause some things as well, you know, I’m fully aware of that.” (Female)

“...I know I have to take my drugs, I’ve gone outside the times. I’ve gone out twice, but what can I do when I’ve done it?...if they say I’m meant to take it at ten o’clock, and I don’t take it till twelve thirty, I make a note in my diary.” (Female)

“...nothing stops me. Really...I’m in a routine to take medication, it’s not a hassle. I’m not so good at taking it bang on the dot, so it doesn’t actually interfere with my life.” (Female)

	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>
	Never	Sometimes	Always
(a) Does being on immune suppression medication worry you?			
(b) Do you take your medications on time?			
(c) Have you stopped taking your medications without the NZLTU’s knowledge?			

Question 19

What is your view of liver transplant recipients who drink alcohol after their transplant?

Statements from liver transplant recipients

“...his wife’s father had a liver transplant...anyway, he went boozing...and it killed him...I said: “Well, it was his own fault. He should have known better really, than drink.” You know, because they tell you not to.” (Female)

“...I think it’s a moral thing. You’ve been given that gift, so you don’t go, like George Best, you don’t abuse it. It wouldn’t, it’s not right.” (Male)

“I just instantly think of George Best. And I think how naughty. How naughty – to go for a second one [second liver transplant], given his history.” (Female)

“...one shocking thing I saw in [hospital]...I happened to walk past...his cubicle, and there he was in there with his family and he was drinking alcohol. In the hospital...I just glared! And I thought: “You mongrel.”” (Male)

Your response:

Please use extra paper if you need to.

Question 20

What role does alcohol have in your own social life after your transplant?

Statements from liver transplant recipients

“...I’m a teetotaler. But every now and again I might like a glass of red wine...” (Female)

“I miss having a beer when I watch the rugby. But I have a cup of tea instead...” (Male)

“...now if I want to have a drink, I’ll have a drink...I’ll have a glass of wine, you know, a glass of bubbles and stuff. But I, my limit would be two glasses, if I have that.” (Female)

“...where I was working, when you’ve finished work we’d sit down and have a few stubbies and that, I’d sit there an’ bring out my can of Coke, bottle of Coke, sit there and talk.” (Male)

“...you know if I go out somewhere and somebody says: “Do you want a drink?” No way! I, you know, I’ve got somebody’s liver that they looked after their liver, obviously, and I intend to as well.” (Female)

“Well, to tell you the truth I have a glass of wine now and then...I know I shouldn’t have it. But it might sound stupid, the days I do have it, I feel good. Now whether it’s psychological or whatever...” (Male)

	☑	☑	☑	☑
	None	Up to 12 std drinks a year	Up to 12 std drinks a month	More than this
(a) How much alcohol did you drink in the <u>first year</u> after your liver transplant?				
(b) How much alcohol do you drink today?				

Question 21

Being immune-suppressed may or may not be an obstacle to enjoying overseas travel. Since my transplant I have been to Europe twice (2002, 2007). Here are statements about overseas travel from other liver transplant recipients. Once you have read them, please mark the boxes below.

Statements from liver transplant recipients

"I've been to the States a few times in recent years, and I was in Berlin this year and in London, so travel has not been a problem." (Female)

"I've got no interest in travelling now, 'cause I've been out of New Zealand ten times...if I wanted to go overseas again I'd go." (Male)

"...if I had lots of money, I'd like to go overseas but I don't think that I could go where I'd like to go. I'd like to go to Peru and, and mountainous areas...you couldn't rough it, could you?" (Female)

"...we took a trip overseas...spent three months over in the UK." (Male)

"I've never wanted to travel overseas before or after...If I really wanted to go, it's [spouse] more of a barrier. He doesn't want to fly, you see, so we don't go." (Female)

"...we went over to Australia, and Ed Gane gave me a letter saying that I'd be alright to travel." (Male)

"...I've traveled, as you have. You take it [medication] with you, you always are aware you've got to have it with you if you go away, have a spare pack. You don't put it in your luggage so it gets lost in the plane!" (Female)

"...we're planning to be going overseas [Europe] next year, for a couple of years." (Male)

"...I'd like to go and live in California but I don't know how on earth I'd handle the cost of medication and doctors...I think it probably would be almost impossible for me to go back and live in the States." (Female)

"...one time I had to nip back to Hong Kong to do something for my father-in-law. I took three months of the medication in case I needed it." (Male)

"I would be very nervous still, about going to some of the Pacific Islands or the places where hygiene is not good now. I don't think I'd be able to do that. I think I'd be too scared..." (Female)

Please write
Yes or No

(a) Did you travel internationally before your transplant?	
(b) Have you travelled internationally since your transplant?	
(1) Have you travelled to Australia?	
(2) Have you travelled in the Pacific (e.g. Fiji, Tonga)?	
(3) Have you travelled to Indo-Asia (e.g. China, India etc)?	
(4) Have you travelled to the United Kingdom/Europe?	
(5) Have you travelled in Eastern Europe/Russia?	
(6) Have you travelled to North America?	
(7) Have you travelled to Central America?	
(8) Have you travelled to South America?	
(9) Have you travelled in the African continent?	
(10) Have you travelled in the Middle East?	
(c) Do you believe being immune suppressed is a barrier to international travel?	
(d) Do you have any interest in travelling overseas?	

Question 22

This question asks you to think about whether you have experienced any prejudice or stigma because of your liver transplant. This could be in social activities, within your family or in relation to employment, etc. You may also like to reflect on the Anthropologist’s comment below.

Page 198

“Transplant patients today are increasingly warned that they are not exchanging a death sentence for a new life but rather exchanging one mortal, chronic disease for another.”

Scheper-Hughes, N. (2000). The global traffic in human organs. [Electronic version]. Current Anthropology, 41(2), 191-211.

Statements from liver transplant recipients

“...I kept thinking to myself: “Why should I have to explain?” But you’d see the look on their faces: “Oh, yeah, yeah, drinker.” And I just couldn’t have them thinking that, knowing how I feel about it. And I noticed that I have stopped saying, explaining now, but for years I did. Which is strange. But that’s what they hear. That’s the word they hear. And relate to. Where as cirrhosis is just injured liver!” (Female)

“...it’s sort of like, you have to qualify. Yes. Yeah, that’s the particular one with the liver, isn’t it? They don’t, whereas with a heart, they’re not going to think: “Oh what, he was doing drugs or, doing. Yeah.” (Male)

“It’s been a hard road for me, coming from my little town of [name], which is a port, and which has a drinking culture, as most ports do. Um, to sort of turning up three months later. It was really quite strange. ‘Cause, you know, the stories that had gone right round were quite interesting...one lady actually did say to me: “That’ll teach you for drinking yourself to death.” Oh, they’re unbelievable.” (Female)

