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The experiences, motivations, and opinions of New Zealand's live liver donors

Claire Gavin, Phillipa Malpas, Adam Bartlett

ABSTRACT

AIM: To explore the motivations and experiences of New Zealand's live liver donors, and their opinions on New Zealand's current organ donation system.

METHOD: An anonymous questionnaire was sent to all 45 of New Zealand's live liver donors in November 2012.

RESULT: 21 responses were collated with an even gender split. Half of the participants were parents of the recipient. Despite the risks of surgery and associated post-surgical pain, all participants were satisfied by how the transplant went for the recipient and for themselves. 90% thought people should save lives if they can, with 18 (86%) disagreeing with New Zealand's current method of allowing family members to veto the deceased person's wishes on organ donation (on their driver's license). 95% thought that education was important in encouraging people to donate.

CONCLUSION: This unique and informed group have experienced both what it means to have a loved one waiting for a transplant and how it feels to be an organ donor. If New Zealand is serious about wanting to increase deceased organ donation rates, we should consider the experiences such as those who have undergone live donation.

There have been studies on New Zealand's liver transplant programme regarding the medical outcomes of recipients and to a lesser extent the medical outcome for donors;¹ no studies have explored the motivations or opinions of live liver donors. Furthermore, there is minimal data internationally.² Information from live donors about their experiences is rare, yet such experiences can provide valuable insights into the motivations of donors as well as how to motivate organ donation within the community.

Participants have experienced a loved one needing an organ and donating part of their liver in response to that need. Although results are not generalizable this study aims to contribute to a wider discussion on increasing organ donation rates in New Zealand.

Live liver donation is a high-risk operation that has been described as "one of the most invasive procedures that could be contemplated for healthy individuals."³

Despite the risks, 5% of adult and 50% of paediatric liver transplants in New Zealand are done using live donors.⁴ The lack of deceased donors, a high mortality rate for those with liver failure, and no equivalent of dialysis all drive the need for live donation. Our hands are forced into considering live donation in New Zealand because of our low deceased donation rates.⁵

Methods

An anonymous questionnaire was sent by post from Auckland Hospital's liver transplantation unit to all 45 of New Zealand's live liver donors in November 2012. A Participant Information Sheet was included and explained the study. Consent was assumed when a participant sent back the completed questionnaire in an addressed envelope.

The questionnaire had two parts, the first dealing with participants' own experiences of organ donation, and the second seeking responses regarding wider concerns about

Table 1: Demographic data for all participants

ID	Age now	Sex	Ethnicity	Occupation	Religion	Donor's relationship to recipient	Time to make decision to donate
1	30–49	M	European	Service	None	Parent	3 months
2	30–49	M	European	Business	None	Parent	Days
3	30–49	F	European	Professional	None	Friend	3 weeks
4	30–49	F	European	Professional	Anglican	Parent	Months
5	30–49	F	Māori	Clerical	AOG	Niece	2 months
6	30–49	F	European	Labourer	None	Parent	2 days
7	30–49	M	European	Professional	None	Parent	None
8	30–49	F	European	Mother	None	Sibling	2 days
9	30–49	M	European	Tradesperson	None	Parent	2 weeks
10	30–49	F	European	Professional	None	Friend's child	2 months
11	20–29	F	Indian	Home-maker	Hindu	Child	1 day
12	20–29	M	Albanian	Chef	None	Sibling	6 months
13	30–49	F	Chinese	Clerical	None	Parent	0 days
14	20–29	F	European	Telemarketer	None	Partner's cousin's daughter	12 months
15	50–69	M	European	Manager	None	Parent	3 months
16	20–29	M	European	Tradesperson	None	Child	Immediate
17	30–49	M	European	Professional	Catholic	Parent	1 week
18	50–69	F	European	Retired	Anglican	Grandparent	2 weeks
19	30–49	F	Māori	Labourer	None	Aunt	Few days
20	30–49	M	European	Tradesperson	None	Child	3 months
21	30–49	M	European	Professional	None	Parent	6 months

New Zealand's organ donation methods. The study received approval from the University of Auckland Human Participants Ethics Committee, reference 8682.

