

'IT'S HARD TO ASK'

EXAMINING THE FACTORS INFLUENCING DECISION-MAKING AMONGST
END-STAGE RENAL DISEASE PATIENTS CONSIDERING
ASKING FRIENDS AND FAMILY FOR A KIDNEY

BY

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A thesis

submitted to the Victoria University of Wellington
in fulfilment of the requirements for the degree of
Master of Nursing Science

2017

Title

Examining the factors influencing decision-making amongst end-stage renal disease patients considering asking family and friends for a kidney.

Abstract

Background: Organ donation is an important facet of healthcare delivery in New Zealand, with donation often leading to an increased quality of life for recipients, and a reduction in healthcare costs for the community. People who require new organs have limited options in regards to organ access: they can receive organs from deceased donors, or if a kidney is not volunteered, they might ask someone to donate. For those that choose to ask someone to donate an organ, one barrier that is sometimes voiced is that it is hard to ask family and friends to donate. This project sought to explore the issues surrounding asking for an organ by end-stage renal disease (ESRD) patients, in order to gain a better understanding of the decision-making process and motivations of patients as they choose or decline to approach others for a kidney.

Methods: Participants were recruited from patients with ESRD through the Hawke's Bay District Health Board. Potential participants were identified as being on the deceased donor list (DDL), or had family or friends being worked up for living kidney donation (LKD). Participants were interviewed and asked about the challenges of asking for a kidney, including such questions as: Who did they ask, and why? Who did they exclude, and why? How did they approach the request, and what were their reasons for asking in this way? Could they identify additional strategies which might have been useful to them, but were either not considered or unavailable? A qualitative descriptive approach was utilised to analyse interview data.

Results: Fifteen participants were interviewed, with most stating that it was hard to ask for a kidney and almost half having never approached anyone for a kidney. For many patients, being expected to recruit donors for LKD was a barrier in itself. Commonly identified themes indicate that recipients may be concerned for the health and wellbeing of their loved ones, or have limited recruitment opportunities, or poor health literacy or self-efficacy. Many Maori recipients stated they favoured a whanau approach to discussing transplant, and most recipients desired more support in order to facilitate approaching donors.

Conclusions: Findings suggest it would be useful to develop a screening tool assessing willingness and motivation to accept a living kidney donation along with self-efficacy, communication and health literacy levels *prior* to recipients initiating conversations with potential donors, in order to provide tailored support to the recipient with their initial approach. Additionally, psycho-social support could be offered to all recipients to help identify unmet needs or further barriers such as reciprocity or relationship concerns. Finally, closer communication between health professionals who provide care for the recipient, as well as positive media stories and campaigns that raise awareness of the need to transplant may create opportunities for LKD to be discussed within the recipient's social network.

Key words

Organ donation, end-stage renal disease, transplantation, living kidney transplant, deceased donor, transplant barriers, donor decision-making, donor recruitment

Acknowledgements

Many people have supported me on this research journey.

I would first like to thank those patients who agreed to take part in this research - who welcomed me into their homes and talked with me about their experience of asking, or not asking, for a kidney. This was difficult for some of you, and I thank you for sharing your stories with me. This research belongs to all of you. Kia ora.

To my supervisor, Dr Jon Cornwall, thank you for your support, encouragement, sound advice, and judicious editing. It has been a two-year commitment, and I am very grateful. Thanks, too, to Dr Martin Woods who, as well as preparing me for writing a research proposal prior to starting this Master's Thesis, provided support with coding when needed.

I also wish to thank Dr Paula Martin whose research into barriers facing NZ donors was inspirational. Dr Martin took the time to talk with me about my initial research question in the face of changing legislation.

My transplant family at the HBDHB consists of many wonderful people. Janine Palmer, nurse practitioner and friend, has mentored me in my coordinator role and provided both academic and personal support. Nephrologists Dr Colin Hutchinson and Dr Andy McNally have also been hugely supportive. Colin actually suggested this research question, and I thank him for this gift. I am privileged to be a part of such a great team. The wider NZ transplant family have also been supportive, and I wish to thank Dr Nick Cross at Canterbury DHB, and Denise Beechey at Counties Manukau. Denise and I trained together at Middlemore Hospital in 1981. Denise also works renal transplantation, and has completed her Masters by Thesis, so has been a great role model.