“...one of the Kaumatua’s on the Marae I belong to up there, he bailed me up about it. And I said: “Yes”, but I said, ah: “Look buddy, it’s my life. If you don’t like it, don’t come and tell me.” I said: “I’m very grateful for what I’ve received, and I’ll always be very grateful.” “Oh, but the Maori tradition, and that.” I said: “I’m only part Maori.” Yeah? “Oh, but you should be doing this, and doing that.” “No way buddy.” And I haven’t spoken to him since. No, to me, it is your choice, not a @#%&* iwi, whanau and all that, it’s your choice. To me it’s got nothing to do with anybody else.” (Male)

“I don’t have a disability. I’ve had surgery, yeah...my boss knew what had happened, ‘cause she’d um, she knew about my surgery and that...and to this day they haven’t discriminated [against] me, which is good, because they shouldn’t, I don’t have a disability as such...” (Female)

“...my Grandfather’s brother had come in and said: “I don’t want you to have a transplant.” ...he’s very traditional, so his thinking would have probably been around...the traditional cultural idea that you shouldn’t tamper with the dead.” (Male)

“...my friends didn’t necessarily live in my little home town. And the ones that did, they’re frightened!...90% of the people that I used to associate with had nothing to do with me. And haven’t since...I used to get stared at a lot.” (Female)

Please write
Yes or No

(a) Have you experienced prejudice or stigma because of your liver transplant?	
(b) Do you feel that becoming immune-suppressed and managing your health post-transplant is equivalent to having a ‘chronic disease’?	

Your response:

Please use extra paper if you need to.

Question 23

This question looks at your financial support after your liver transplant. It builds on Question 8.

Statements from liver transplant recipients

[Four months after transplant] *"I was doing what, 70/80 hours a week; 7 days a week, like."* (Male)

"...within about that three months date, the pain went, and I was bored out of my brain, and ready to go back to work..." (Female)

"...I went back half time. And that was good...the trouble with having that year off was the money. The finances...I got the Sickness Benefit and we got tax breaks 'cause we've got three kids." (Male)

Please tick your employment status in the three categories below, post-transplant.

	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>
	6 months after your transplant	1 year after your transplant	3 years after your transplant
(a) Working full-time			
(b) Working part-time			
(c) Self-employed (full-time hours)			
(d) Self-employed (part-time hours)			
(e) Sick leave/other financial support from employer			
(f) Income support from WINZ			
(g) Working for Families tax credits			
(h) Retired			
(i) Other			

Question 24

Do you think your outlook on life has changed since your liver transplant?

"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...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." (Female)

"...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)

"...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)

Your response:

Please use extra paper if you need to.

Section 8 – The Donor

This section allows you to reflect on your donor and donor family.

Question 25

Please read the comments from other liver transplant recipients on their donor, then write Yes or No in the boxes and share your comments.

Statements from liver transplant recipients

“...that’s one of the most difficult parts of transplantation for me, is like the donor and their family and kind of guilt that maybe I’m not being a rocket scientist or making the best use of [it],...I don’t feel like I’m living up to what I’ve been given.” (Female)

“...it was nearly two years before I wrote a letter. Because I really didn’t know what to say...I know that some family has lost somebody, and I’m living because of it.” (Male)

“I haven’t gone that next step which...a lot have done, and that has made contact with them, ...I have to be honest about this, it’s because...I don’t think I want to go there, and I think it’s because, and it may be very selfish of me, because...I do know...that that family has, they accept it, what their loved one had, did, and they know that someone else’s life has been, I mean, I know that, but it’s mine!” (Female)

“...I think if you could write to them and say: “Would you like to meet me, to see how your husband or your wife or your daughter or your son’s liver is helping me...We’ll meet at...a neutral place.” But they [NZLTU] say no, so I accept that. But...how do you say thank you to someone who’s given you life?” (Male)

“...if I found out who my donor family were I would stand and cry in front of them first, I think, because I would feel their loss...Because they had to lose somebody, and that’s awful!” (Female)

“...I would like to know who my donor is...I would like to know his name, and where he’s buried,...if I knew where my donor was buried, on that day...for the rest of my life I would go there. And I’d sit there...from daylight to dark.” (Male)

Please write
Yes or No

(a) Have you written to your donor family?	
(b) If you have not written to your donor family, have you tried to write but couldn’t?	
(c) Have you received a letter or card from your donor family?	
(d) If you have received a letter from your donor family, have you replied to them?	
(e) Do you see your new liver as a ‘gift’?	
(f) Do you see your new liver as a ‘burden’ or an ‘obligation’?	

Your response:

Please use extra paper if you need to.

Question 26

In the course of my interviews I have discovered that we have various levels of information about our donor from none to quite a lot. Please read the quotes and answer yes or no in the boxes.

Statements from liver transplant recipients

"...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..." (Female)

"...I know my donor was a man, ...and he was in his fifties." (Female)

"... you did naturally think who it was...later on they [NZLTU] told me it was a middle-aged man." (Male)

"[Liver Transplant Co-ordinator] told me that she was a female...and she was quite sporty...I'd still like to find out more... 'Cause you go to the Thanksgiving [Service] 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)

"...I did not want to know who it was...the pain the Donor family must have gone through, it's too hard for me to even think about. If they would ever come to me, or want to track me down, I would be open to meeting them, but I felt that what say they didn't like me, you know, that would just be too awful, too awful, for them." (Female)

"...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...that makes it a bit more distant." (Female)

Please write
Yes or No

(a) Should the NZLTU offer consistent information to us about our donors?	
(b) Are you happy with the amount of information you have about your donor?	
(c) Do you want to know your donor's gender?	
(d) Do you want to know if your donor came from New Zealand or Australia?	
(e) Do you want to know your donor's age range?	
(f) Do you want to know your donor's ethnicity?	
(g) Do you want to know the reason for your donor's death?	

Your response:

Please use extra paper if you need to.

Section 9 – Community

This section looks at liver transplant recipients as potentially a ‘community of interest’.

Question 27

This question asks you to comment about whether you feel gratitude, and to whom, and if you feel any need to reciprocate in some way. There is a quote from a textbook to consider as well as quotes from fellow liver transplant recipients.

Page 67

“Recipients also feel gratitude toward the medical system that mediated the transplantation, to the dead person from whose body the organ was taken but who remains insubstantial for the recipient, and to society for providing the cultural milieu that encourages the donation of organs.”

Ben-David, O.B. (2005). *Organ donation and transplantation: Body organs as an exchangeable socio-cultural resource*. Westport, Praeger Publishers.