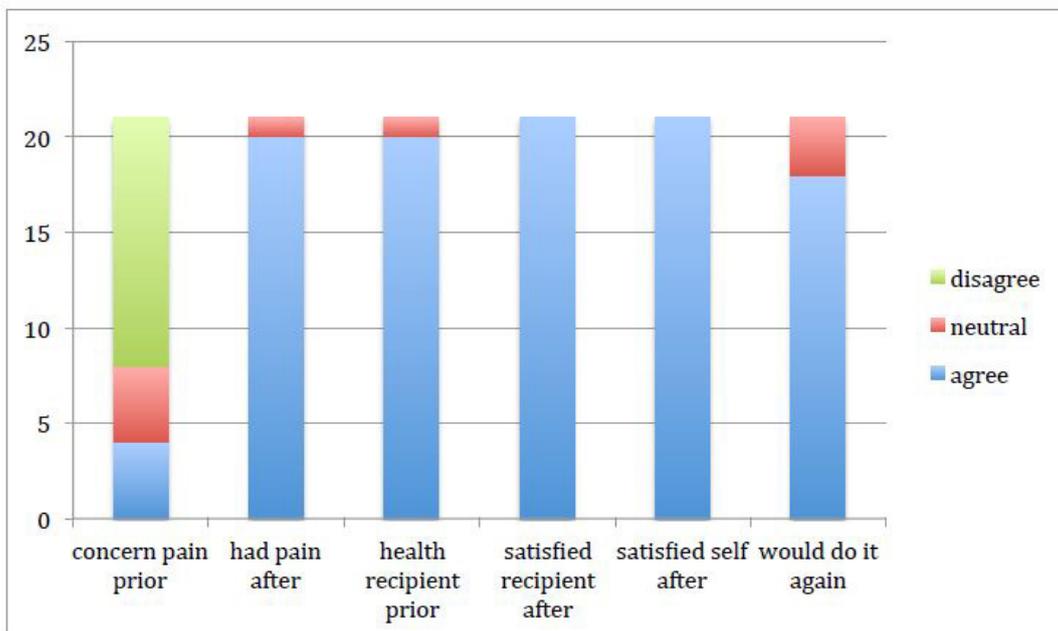
The questionnaire was divided into five sections. Section A requested participants' demographic information, including their relationship to the recipient and the amount of time within which they had to make their decision to donate. Section B asked questions about their experiences of the transplant procedure, including any concerns prior to and feelings after donation.

Responses were captured on a Likert Scale. (The Likert scale scales responses to give a better range of answers such as:

strongly agree, agree, neutral, disagree, and strongly disagree.) Section C enquired about donors' motivation to donate to both their particular recipient and donating in hypothetical situations. Section D asked for their opinions about New Zealand's current system for deceased organ donation. The final section, E, related to participants' opinions on why they thought other people should donate organs, why people might refuse to donate, and how best to encourage more people to donate. Qualitative comments were sought from participants.

Results

Of the 45 questionnaires sent out, three were returned due to out-of-date addresses.

Figure 1: Comparison of donor concerns, before and after organ donation

Of the 42 remaining, 21 were completed making a 50% response rate.

Demographic data

Fifteen (71%), live liver donors, were aged 30–49 at the time of donation and gender was evenly split. The time they had to decide to donate ranged from days to months, with six (29%) having only a few days (including some who had only hours) to make the decision to donate. The relationship of donors to recipients covered a wide range, but ten (48%) were parents, three (14%) were children, and two (9.5%) were siblings. Fifteen (72%) were therefore immediate family members. Six (29%) of the donors had a more distant relationship (outside the immediate family) and all were female. Males made up seven (70%) of those donors who were parents of recipients

Experiences of the donation procedure

Prior to the procedure 17 (81%) were not “worried about their own death during the surgery”, 16 (76%) were not “concerned about their future health after the surgery”, and 4 (20%) were “concerned about pain after the surgery”. However, 20 participants (95%) were always or often “concerned about the health of the person they were donating to”.