I also wish to acknowledge the NZNO & Nursing Education Research Fund. I am incredibly grateful to have received a McCutchan Trust scholarship at the beginning of this project. This support was hugely encouraging at a time when I felt bogged down with gaining approval for the project. I also wish to acknowledge Health Work Force NZ. This generous funding provides nurses with the opportunity to undertake post-graduate study, paying for University enrolment fees and paid study days. Thanks also to Kidney Health NZ and

Baxter Healthcare for support which enabled me to present the findings of this study at the RSA Annual Conference in Sydney in June 2017.

To my wonderful husband Justin, thank you for carrying on with all the mundane household tasks when I have been head down working. I apologise for taking over all the household surfaces with paperwork at different times over the last 2 years. Your tolerance has been incredible...I am just glad we will now have office space.

Thank you, too, to my amazing children who have all supported in different ways. You know what you have done to help, and I thank you for the love and support you show me every day. Lastly, I wish to acknowledge my whanau, living and deceased – my parents, grandparents, uncles and aunties, and my brother and sister. You have all helped to shape who I am, and also my core values. I am grateful to you all.

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List of Abbreviations

ANZDATA	Australia & New Zealand Dialysis & Transplant Registry
CKD	Chronic kidney disease
CMDHB	Counties Manukau District Health Board
DDL	Deceased donor list
DHB	District Health Board
ESRD	End-stage renal disease
GP	General Practitioner
HBDHB	Hawke's Bay District Health Board
HD	Haemodialysis
HHD	Home haemodialysis
LDKT	Living donor kidney transplant
LKD	Living kidney donation
MDT	Multi-disciplinary team
MoH	Ministry of Health
NGO	Non-governmental organisation
NZ	New Zealand
ODNZ	Organ Donation New Zealand
OTD	Organ & tissue donation
PD	Peritoneal dialysis
QD	Qualitative descriptive
WHO	World Health Organisation

Background

Organ and tissue donation (OTD) allows those with serious medical conditions the opportunity to have improved health outcomes and life expectancy. Those people who are potential candidates for a transplanted organ can receive organs from either deceased donors or living donors. In New Zealand, there are a small number of deceased donors in relation to those who require them (Cornwall, Schafer, Lal, D'Costa, & Nataraja, 2015). To help meet the need for organs, there is the potential for living donors to provide organs where it is medically safe to do so. With advancements in surgical procedures in the last five decades, living donors may safely donate a kidney or part of their liver to meet the need of those with end-stage renal and hepatic disease, with Organ Donation New Zealand (2016) reporting a record number of kidney and liver transplants taking place in NZ in 2016 (p. 15).

To provide some context with regards to live donation in NZ, donors are required to be altruistic; there is no payment granted to living donors, save a Government-funded sickness benefit being available to donors while they are unable to work. In December 2016, the 'Compensation for Live Organ Donors Bill' was passed in Parliament, which agrees to refund donors their full loss of income and costs associated with donating, such as travel, accommodation and childcare. However, as at August 2017, donors are still unable to access compensation for lost wages, because the model for payment is still being developed. Financial barriers may be a factor in NZ's low rates of living kidney donation (LKD) when compared with some countries in the developed world (WHO, 2011), but cultural influences and psycho-social barriers may also play a part.

In order to treat end stage renal disease (ESRD), patients have two renal replacement therapy options available to them – dialysis or kidney transplant, with transplant being the best option for the long-term health of the patient. Kidneys may be transplanted either from a deceased donor or a living donor, with transplant from a living kidney donor (related, non-related, altruistic or kidney exchange) being the best option as good tissue matching facilitates the potential for optimal outcomes. Living kidney donation yields better patient and graft survival rates, can pre-empt the need for dialysis, limits time on waiting lists, and means that patients without a suitable living donor have a better chance

of getting a kidney from the deceased donor list (Davison, Kromm & Currie, 2010). Patients who are well enough to meet strict criteria to be listed on the deceased donor list (DDL), as well as having a friend or family member who offers to donate, have two opportunities to receive kidneys. However, for those who are not eligible for inclusion on the DDL, their only option is to find a donor amongst their network of family and friends.