Statements from liver transplant recipients

“Having somebody sitting in your room that’s a family member, at 5 o’clock in the morning or 7 or 8 or 9, when you’ve just woken up from a big sleep. It’s terribly comforting.” (Female)

“...the gratitude, to me, becomes, um, it, 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.” (Female)

“...they paid for us all that time up there in the Unit...if I ever won Lotto or anything I’d gladly pay the money back for, to them. And more probably because I wouldn’t have been here otherwise.” (Female)

“I was lying there, thinking to myself I’m very lucky, you know? Very grateful. I’d never been a religious sort of a man, but I’m very grateful.” (Male)

“I feel incredibly grateful and slightly guilty at the amount that’s been spent on me.” (Female)

“I was looked after by [employer] in that respect. I’m very grateful for that.” (Male)

“...it’d be nice to be able to give something back to the Liver unit, you know, like, if I won a couple of million in Lotto, I’d probably give them a donation or something or to the Transplant House.” (Female)

Please write
Yes or No

(a) Do you feel gratitude in relation to your liver transplant?	
---	--

If you answered Yes to the question above, please respond Yes or No to the questions below:

(b) Your own family?	
(c) Your donor and donor family?	
(d) The New Zealand Liver Transplant Unit?	
(e) Organ Donation New Zealand?	
(f) New Zealand society in general?	
(g) Your employer?	
(g) Other (please note)	

(h) Do you feel a need to reciprocate in some way?	
(i) Do you want the NZLTU to call on you to help others facing transplant?	
(j) Do you believe the experience of our caregivers should be researched?	

Question 28

As a liver transplant recipient, do you feel part of a ‘club’ or ‘family’ that is ‘special’ or ‘unique’?

Statements from liver transplant recipients

“...[Transplant Co-ordinator] said to me, she says: “We’ll be part of your family for forever now”, she says, you know: “We’re all a family.”” (Female)

“...I feel like we’re a part of a special club, because we’re pretty, there’s not that many of us...And so we’re special, you know.” (Male)

Your response:

Please use extra paper if you need to.

Question 29

Please comment on whether you feel a support group, or support groups, are useful.

Statements from liver transplant recipients

“...for people waiting for a transplant, to see people who have had transplants, and to see them look, look normal when they walk in the room, you know, I think that’s quite a big thing.” (Female)

“I was so little involved in it, that it wasn’t a lot of use...” (Male)

“...the support group for me were my life saver. Because through that I spoke to those who had already had transplant, others who were waiting. I was able to learn through the various speakers they had at the support meetings, how the actual process worked. How your life was going to be after transplant. I spoke to actual real people who’d had a transplant to see physically how, and mentally how they were coping with life after transplant. It gave me every bit of support I needed...” (Female)

“I think the support group for them [caregivers] is more important than what it is for the likes of me.” (Male)

“[Social Worker] talked [caregiver] into going to a meeting, [caregiver] didn’t realize [what] it was, and when [caregiver] was sitting in there, [caregiver] was absolutely mortified. And very, very upset...” (Female)

Please write
Yes or No

(a) Should the NZLTU provide a support group for recipients?	
(b) Should the caregivers be able to attend the recipients’ support group?	
(c) Should the NZLTU provide a separate support group for caregivers?	
(d) Should the NZLTU provide the facilitator for the support group?	
(e) Should the facilitator be a liver transplant recipient with facilitation skills?	
(f) Should the facilitator be a caregiver with facilitation skills?	
(g) Should there be joint facilitation between recipients/caregivers and the NZLTU?	
(h) Should meetings be held during working hours in the hospital?	
(i) Should meetings be held after working hours (e.g. evenings) in the hospital?	

Question 30

Liver transplant recipient #27 (John) and I (#62) established the web site www.livers.org.nz in late 2000 which I still maintain. Here are some questions specifically relating to this web site.

“I looked at your web site, before me transplant. Is that still going?” (Male)

“Every now and again I’ll go on your web site too. Hasn’t changed much...” (Female)

	Please write Yes or No
(a) Do you have easy access to the Internet?	
(b) Before this survey, did you know about the www.livers.org.nz web site?	
(c) Have you visited this web site?	
(d) Do you feel there is a place for a web site like this in New Zealand?	
(e) Should more effort go into updating this web site?	
(f) Should I look for financial support for it, to make it more professional?	
(g) Do you have any interest in contributing to the web site? For example sharing your story, or links to other web sites you have found useful.	
(h) Are you a professional web publisher looking for a project? 😊	

This will help me understand what I need to prioritise.

Question 31

After my transplant (and before I got too busy once back working full-time) I created, printed and distributed a small newsletter called *Hepatic Happenings* seven times (still available online at <http://www.livers.org.nz/Newsletter/Newsletter.htm>). Seven years later, while doing interviews, I was surprised to find it was remembered. This question relates to the newsletter.

“...the little newsletters we used to get too. Yeah. It was great.” (Female)

Please write
Yes or No

(a) Have you seen a copy of <i>Hepatic Happenings</i> ?	
(b) Do you think there is a place for a newsletter like <i>Hepatic Happenings</i> ?	

If you answered Yes to (b), please answer the questions below:

Please write
Yes or No

(c) Should <i>Hepatic Happenings</i> be compiled and distributed once a year? (e.g. December)	
(d) Should <i>Hepatic Happenings</i> be compiled and distributed twice a year? (e.g. June and December)	
(e) Should a <u>Liver Transplant Support Trust</u> be established which then applies for funding to support both <i>Hepatic Happenings</i> and the www.livers.org.nz website and possibly further support mechanisms, such as an 0800 number?	

Question 32

I do not want you to feel that there have been parts of your liver transplant experience which you have not been able to comment on, because my questions did not always match your experience.

These pages are an opportunity for you to share anything else about your experience that you wish to. For your information, I sent this survey (in draft form) to seven liver transplant recipients across New Zealand, in order to gauge feedback as to length, appropriateness of questions and so on. From this feedback I have added two questions and provided additional information here for you to consider commenting on.

- Thoughts about death and dying after being listed for transplant – others have commented on death being a release, fearing a painful death, not thinking they would die...
- Thoughts about attitude and acceptance after being listed for a transplant – others have shown they think of this as an ‘adventure’, that it’s important to think positively about it, it’s a ‘blip’ in life...
- Thoughts about humour – others have talked of getting their sense of humour back after the transplant, using humour and dark humour before the transplant...
- Thoughts about family dynamics – there are examples of family tensions, family breakdowns in the immediate post-transplant period, parents and adult children in close confines...
- Thoughts about tensions in intimate relationships – there are examples of relationships stressed to breaking point that survived, examples of partners not wanting to talk about the transplant experience when recipients wanted to, and vice versa...
- Thoughts about caregiver well-being and the need for caregiver support (short and long-term) – caregivers’ health can break down, it can be hard to find a GP close to the hospital, there may not be social support available to them...
- Thoughts about nursing care on the Ward, for example, women have commented on menstruation immediately post-transplant, when they are immobile and in pain, and not receiving adequate support and nursing care...
- Thoughts about medical care after the transplant, when we are back in our communities – others have commented on their confidence in local specialists, and confidence that the New Zealand Liver Transplant Unit still gets blood test results and is always there...
- Thoughts about how life may be different now and whether this is transplant or medication related or ageing – there are a number of comments about sleeplessness, of being tired and needing naps, of having memory gaps...
- Thoughts about income support and social welfare – there are a number of comments about the difficulty of dealing with the bureaucracy, both pre-transplant (everything may be too hard to concentrate on, the required identification and paperwork may be in a different town or city), and post-transplant (you may look healthy but not be able to work immediately, lack of understanding by case managers, feeling embarrassed, not feeling you get what is available unless you know what to ask for)...
- Thoughts about eating when out in public – there are comments about what may not look safe to eat in a bakery, comments on smorgasbord and buffet meals...
- Thoughts about organ donation – there are comments on xeno-transplantation (e.g. receiving a pig’s liver in the future), living donor liver transplantation, cultural norms in relation to organ donation, scientific research on stem cells...
- Thoughts about the ‘donor’ status on driver’s licences – there are comments about this should not be negotiable, the individual’s wishes should override family considerations...
- Thought about spiritual beliefs and have they changed – there is a comment about the concept of ‘God’ being broadened to include science and technology...