Although 4 participants (20%) had been “concerned about pain after surgery” prior to the procedure, all but one, (95%),

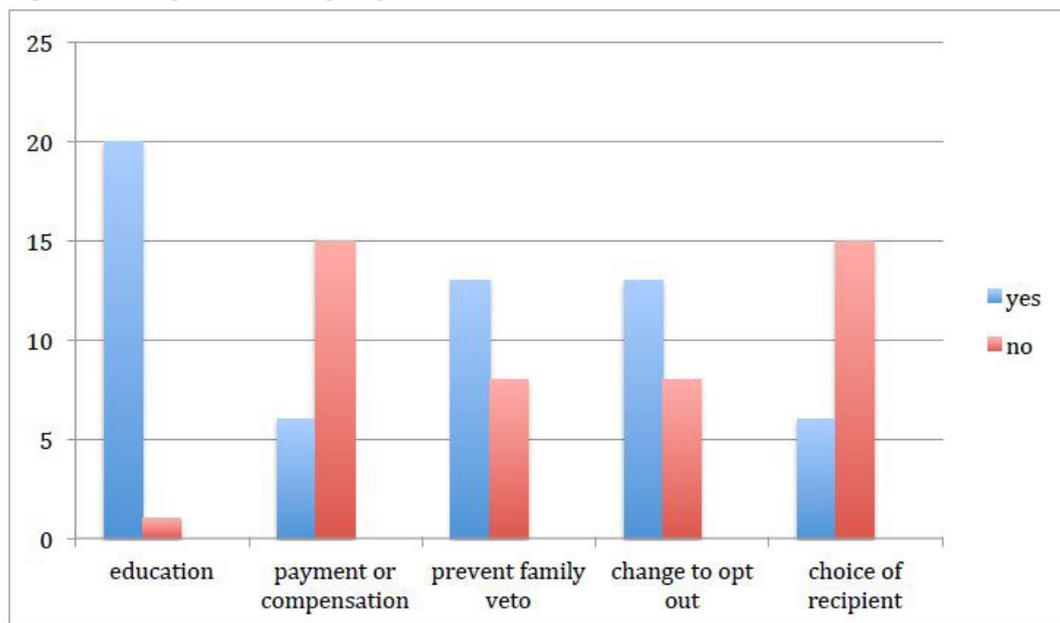
“experienced pain” after the surgery. Nine participants (44%) agreed with the statement “I have on-going health concerns”. Despite this, all 21 (100%) participants agreed or strongly agreed with the statements “I am satisfied with how the liver transplant went for me”, and “I am satisfied with how the liver transplant went for the recipient”. Eighteen (86%) participants agreed, “That if it were possible, I would donate a part of my liver again”.

Motivation to be a donor

Participants were then asked about their motivations to donate to their recipient, and whether in hypothetical situations, they would donate to others. They were all motivated by “wanting the recipient to live”, and nearly all (90%), “felt close to the person who needed a liver transplant”. There was strong disagreement with statements relating to pressure from recipients or families to donate. 19 participants (90%) disagreed that they were “asked by the person who needed the transplant”, and 18 (86%) disagreed with being “asked by my family”. All participants disagreed with having been persuaded either “by the person I was donating to”, or “by my family”. While 14 participants (66%) disagreed with the statement “I felt I had no choice”.

Regarding their motivations to donate to others in a hypothetical situation (living

Figure 2: Strategies to encourage organ donation



donation), 5 participants (24%) agreed that they “would donate to a stranger”. This percentage was not altered “if I could choose who it was”. Three participants (14%) indicated they would donate to a stranger, “if I was compensated for it”. Regarding deceased donations, 20 (95%) said they would be “a deceased donor”, while 16 (76%) said “I would agree to donate a deceased family member’s organs to a stranger”.

New Zealand’s Current System

Sixteen participants (76%) were “currently an organ donor on their driver’s licence”, with 9 (43%) having previously “donated blood”. When asked about New Zealand’s current policy of allowing families to veto organ donation even if an individual had indicated their preference to donate on their driver’s licence, 18 participants (86%) disagreed that “the family’s wishes should override the deceased person’s wishes”. Sixteen (76%) participants thought that changing to an opt-out system was a good idea. (Opt-out systems mean donation is the default position unless you state otherwise, in contrast to opt-in systems where the default is non-donation, unless requested.)