There are many barriers to transplant that are identified by patients, including financial hardship, social responsibilities, geographical isolation, poor health literacy, and lack of suitable donors (Martin, 2013b; McGrath & Holewa, 2012). If communication difficulties, poor health literacy, or cultural and family pressures are present, then the likelihood of successful donor recruitment may be compromised (Rodrigue et al., 2014; Waterman, Rodrigue, Purnell, Ladin & Boulware, 2010; Weng, Reese, Malgaonkar, & Patel, 2010).

One barrier that is sometimes voiced by patients with ESRD is that it is hard to ask family and friends to donate a kidney (Barnieh et al., 2011; Pradel, Mullins, & Bartlett, 2003; Reese et al., 2008; Waterman et al., 2006). Anecdotal evidence within NZ suggests this is also the case, although there is currently no published evidence to support this suggestion.

As a Living Kidney Donor Liaison Coordinator and Registered Nurse working in the haemodialysis unit at Hawke's Bay District Health Board (HBDHB), I often talk with patients who have made assumptions about who would, or would not, be a suitable donor within their networks of family and friends. The patient may approach some members of their family, and not others, based on preconceptions of what makes for a successful donor. Alternatively, the patient may not ask at all, preferring to wait for family or friends to offer.

I was also interested to note that twenty percent of the patients listed on the DDL in Hawke's Bay did not have any living kidney donors being actively worked up. This is a significant figure, and raises several questions: does that twenty percent of patients have no family or friends who are willing or able to donate? Does being listed on the DDL mean that they feel there is no urgency to approach family and friends for a kidney? Does the patient believe that they might receive a deceased kidney in a timely manner? Does the patient feel that a deceased kidney is preferable to a living kidney donation? Are there

other reasons that patients eligible for deceased kidney donation are not proactive in pursuing a living kidney donation while still being active on the DDL? If living kidney donation is the gold standard transplant option in NZ, and the DDL is unable to meet the growing demand of those who are waiting, then having living kidney donors being actively worked up while a patient is listed on the DDL is an aspirational goal for both the patients and the health service.

Along with understanding the motivations and experience of patients who perhaps have not approached their networks for a kidney, I am interested in the reasons why recipients might ask some family members for a kidney, and not others. An understanding of whom patients choose *not* to ask has a bearing on how health services can tailor future support to patients who are eligible for transplant. It also helps to identify whether there is group of people who are being lost to workup, at a time when the Ministry of Health is seeking to grow the network of people who are available as potential donors (Live Kidney Donation Aotearoa, 2017).

Finally, in an age when we hope to foster more living kidney donations through timely recruitment of donors and improved health literacy, I am interested in how we reach those in the community who could potentially give kidneys to friends and family. From a policy and health education perspective, what works, and what doesn't? The information generated in this study will be transferable to other DHBs within NZ, as data gathered would be able to be generalised to the donor population.

Research Aim

This study aims to examine the factors influencing decision-making amongst ESRD patients considering asking family and friends for a kidney.

Literature Review

A literature review was undertaken for the purpose of determining what information was available that examines recruitment of living kidney donors, and to identify any knowledge gaps. The search strategy employed for this literature review began by sourcing original research and reviews published in the English language between 2000 and 2016, using combinations of the following keywords: *organ donation, living kidney transplant, transplant barriers, donor decision-making, and donor recruitment*. As a follow-up search, the term *health literacy* was added. Databases searched included PubMed, CINAHL, ProQuest, and Google Scholar. The reference lists in the retrieved articles were then reviewed to identify further relevant material. Articles already known to the author were also accessed and scrutinised to identify material relevant to this review.