Please feel free to comment about anything!

What will be the *outputs* from this research?

The researcher, Bethli, received her liver transplant in August 2000, and met a number of other liver transplant recipients through this time. One of them, the late John Russell, shared a vision with Bethli about how recipients, who had already started the transplant journey, could make life a bit easier for other New Zealanders approaching transplantation.

They established a website called www.livers.org.nz. This web site, although not regularly updated, continues to receive regular feedback (through the *e-mail us* button on the home page). Feedback typically is from family members of someone about to be listed, or newly listed, for a liver transplant. They tend to be looking for non-medical information such as: what is life like after a transplant; should I accept a transplant; what support can I receive; etc.

This research will have two *outputs* that, I hope, will complement the information and support available on the web site.

The first is a doctoral thesis. Once completed, it will be available on the AUT University library website or on request, at no charge, to any liver transplant recipient who participates in this research.

The second will be a booklet highlighting what the liver transplant experience has been like for those of us transplanted in the first eight years that the New Zealand Liver Transplant Unit has been operating. It will be distributed by the Unit to newly listed liver transplant candidates and their families (again, at no charge). This booklet can also be made available to any research participant on request.

Neither *output* will identify any liver transplant recipient beyond the researcher, herself.

About the researcher

After being unwell for three years, Bethli was diagnosed with Wilson's Disease at the age of 8, in 1974. She presented at Taranaki Base Hospital with jaundice, ascites, and severe cirrhosis of the liver. After 25 years on medication, a splenectomy and splenic-renal shunt (1987) and about 23 years of denial of having anything 'wrong' with her, she was admitted to Ward 7B in March 2000 both acutely and chronically ill. Her diagnosis of porto-pulmonary hypertension and right heart failure secondary to liver failure meant it took some major effort on the part of the NZLTU team to get her to an operable condition. She received her liver transplant in August 2000, after being listed for two weeks. Once she saw her own liver after the transplant, she understood for the first time how sick she actually had been. Since then she has been back at work full-time, bought a house, traveled overseas, written a text book, fought breast cancer (2009), and become an Auntie to twins Lennard and David. She is grateful for every day.

Appendix 16 Example of Monthly Research Updates

THE LIVED EXPERIENCE OF LIVER TRANSPLANTATION UPDATE ON AUT RESEARCH

Update #1

December 2008

Welcome to this first update!

Happy Holidays!

You are receiving this update because you have agreed to participate in my research project. I hope to send you an update twice a year until the research is complete.



Qualitative Research Methods paper

In Semester 1 this year, I enrolled in the AUT University Master's paper **Qualitative Research Methods** (588639) taught by Dr. Lynne Giddings. This was a really interesting paper, and through my reading for my assignments, I came across many useful articles for this research project. I'm pleased to be able to tell you that I passed this paper with B+.



Ethics Approval from ATEC

ATEC, or the Auckland University of Technology Ethics Committee, had to approve my research before I could contact you. I completed the AUT University form EA1, also known as the **Application for Ethics Approval for Research Projects**, in late April 2008 for the ATEC May Committee meeting. My application is 08/81 and I received Ethics approval on 25 June 2008.



Interviews

I have commenced interviewing liver transplant recipients, which is a great privilege. So far I have interviewed myself, three other women and four men. The majority of these have been in Auckland, however I have now commenced moving out of the Auckland region into wider New Zealand. For those of you that I have not yet contacted to schedule an interview, I am not trying to book too many at a time, as I need time in between interviews to type up the transcripts. This is certainly not something I am very fast at, but I am sure I will gain experience (and speed) with practice! I hope to have interviews completed by April 2009.



Contact Me

Please don't hesitate to contact me at any stage. I really appreciate the information that some of you have already provided, including notification of books I may be interested in reading. You can reach me on:

 (09) 8181-770

 betwai83@aut.ac.nz

Have a wonderful Christmas and New Year, and best wishes for 2009.

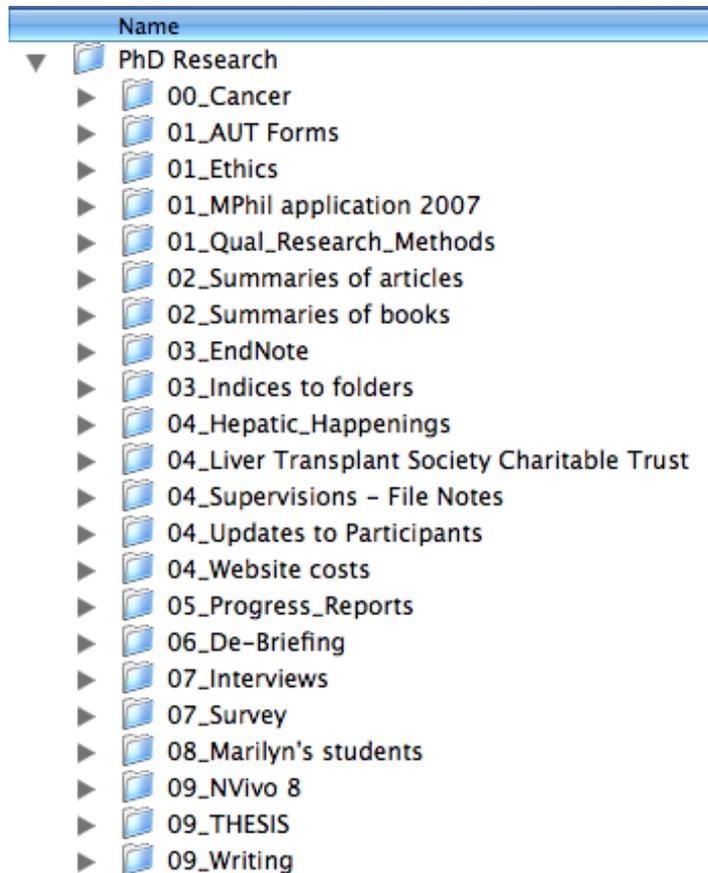
Bethli

No. 62



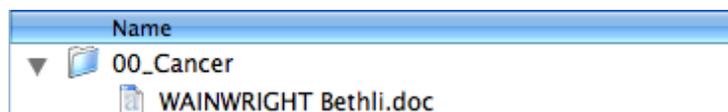
Appendix 17 Summary of Research Files from Bethli's PC

Bethli was nothing if not methodical, and what she has left us with for completion of her thesis was mined from the data contained in the following file structure on her computer.