Societal reasons for organ donation

When asked, “What reasons do you think people *should* donate living or deceased organs?”, 19 participants (90%) agreed

with two statements: “We should do for others what we would want others to do for us”; and “We should save lives if we can.” Participants could tick as many options as they wished.

When participants were asked, “What reasons do you think people refuse to donate living organs?”, 18 (86%) stated “religious reasons”, and 19 (90%), stated “fear for their own health.” Most participants (71%) disagreed with the statement that refusal may be because “they should be paid or compensated in some way.” Similar figures were found regarding “reasons for refusing to become deceased donors”, with 18 (86%) participants stating “religious reasons”, and 15 (71%) participants “not wanting to further upset family at this time”. Sixteen (76%) participants disagreed with the statement “because they get nothing in return” for donating.

The final question asked participants, “Which factors do you think will encourage more people to donate organs?” Education was the most significant response for 20 (95%) participants, followed by “assume everyone is a donor unless they object” and “stop families going against the wishes of a deceased donor.” Six participants (29%) disagreed with the statements, “donors get a say on who gets their organs” and “payment or compensation for donating.”

Overall, qualitative comments revealed

that participants thought it was important to have conversations about donation before death, and to be very clear to family members about one's wishes. There were also preferences that a prospective donor's choice on their driver's licence should be upheld. Other comments reflected that it was a good feeling to be able to help.

"I was in my early [fifties] when I gave my baby grandson his new liver. NOTHING gives me more joy than to see him now (11yrs) leading a healthy life. So many lives can be transformed by donation. We have leading experts that can save so many lives by people donating. Words cannot express the personal feelings of helping to save my grandson[']s life. YES I would do it again."
Participant ID #18

Discussion

Living donors are in the unique position of experiencing the needs of potential recipients and undergoing surgery for the benefit of someone other than themselves. While it is not surprising that this group were very concerned about the health of the recipient (95%), and had plenty of incentives to want to help, one might also expect that undergoing surgery would also result in concern about their own health. There were, however, low levels of concern about the risk of death (19%), or their future health (24%) as a result of the surgery. Studies show that donors are influenced by the large potential benefits to the recipient,⁶ rather than themselves, and that donors often decide to donate rapidly without a thorough consideration of risks.⁷

There are concerns in the medical profession regarding the level of acceptable risk, particularly for live donors.⁸ In our study, all participants were satisfied with how the procedure went, with a majority saying they would do it again if it were possible. It is important to note though, that these respondents only represent half of all possible live liver donors. It is possible those who did not participate in the study were less positive with their experiences.

Nevertheless, these results are similar to those observed in other quality-of-life studies following live donor liver trans-

plant, where nearly all stated that they would donate again, irrespective of donor outcome.³ There is a need to safeguard against donors' potential desperation and lack of concern for personal risk, while balancing the great benefit that comes with donating and the need to respect the autonomous decision of the donor.

New Zealand's living donor rates are relatively high compared to other Western countries, however deceased donation rates in New Zealand are comparatively very low.¹⁰ If New Zealand could increase deceased donation rates, the difficulties and risks of live organ donation (particularly that of live liver donation) would be greatly reduced, and only required in emergent situations.

Regarding strategies to promote and increase deceased and living organ donation, there are numerous ethical concerns that need to be considered. No participants in this study reported any persuasion to donate and only a few were asked by the recipient or a family member to donate. Paula Martin's study of New Zealand patients waiting for kidney transplantation showed that the task of finding a living donor is usually the responsibility of recipients.¹¹ She found that asking people to consider donation is consistently reported by (potential) recipients as being extremely difficult and many wait for potential donors to approach them.

Another strategy to increase organ donation would be to consider some form of payment, either for organs or for time off work and related costs.¹² The majority of participants in this study were against such a strategy. Although, if a payment scheme increased deceased donation rates, this may have negated the need to consider live donation. The participants in this study were a select group who were willing to be a living donor, and who were very altruistic. Other potential recipients and their families might feel differently towards reimbursement.