The main findings from the literature review have been grouped and presented in sections under the following headings: ethnicity and socio-economic barriers; difficulty with asking or accepting offers; health literacy; transplant preferences; donor decision-making. At the end of this chapter, a conclusion summarises pertinent findings. The majority of the articles identified were from research that had taken place in North America and Europe, however several NZ studies were found, and these are identified in each section.

Ethnicity and Socio-economic Barriers

Socio-economic constraints are an acknowledged barrier to live organ donation. Research demonstrates that lower socio-economic groups suffer from poor transplant rates (Grace, Clayton, Cass & McDonald, 2012; Reese, Boudville & Garg, 2015; Rodrigue et al., 2014). Indeed, Reese et al. (2015) demonstrated that there was a 31% decline in the number of living kidney donations in Australia and NZ between 2008 and 2012, highlighting financial constraints faced by donors in the face of global economic recession.

As well as economic barriers, there are ethnicity challenges to living kidney donation in NZ. Shih & Honey (2011) state NZ Māori are at higher risk of kidney disease compared

with non-Māori, and while Māori make up 15 percent of the population in NZ, they are over-represented when it comes to renal disease. Similarly, Pacific people make up 6% of the population in NZ, and they, like Māori, suffer disproportionately from kidney disease. Denise Beechey's (2012) research focussed on Pacific peoples' uptake of pre-dialysis education at Counties Manukau District Health Board (CMDHB) in South Auckland. Beechey states that "there is no longer any serious doubt that there are marked disparities in the incidence and prevalence of chronic kidney disease between the white populations of developed nations and indigenous and migrant groups either residing within those countries or within the developing world" (p. 57). Within CMDHB, the pre-dialysis population has a high prevalence of diabetes, obesity and cardiovascular disease. If this population group are not accessing timely support to address their treatment options in the pre-dialysis period, they are more likely to end up on dialysis acutely as their kidneys fail completely. Further evidence of ethnic disparities is found in a study of the health and wellbeing of older Pacific people in NZ by Lotoala, Breheny, Alpass & Henricksen (2014). The authors found that (after controlling for multiple health risks, socio-economic and demographic values) ethnicity continues to predict lower levels of physical health, suggesting that "there are other factors which contribute to higher rates of poor health for people of Pacific ethnicity" (p. 27).

The National Renal Advisory Board's (NRAB) *Dialysis and Transplantation Audit 2012 and 2013*, published in 2015, states that there is a marked disparity in the incidence of end-stage kidney disease based on ethnicity, with Māori and Pacific New Zealanders 3-5 times more likely to experience end-stage kidney disease (p. 8), while Ministry of Health (2015) statistics suggest that among people with diabetes, Māori are 2.8 times as likely as non-Māori to have renal failure. In an editorial in the NZ Medical Journal addressing health inequities for Māori, Pacific people, and others, Professor Norman Sharpe stated that, "re-orientating healthcare and allied services to achieve reduction and eventual removal of these inequalities represents a considerable challenge and should be a topmost priority for the immediate future" (Sharpe, 2011).

The prevalence of co-morbidities and general poor health within Māori and Pacific people can potentially make finding a living donor very hard within a family/whanau group. This is evidenced in transplant rates published in the 2016 Australia and NZ Dialysis and

Transplant Registry (ANZDATA) report, which demonstrates that Māori and Pacific people are under-represented in transplant figures compared with their Caucasian counterparts. In 2014, there were 829 Caucasian patients on dialysis in NZ, with 1249 transplanted patients. There were a slightly larger group of Māori on dialysis with 849 patients, while only 170 Māori patients had been transplanted (20%). Pacific people fared even worse, with 695 patients registered on dialysis, and 118 patients listed as having had a transplant (16%). Significantly, of the 24 people who received a pre-emptive kidney transplant instead of receiving dialysis as their first treatment for kidney failure in 2014, there was only one Pacific patient, and no Māori patients.