A summary of these files is provided below, and each is addressed in the sequence in which Bethli filed the data.

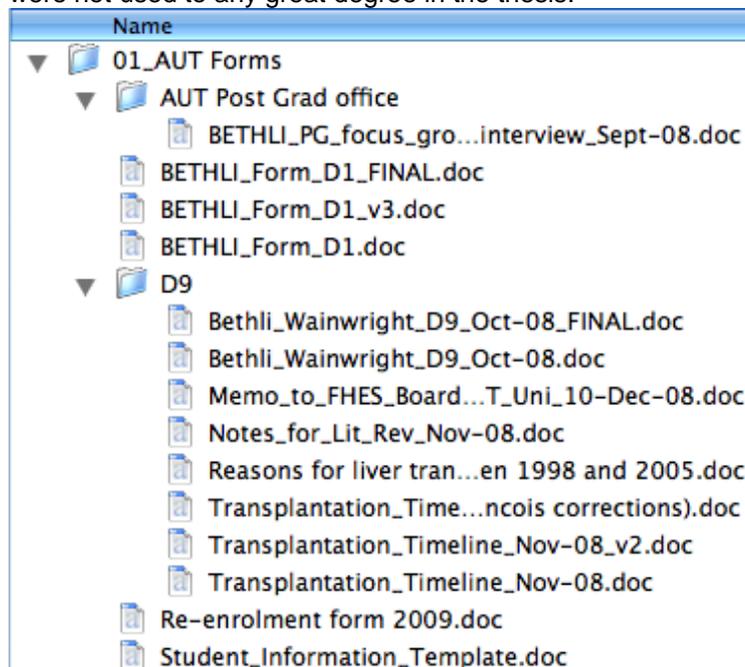
00_Cancer



Folder 00_Cancer contains just one file, a letter from Bethli's hepatologist regarding the discovery of breast cancer. This file was not used in the thesis.

01_AUT Forms

Folder 01_AUT Forms is self-explanatory. This folder contains the forms required as part of the MPhil or PhD process. These are academic bureaucratic forms in nature, and most of them were not used to any great degree in the thesis.

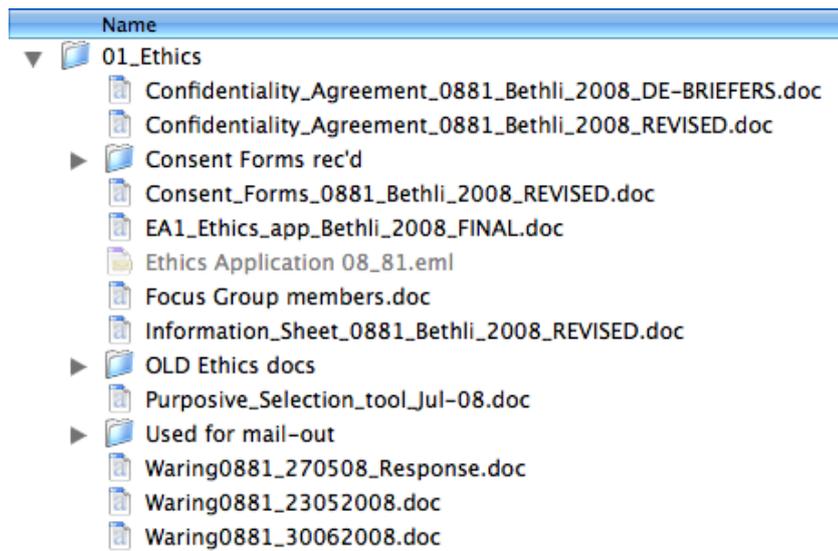


The D1 forms were from 2007, the generic focus-group document and re-enrolment document are from 2008, and the student information template is from 2009, and these documents contain no data for inclusion in the thesis.

The folder named D9 contains documents used, or partially used, in the thesis. The document "Bethli_Wainwright_D9_Oct-08_FINAL" from 2008/09 contains information pertinent to the topics of 'how' and 'why' Bethli would be doing this research. This forms the 10,170 word Research Proposal, which has been heavily drawn on for completing the thesis.

The document "Notes_for_Lit_Rev_Nov-08" contains Bethli's own experience while in hospital awaiting liver transplantation, much of which is used in the D9 application. Documents about reasons for transplantation or timelines contain statistical or historical information used within the final D9 application, and contained in the thesis. These, and the other documents within the folder D9, are from 2008 and are all part of the application process.

01_Ethics

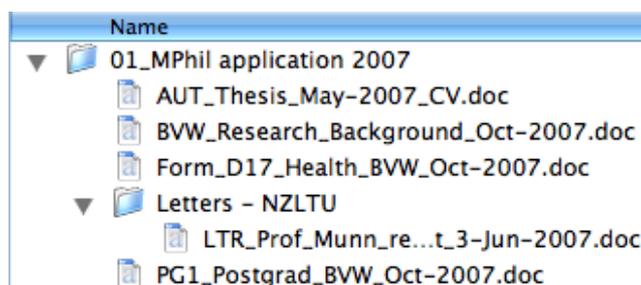


Folder 01_Ethics contains documents from 2008, the majority of them bureaucratic in nature. The document “EA1_Ethics_app_Bethli_2008_FINAL” contains some generic information about the ‘how’ and ‘why’ of the research, similar to that contained in the 10,000-word Research Proposal, and has been drawn on as a source document for completion of the thesis. All ethics documents will be included in Appendices.

The document “Purposive_Selection_tool_Jul-08” contains details of the sampling strategy. This has been drawn on as a source document for completion of the thesis.

The documents contained within the folder “Used for mail-out” are participation forms included in appendices of the thesis.

01_MPhil application 2007



Folder 01_MPhil application 2007 is self-evident. It relates to Bethli’s application in 2007 to perform research for a Masters degree (later upgraded to a Doctoral degree). Nothing from this folder or subfolders has been used as a source document in the thesis.

01_Qual_Research_Methods

Name	
▼	01_Qual_Research_Methods
	AA Postgraduate Timetable-09.doc
▼	Activity 2 - Rigour
	Bethli_Activity_2_Rigour_Exercise_Apr-08.doc
▶	Assessment One
▶	Assessment Two
	AUT_Receipts_Qual_Research_paper_Feb-08.doc
	Bethli_Essay_1_March-2008.doc
▼	Critical Group (Research Paper)
	Members_Health_Resea...roup_9-Mar-2008.doc
	Register_of_DVDs_Videos_viewed.xls
	Handout_Sat-7-Jun-08.doc
▼	New Folder
	Ballinger 2.pdf
	Liamputtong 2 .pdf
	Thesis_timeline_May-08.xls
▼	Timetables
	Timetable_2007-08.xls

Folder 01_Qual_Research_Methods contains files from 2007 and 2008 on research methods that formed prerequisite assessments and other preliminary work for the thesis. These have been used as source documents for the thesis.