There is an important distinction to be made here between receiving money as compensation for losses incurred and money used as an incentive to encourage people to consider donating when they otherwise may not.¹⁴ Several comments

reflect participants' views that potential donors should have sufficient compensation to help with income loss and expenses:

"I feel that compensation support for live donors is insufficient. For donors that are travelling from outside of Auckland, it is important that they do not have to leave family or recipient in Auckland because they need to return to work to cover living costs. While I was lucky enough to be able to do this, and stay with my family, others may not be so lucky and in a worst case scenario unable to donate because of this reason." (ID# 7)

With regard to written qualitative comments, most were in response to the family veto question ("the family's wishes should override the deceased person's wishes"). Most participants (86%) did not agree with this statement. In regard to the hypothetical question (being a deceased donor themselves), 95% of participants were willing to be a deceased donor but this decreased to 76% when considering donating another family member's organs. This may illustrate the difficulties families have with consenting on behalf of others for donation, especially when they do not know the wishes of the deceased individual. A UK study looking at this question from the families' perspective, found that families found it significantly easier to consent if they knew the donor had registered their wish to donate.⁶ Participants in this study felt strongly that the decision of an individual to be a donor should be respected by their loved ones. Participants' comments emphasised that individuals should make their wishes clear to their family before death and that if a decision to donate had been made, that this should be upheld:

"If the deceased person has made their wishes to donate clear, then their wishes should not be able to be

overturned by their family." (ID# 6)

These views mirror those found in a 2012 New Zealand poll of 1,029 people, which showed that 87% were adamant that the wishes of a deceased individual must be followed by the family.¹⁴ The comments from the poll included, "The needs of the many are far more important than the wishes, for whatever spiritual or other reason, of a surviving relative."

International comparisons indicate that a change to New Zealand's organ donation system is overdue.¹⁵ Currently, New Zealand policy is promoting living organ donation which is both risky and costly, but little is being done to promote deceased donation, which not only helps more recipients, but also does not place additional demands and risk on recipients' healthy supporters. Two areas in which progress could be made include decreasing the power given to the family veto and educating the public about the process of deceased organ donation. Organ Donation New Zealand medical staff express concerns about both of these strategies. Streat and Silvester write that the previously expressed wishes of the deceased should not be used to influence the family,¹⁶ and Judson commented that, as only a small percentage of the population will ever be in a position to donate, there was no need to educate everyone.¹⁷ These views are not supported by the results of this study, a poll of the New Zealand public,⁹ nor by overseas practice.¹⁸ A wider ethical lens needs to be used in order to represent more views, such as those of other medical staff and the New Zealand public. Rates of deceased and living organ donations are interrelated, as are the lives of potential recipients, living donors, and deceased donor families. If, as a society, New Zealand is serious about wanting to increase organ donation rates, we should consider the experiences, insights, and views of those individuals who have been living donors.

Competing interests: Nil**Acknowledgements:**

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Data from this study and discussion of the ethical implications of it have been presented at three conferences where feedback was gathered. The conferences were: the New Zealand Bioethics Conference, Otago University, January 2014; The Transplantation Society of Australia and New Zealand Conference, Canberra, June 2014; and The Australasian Association of Bioethics and Health Law, Perth, October 2014.

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www.nzma.org.nz/journal/read-the-journal/all-issues/2010-2019/2015/vol-128-no-1425-20-november-2015/6725

REFERENCES:

1. Gane E, McCall J, Streat S, et al. Liver Transplantation in New Zealand: The First Four Years. *NZMJ*. 2002; 115: 1159 <http://journal.nzma.org.nz/journal/115-1159/120/>.
2. O'Carroll R. Psychological Aspects of Liver Disease and Its Treatment. *Health Psychology Review*. 2011; 6. doi:10.1080/17437199.2010.550205.
3. Middleton et al. 2006 cited by O'Carroll. Psychological Aspects of Liver Disease and Its Treatment. *Health Psychology Review*. 2011; 6: 5.
4. Harrison B. Liver Allocation Audit. Auckland District Health Board. 2012.
5. Bartlett A. Auckland District Health Board Liver Unit. Personal Communication, 11 June 2012.
6. Garwood-Gowers A. Living Donor Organ Transplantation: Key Legal and Ethical Issues. Aldershot: Ashgate. 1999: 46-50.
7. Garwood-Gowers A. Living Donor Organ Transplantation: Key Legal and Ethical Issues. Aldershot: Ashgate. 1999: 67.
8. Strong R. The Enigma of Living Donor Transplantation. Paper presented at The Transplantation Society of Australia and New Zealand 32nd Annual Scientific Meeting. Canberra, Australia, 11-13 June 2014.
9. Robinson, M. Incentives wanted for NZ Organ Donors. *Sunday Star Times*, 1 July 2012: A1.
10. Organ Donation New Zealand. Annual report 2015. <http://www.donor.co.nz/statistics/international-donor-rates>
11. Martin P. Finding a Living Kidney Donor: Experiences of New Zealand Renal Patients. *Australian Health Review*. 2013; 37: 49.
12. White M. Kidney for sale: One careful owner. *North & South*. 2013, December: 62-69.
13. McCall J, Johnston M, Harrison B, et al. Live Donor Liver Transplantation in New Zealand: A Report on the First 20 Cases. *NZMJ*. 2009; 122 no. 1289: 20.
14. Robinson M. Incentives Wanted for NZ Organ Donors. *Sunday Star Times*. 1 July 2012: A10.
15. Murphy C, Allen J, Potential Donor Audit. Summary Report for the 12 Month Period 1 April 2011 - 31 March 2012. *NHS Blood and Transplant*. July 2012; 6.
16. Streat S, Silvester W. Organ Donation in Australia and New Zealand –ICU Perspectives. *Critical Care and Resuscitation* 3, no.1: 50.
17. Judson J. cited by White M. Kidney for sale: One careful owner. *North & South*. 2013, December: 62-69.
18. Gavin C. Increasing New Zealand's Organ Donation Rates: Ethical Considerations. [master's thesis on the Internet]. [Auckland (NZ)]: Auckland University. [cited 2015 Oct 4]. Available from: Proquest Dissertations and Theses.

Attitudes and risk of withdrawal in general surgical registrars

Rewena Keegan, Robyn Saw, Katie De Loyde, Christopher Young

Attrition during surgical training program is an important issue which affects individual doctors, the medical workforce and the community. This study found that more than half of the respondents had thoughts about withdrawing from their surgical training program. Those that thought of withdrawing were more likely to be female and to be locally educated in Australia or New Zealand. These registrars at attrition risk were less satisfied with many aspects of their education and training. This study may help us in the future to identify at risk trainees and institute strategies to improve training experiences and attrition rates.

The experiences, motivations, and opinions of New Zealand's live liver donors

Claire Gavin, Phillipa Malpas, Adam Bartlett

New Zealand's live liver donors offer their motivations and experiences of undergoing a risky procedure due to a lack of deceased organs for transplant. They have a unique and valuable perspective on New Zealand's current organ donation system. Most disagreed with the 'family veto' on deceased organ donation and thought education was important in encouraging people to donate. New Zealand's current organ donation system is unethical and needs balance from including a wider range of views including donors, potential recipients and the general public.

Intravenous magnesium sulphate as an adjuvant therapy in acute exacerbations of chronic obstructive pulmonary disease: a single centre, randomised, double-blinded, parallel group, placebo-controlled trial: a pilot study

S Mukerji, B Shahpuri, B Clayton-Smith, N Smith, P Armstrong, M Hardy,
G Marchant, E Marsh

We were investigating whether magnesium sulphate could help treat an acute COPD attack in patients presenting to the emergency department. We gave about half of our patients magnesium sulphate whilst the other half received a placebo intravenously, on top of the standard treatment they would normally get currently in the emergency department. We found that Intravenous magnesium sulphate improved patients' breathing function when compared to the placebo group. Further studies should be carried out to investigate this effect further.

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