To explore the impact of socioeconomic factors rather than ethnicity influencing transplant uptake, Grace et al. (2012) examined ANZDATA statistics between 2000 and 2010. The researchers purposefully removed indigenous patients from the participant population, so that socioeconomic factors were examined in isolation. They found that there was a correlation between greater socioeconomic advantage and receiving both pre-emptive and subsequent transplants, although socioeconomic status had no bearing on the deceased organ donation rates. Their research argues that potential donors (rather than recipients) from disadvantaged areas may face barriers to donation, due to financial constraints and higher rates of co-morbidities present (p. 141).

Internationally, there were several studies that focussed on racial disparities in accessing LKD, including limited access to funded health care, low donor recruitment, particularly in ethnic minorities, and low health literacy (Dageforde et al., 2014; Siegel, Alvaro & Hohman, 2011; Skelton, Waterman, Davis, Peipert & Fish, 2015; Tamura et al., 2014). Many of these found that provision of home-based or family based education to promote LKD, or the use of transplant navigators, improved the rate of donor recruitment.

Rodrigue et al. (2014) studied 152 African-American patients on the kidney transplant waiting list, finding 60% of patients were not actively pursuing living kidney donation. Only 11% had initiated any conversation with family and friends about the need for living kidney donation. The authors suggest that tailored education strategies be adopted to try to increase living donation rates amongst this patient group with view to reducing racial disparities in LKD. Similar results were found in a large study by Weng, Reese, Mulgaonkar

& Patel (2010) involving 1617 transplant candidates. This research found that African-American transplant candidates were less likely to recruit and receive living kidney donations than Caucasian candidates. This poorer recruitment and transplant conversion was also true for older candidates.

In contrast to the previous studies that focussed on ethnicity as a barrier to LKD, Gill et al. (2013) researched 57,896 living kidney donations between the years 1998 and 2010 examining ethnicity along with household income, finding that any disparities in racial uptake of living kidney donor transplantation were due to socio-economic factors rather than cultural differences. Notably, there was a greater total incidence of LKD in the African-American population than the white population, but in the lowest income bracket, African-Americans fared poorly. This finding may support the concept of poor access to medical care and early intervention for those on low incomes.

Difficulty with asking or accepting offers

By far the most common barrier found was that of difficulty initiating the discussion about the need for a kidney; Barnieh et al. (2011), studying patients on a transplant waiting list, found 71% of respondents struggled with how to ask someone for a kidney. This is a concerning number of patients who do not have the skills or inclination to initiate a conversation about their need for a kidney, and represents a significant barrier. The authors found that those patients who understood how and why they should pursue donation were more likely to initiate a discussion with potential donors.

In a similar vein, Kranenburg et al. (2009) found that while almost all patients in their study recognised the benefits of living kidney donation, and may even accept an offer of a kidney, many found it difficult to approach donors directly. The authors suggested that professional support programmes should be developed to assist patients to discuss LKD with potential donors, while protecting these valued relationships. A study by Garonzik-Wang et al. (2012) stated that “transplant candidates are ill-equipped to seek live donors” and that advocates, in the form of friends and family members, should be the ones initiating requests (p. 1147).

In NZ, Paula Martin's research (2013b) examined barriers to transplantation faced by transplant candidates. Martin surveyed nearly two hundred participants with ESRD from several DHBs within NZ, and then interviewed seventeen patients and twelve health professionals. Martin found that "NZ patients are not systematically informed about living donor transplantation, would like to receive a transplant but have concerns about health and financial impacts on donors, and face challenges in approaching people in their networks about living donation" (p. i).

Martin's survey asked participants whether they had discussed living donation with family (82%) and whether they had asked family to consider living donation (30%). The survey also enquired as to whether participants had discussed living donation with friends (62%) and asked friends to consider living donation (11%). Results demonstrated that, while most patients surveyed had had a discussion with family about live donation, less than one third of patients had actually asked family member(s). The figures decreased to around one tenth when it came to asking friends.