02_Summaries of articles

Name	
▼	02_Summaries of articles
	Liver_Tx_History_Ethics_Living_Donor_Xeno_Article_Summaries.doc
	Liver_Tx_The_Wait_Article_Summaries.doc
	Organ_Donation_Article_Summaries.doc

Folder 02_Summaries of articles contains summaries written by Bethli of the pertinent articles. These documents have been drawn upon as source documents in the thesis.

02_Summaries of books

Name	
▼	02_Summaries of books
	1_Dead_Tomorrow_FICTION_2-Jan-2010.doc
	2_Hauora_o_te_Tinana_me_ona_Tikanga_2-Mar-2010.doc
	2_Organ_Donation_&_Transplantation_2-Jan-2010.doc
	2_Wrapped_in_Mourning_8-Jan-2010.doc
	3_Coma_Life_8-Jan-2010.doc
	3_Extra_Time_NZ_3-Feb-2010.doc
	3_I'm_glad_youre_not_dead_19-Dec-2009.doc
	3_Sweet_Reprieve_17-Dec-2009.doc
	3_Will_I_live_will_I_die_8-Jan-2010.doc
	4_Final_Exam_surgeons_reflections_8-Jan-2010.doc
	5_The_Spaces_Within_THESIS_17-Jan-2010.doc
	Michael_OHalloran_Carrel_backs.doc

Folder 02_Summaries of books contains summaries written by Bethli of the pertinent books, many of which are memoirs of other recipients' experiences. These documents have been drawn upon as source documents in the thesis.

03_EndNote

Name	
▼	03_EndNote
▶	Articles to print - check
▶	Back-ups
▶	Bibliography
▶	Bibliography.Data
	Bibliography.enl
▶	Exported EndNote Refs
▶	Journal articles full text
▶	NZLTU Annual Reviews
▶	PDFs
▶	Webpages
▶	Work and Income info

Folder 03_EndNote contains 238 bibliographic references and files stored in EndNote software. The files date from 2007-2009, and form part of the thesis in the Bibliography. The full Endnote library will be contained in the Appendices.

03_Indices to folders

Name	
▼	03_Indices to folders
	1_BOOKS_AUT_Library_copies_Nov-2009.doc
	2_Heart_Tx_suppl_articles_index_4-Jul-2009.doc
	3_Int_Tx_Units_&_Health_systems_index_1-Mar-2009.doc
	4_BOOKS_Liver_Tx_surgeons_memoirs_Nov-2009.doc
	5_Liver_Tx_Ec_&_Emp_folder_index_16-Feb-2009.doc
	6_BOOKS_Liver_Tx_history_ethics_organ_donation_index_Nov-2009.doc
	7_BOOKS_Liver_Tx_memoirs_biographies_index_Jun-2009.doc
	8_Liver_Tx_Soc_&_QoL_folder_index_26-Oct-08.doc
	9_BOOKS_Liver_Tx_in_fiction_Nov-2009.doc
	A_Liver_Tx_History-Ethics-Living_D-Xeno_folder_8-Mar-09.doc
	B_Liver_Tx_The_Wait_folder_index_1-Mar-2009.doc
	C_Miscellaneous_books_and_articles_Nov-2009.doc
	D_Mortality_Statistics_index_22-Feb-2009.doc
	E_NZLTU_folder_index_16-Feb-2009.doc
	F_Organ_donation_folder_index_8-Apr-2009.doc
	G_THESES_Phenomenology_Nov-2009.doc
	H_BOOKS_Phenomenolgy_Philosophy_Nov-2009.doc
	I_Philosophy_Methodology_folder_index_21-Feb-2009.doc
	J_BOOKS_Qualitative_Research_Nov-2009.doc
	K_Social_Wellbeing_folder_index_8-Feb-08.doc
	L_THESES_Transplantation_Donation_Nov-2009.doc
	M_Women_and_Liver_Tx_folder_index_8-Apr-2009.doc

Folder 03_Indices to folders is also self-evident. These indices are used in paper filing systems, and group by theme the source articles, books, and other information gathered for the thesis.

04_Hepatic_Happenings

Name	
▼	04_Hepatic_Happenings
	Article for Hep Hap full stats.doc
	Article for Hep Hap.doc
	Hep_Hap_Dec-2010_v2.pdf
	Hep_Hap_Dec-2010.doc
	Hep_Hap_Dec-2010v1.pdf
	Hep_Hap_Dec-2010v3.pdf
	Hep_Hap_Dec-2010v5.pdf
	Hep_Hap_Dec-2010v9.pdf
	Hep_Hap_Dec-2010v10.pdf
	Hep_Hap_Jun-2010.doc
▼	June 2010 issue
	Dr Michael Burt_23-Mar-2010.doc
	Hep_Hap_Jun-2010.doc
	▶ Photos
	Roxannes_story_recd_17-Mar-2010.doc
	LTR_to_Australian_Tx_Units_re_newsletters_8-Feb-2010.doc
	What_to_do_with_Hep-Hap_Mar-2010.doc

Folder 04_Hepatic_Happenings contains information for, and recent copies of, the newsletter Bethli produced for liver transplant recipients. It is called Hepatic Happenings, and she produced a number of issues in the early years post-transplant. She had been unable to continue producing these newsletters when working full-time, but during the interview phase of her research for the thesis she discovered that recipients remembered the newsletters and wanted them to continue, so she recommenced production of these in 2010. They do not form part of the source documents for the thesis, but their renaissance is a direct result of her research for it.

04_Liver Transplant Society Charitable Trust

Name
▼ 04_Liver Transplant Society Charitable Trust
Liver Transplant Society Charitable Trust musings.doc

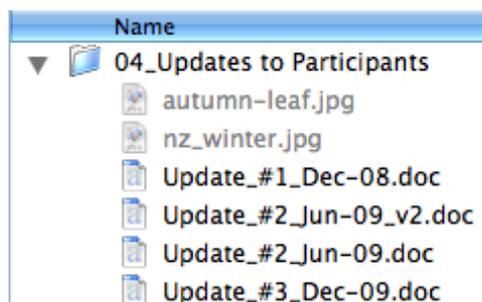
Folder 04_Liver Transplant Society Charitable Trust contains just one document containing Bethli's thoughts on how a charitable trust might work, and she intended to get this trust up and running before she died. This document was not used as a source document for the thesis.