Martin recognises that patient decision-making is a complex issue, and that "patients may decide that they are not interested in any transplant (live or deceased) or may be willing to accept a transplant from a deceased but not a living donor" (p. 66). The decision to consider transplant is influenced by the patients' beliefs and preferences, their understanding of risks and benefits when considering dialysis versus transplant, and also their understanding of the risks to donors and transplant procedures. Decision-making is not necessarily a linear journey, and that feelings about transplantation often change as time goes on, as the patient gathers more information about transplant or dialysis, or their health situation changes. Martin's research is valuable in that it provides a comprehensive overview of barriers to LKD in NZ, but highlights the need for more research with regards to how recipients might recruit donors.

Similar to Martin's (2013b) research, Elisa Gordon's (2001) USA study examined patient's decisions to decline living kidney donations and reluctance to approach potential donors. Gordon studied 79 participants over 18 months, finding that only twenty-two percent ($n=17$) of her sample would ask someone to donate and that, where participants had received offers of a kidney and were pro-transplant ($n=23$), only one third of this group

($n=7$) would have asked someone to donate. Participants in Gordon's research drew attention to the difference between asking someone to donate versus accepting an offer of a kidney, and this finding is raised in many studies (Frade et al., 2011; Kranenburg et al., 2009; Waterman, Barrett & Stanley, 2008). Gordon's participants raised two major issues: "(1) asking people to donate is difficult to do, and (2) asking people makes them feel obligated to donate, which is not good because organ donation should be voluntary" (p. 259).

For many patients, there is a perception that kidney donation might increase health risks for donors, and they state that this is why they choose not to approach family and friends. Kranenburg et al. (2005) found that unwillingness to burden a loved one and anticipation of psychosocial change post-transplant were barriers to accepting a living kidney donation. Pradel, Mullins & Bartlett (2003) state that "The main perceived impediment to donate a kidney was the potential recipients' reluctance to accept the offer. Potential recipients found it difficult to ask for a kidney and worried about the consequences of a kidney removal on their donor's health" (p. 203). There were a number of articles that examined reluctance on the part of the recipient to accept an offer of a kidney (Bailey, Ben-Shlomo, de Salis, Tomson & Owen-Smith, 2015; Zimmerman, Albert, Llewellyn-Thomas & Hawker, 2006).

Kranenburg et al. (2007) found that 78% of participants (waiting for a deceased kidney donation) interviewed would accept the offer of a kidney from a living donor while, conversely, de Groot et al. (2012) found that 75% of the recipients that they interviewed on the DDL had living kidney donors available, but had declined offers of a kidney due to concerns for the donors' health. Yet according to Siegel et al. (2011) recipients typically overestimate the level of discomfort and time that it takes for a donor to recover (p. 761). This finding was also iterated by Ingelfinger (as cited by Zimmerman et al., 2006), reflecting that the risks to living kidney donors are very low. Delanaye et al. (2012) examined the surgical risks and short and long term effects on donor health post-transplant, and considered that living kidney donation may be considered safe, although the authors maintain that donor safety is dependent on retention of stringent selection criteria, particularly with regards to presence of pre-existing obesity or proteinuria.

Health Literacy

The World Health Organisation (2015) define health literacy as 'the personal characteristics and social resources needed for individuals and communities to access, understand, appraise and use information and services to make decisions about health.' Improving not only people's access to health information, but also their capacity to use the information effectively is seen as critical to empowerment.

In NZ, Martin's (2013a) research found that health literacy was a major factor in uptake of transplant and that, where patients had social networks that were knowledgeable about transplant, there was a higher likelihood of transplant uptake. Those patients who also understood the value of transplant with regards to their longevity and better health outcomes were also more likely to consider transplant. Where social networks included those who had had previous negative experiences in transplantation, there was a tendency to negatively influence the uptake of transplant. This was also the case where patients or their social networks did not fully comprehend the long-term risks associated with dialysis.