04_Supervisions – File Notes

Name
▼ 04_Supervisions – File Notes
▼ 2007
FILE_NOTE_5-Oct-2007_mtg_with_Dr_Waring.doc
FILE_NOTE_19-Dec-2007_mtg_with_Dr_Waring.doc
FILE_NOTE_21-Jun-2007_mtg_with_Dr_Waring.doc
FILE_NOTE_30-Oct-2007_mtg_with_Dr_Waring.doc
FILE_NOTE_31-May-2007_mtg_with_Dr_Waring.doc
▼ 2008
FILE_NOTE_6-Jun-08_mtg_with_Dr_Waring.doc
FILE_NOTE_8-Feb-2008_mtg_with_both_Supervisors.doc
FILE_NOTE_9-Dec-08_mtg_with_Dr_Waring.doc
FILE_NOTE_10-Oct-08_and_17...t-08_both_Supervisors_sep.doc
FILE_NOTE_11-Apr-2008_mtg_with_Dr_Waring.doc
FILE_NOTE_18-Jul-08_mtg_with_Dr_Waring.doc
▼ 2009
FILE_NOTE_18-Dec-09_both_Supervisors.doc
Interview_Progress_Feb-2010.doc
Supervision_Document_11-Dec-2009.doc
▼ 2010
FILE_NOTE_12-Mar-10_both_Supervisors.doc
FILE_NOTE_24-Sep-10_both_Supervisors.doc
Interview_Progress_Mar-2010.doc
Key_Quotes_from_Interviews_Mar-2010.doc
Supervision_Document_12-Mar-2010.doc

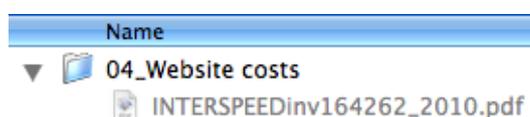
Folder 04_Supervisions – File Notes contains Bethli's notes of meetings with her supervisors. These documents have been used as source documents for the thesis, usually to extract a sentence or two to give added depth and texture to, for example, her fieldwork experience.

04_Updates to Participants



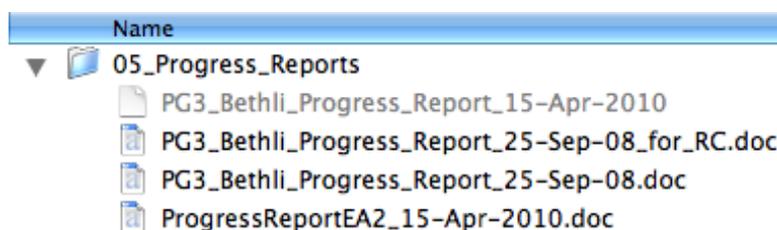
Folder 04_Updates to Participants contains Bethli's progress updates sent to interview participants. These documents have not been used as source documents for the thesis.

04_Website costs



Folder 04_Website costs contains one invoice pertaining to the cost of running the website www.livers.org.nz. This document has not been used as a source document for the thesis.

05_Progress_Reports



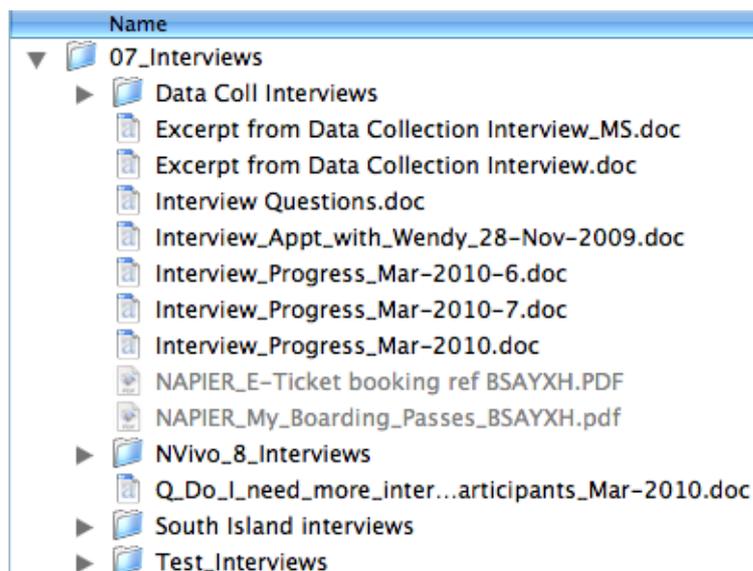
Folder 05_Progress Reports contains the reports Bethli made to the AUT Ethics Committee on her progress. These documents have been used as source documents for the thesis, usually to extract a sentence or two.

06_De-Briefing



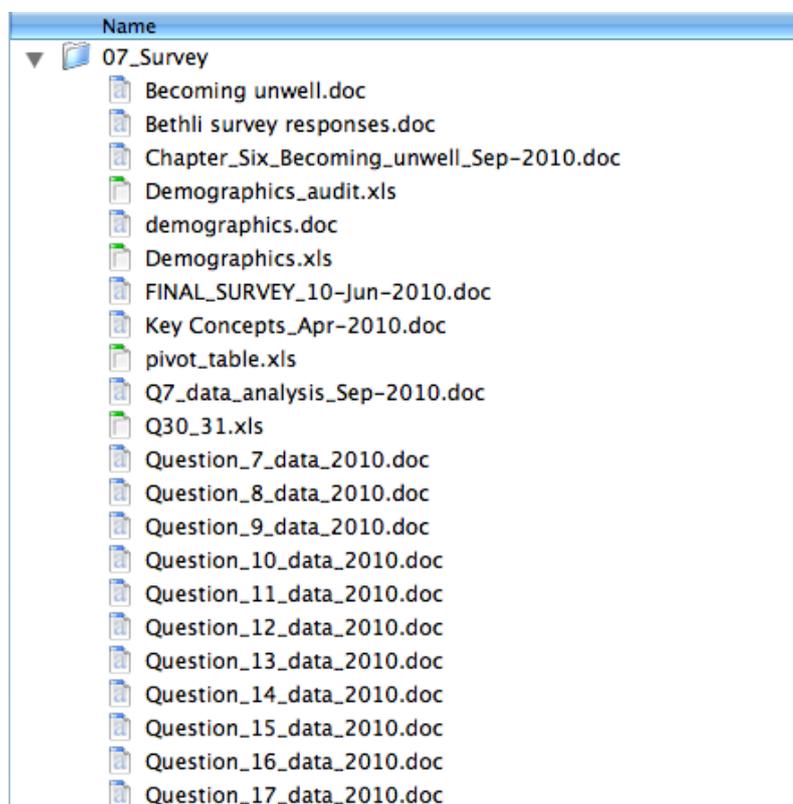
Folder 06_De-Briefing contains documents relating to Bethli's team of de-briefers. These documents have not been used as source documents for the thesis.

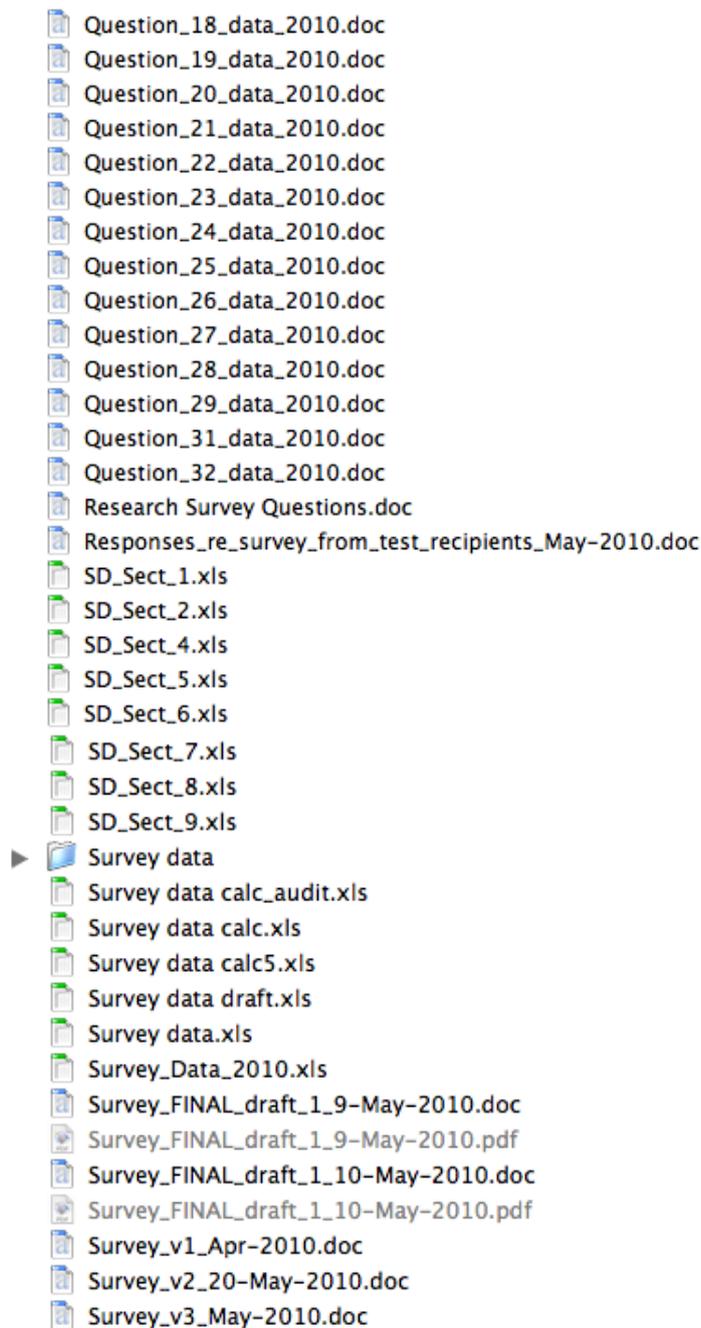
07_Interviews



Folder 07_Interviews contains transcriptions from the 17 interviews (and two pilot interviews) Bethli held with a cross-section of liver transplant recipients around New Zealand. These interviews have been heavily drawn upon for the thesis, mostly by Bethli herself, but also a little by her supervisors in order to tie up the remaining loose ends, primarily Bethli's self-interview of 8,975 words which is contained in the Test Interviews sub-folder. This document has allowed her supervisors to maintain the authenticity of Bethli's own 'voice' in the first person narrative in the completion process. It is 8,975 words long.

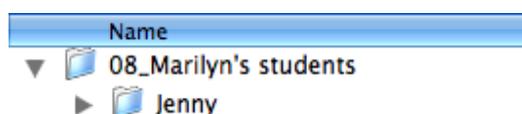
07_Survey





Folder 07_Survey contains the survey document and the results from the 49 survey responses received from a cross-section of liver transplant recipients around New Zealand. The results have been compiled into documents grouped by question number, and also in raw data in Excel for statistical analysis and graphing purposes. These results have been heavily drawn upon for the thesis, mostly by Bethli herself, but also a little by her supervisors in order to tie up the remaining loose ends. Bethli was participant no. 1, so we have used her responses to open-ended questions, particularly in Chapter Eight.

08_Marilyn's students



Folder 08_Marilyn's students contains nothing pertinent to the contents of the thesis.

09_NVivo 8

Name
▼ 09_NVivo 8
Notes from Nvivo 8 course_20-Nov-09.doc
QSR_Order_Form_Global_Bethli_Ak_NZ_25-Nov-09.doc

Folder 09_NVivo 8 contains information about the NVivo 8 software, but no source documents for completion of the thesis.

09_THESIS

Name
▼ 09_THESIS
Chapter_1.doc
Chapter_Five_Survey_Tool_Sep-2010.doc
Chapter_Four_The_Wait_3-Nov-09.doc
Chapter_One_3-Nov-09.doc
Chapter_Six_Becoming_unwell_Sep-2010_v3.doc
Chapter_Six_Becoming_unwell_Sep-2010_v5.doc
Chapter_Six_Becoming_unwell_Sep-2010.doc
▼ Distribution Lists
Academics to send my Thesis to upon completion.doc
INDEX_Appendix_A.doc
INDEX_Appendix_B.doc
INDEX_Chapter_1.doc
INDEX_Chapter_2.doc
INDEX_Chapter_3.doc
INDEX_Chapter_4.doc
Q9_data_analysis_Nov-2010.doc
Q10_data_analysis_Nov-2010.doc
QUOTES_Chap_7_the_wait_Nov-2010_CONCEPTS_v2.doc
QUOTES_Chap_7_the_wait_Nov-2010_CONCEPTS-1.doc
QUOTES_Chap_7_the_wait_Nov-2010_CONCEPTS-2.doc
QUOTES_Chap_7_the_wait_Nov-2010_CONCEPTS.doc
Recommendations_Mar-2010.doc
Thesis_2010_v1-2.doc
Thesis_2010_v1.doc
Thesis_2010_v2.doc
Title_Page.doc

Folder 09_THESIS contains all the working documents pertaining to the thesis at the time of Bethli's death on Christmas day 2010. The majority of these were already incorporated into the current draft, but those that were not completed for Chapter Eight, have been completed, and incorporated into the finished thesis.

09_Writing

Name
▼ 09_Writing
Concepts_of_wellbeing_Nov-2007_v1_sent_9-Dec-07.doc
Expectations_document_DRAFT_1_9-Oct-2007.doc
Expectations_document_DRAFT_2_14-Oct-2007.doc
PhD_Thesis_scope_May_2007.doc
READING_summary_Jan-08_3-Feb-08.doc
READING_summary_Jan-08_5-Feb-08.doc
READING_summary_Jan-08_6-Feb-08.doc
READING_summary_Jan-08_7-Feb-08.doc
READING_summary_Jan-08_29-Jan-08.doc
READING_summary_Jan-08_31-Jan-08.doc
READING_summary_Jan-08.doc
Why_me_and_why_this_topic_Oct-2007_v1.doc

Folder 09_Writing contains predominantly documents that predate work on the thesis proper. The reading summaries contain detailed notes on Bethli's academic reading requirements, and the other documents relate to the rationale behind the research. The document 'Why_me_and_why_this_topic_Oct-2007_v1' contains almost 7,000 words about Bethli's life and experiences in her own voice, and has been a vital component in maintaining the first person narrative in completing the thesis.