Dispelling preconceptions is an important aspect of health literacy. Coorey, Paykin, Singleton-Driscoll & Gaston (2009) found half of survey respondents (patients who had CKD, but had not yet undergone transplant) believed that dialysis must precede transplantation, and 60% viewed transplant "as a last resort" (p. 28). The authors also found that recipients who were successful in recruiting donors generally had higher incomes and level of education, were more often Caucasian, and were less misinformed about transplant, being more likely to have learned about treatment options from a physician. Concurring with this finding, Siegel et al. (2011) found that those with a postsecondary education were significantly more likely to report being comfortable asking for a kidney than those without postsecondary education (p. 758). Reese et al. (2009) described similar results in 203 transplant candidates. The authors found younger transplant candidates, and those patients who had higher incomes, were more likely to attract a potential living kidney donor.

Several studies correlated baseline level of education and living donor transplantation rates, including a single centre retrospective review by Dageforde et al. (2014)

demonstrating that living donors generally had high health literacy, while deceased donor recipients were more likely to have poorer health literacy than living donor recipients. Poor education and the correlation with low uptake of transplants was the focus of other research (Kucirka, Grams, Balhara, Jaar & Segev, 2012; Sieverdes et al., 2015). Some articles examined readiness to pursue LKD, and predicting factors common to success in finding a potential live donor (Boulware et al., 2013; Pradel, Suwannaprom, Mullins, Sadler, & Bartlett, 2009). Pradel et al. (2009) found that less than half of the patients who knew about LKD were actually considering it, and 54% of the patients had not asked anyone for a kidney. The authors drew a correlation between patient satisfaction with the information they received on LKD and higher likelihood of discussing LKD with someone and asking for a kidney.

In order to address low rate of living kidney transplant in relation to poor health literacy, other studies examined how educational resources should be prioritised, and to whom. Waterman, Robbins and Peipert (2016) suggested strategies for improving education regarding living donation should include both recipients and donors, and should address health literacy, psychological and socioeconomic barriers. Other research suggests that it is recipients, rather than donors, who should be the target audience for education strategies, as they argue that most donors will make decisions to donate without lengthy deliberation of research about kidney donation (Martin, 2014; Stothers, Gourlay & Liu, 2005). In a randomised clinical trial by Sullivan et al. (2012), trained transplant recipients were employed to act as navigators to support the workup process. They found participants in their intervention group completed more than twice as many steps towards transplantation as the control group participants. The use of recipients as navigators was also echoed by Sieverdes et al. (2015), who interviewed 27 African American kidney transplant recipients about the barriers they had faced, including lack of knowledge. Participants felt that an educational programme that was led by an African American recipient, and that included practice in approaching others, would increase the likelihood of patients pursuing live kidney donation.

In further research exploring how health education impacts kidney donation, Skelton et al. (2015) state that “best practices in chronic disease education generally reveal that education that is individually tailored, understandable for patients with low health

literacy, and culturally competent is most beneficial. Effective education helps patients navigate the complex health care process successfully” (p. 77). Pradel et al. (2009) also advocated for tailored educational programmes that take into account the patient’s health literacy, attitude towards transplant, and stage of readiness.

Finally, it is worth noting two further studies that are part of the health literacy discussion. The first examines the role of early intervention and its positive influence on transplant outcomes for patients. This is highlighted in the Kidney Early Evaluation Program (KEEP) research whereby participants who took part in community-based screening for renal disease and an education programme had significantly higher rates of pre-dialysis care, and pre-emptive transplants (Tamura et al., 2014). The second study focuses on self-efficacy, rather than health literacy. While Reese et al. (2009) found that younger patients and more affluent patients had higher uptakes of LKD, the authors propose that it is self-efficacy, not education, which is the greater predictor for recruiting a donor. The authors argue that:

The knowledge level of transplant candidates does not seem to be a crucial barrier to having a potential donor. This finding corroborates the results of our previous study in which knowledge was also not associated with having discussed donation with any potential donors. We propose that the majority of candidates learn—through their physicians, coordinators or reading—that living donor transplantation has advantages. The problem in attracting a donor may instead lie in the unwillingness of candidates to ask potential donors to come forward, to make their renal disease known in their community or the inability of candidates to motivate potential donors. (p. 2796)

Reese et al. summarise their findings by stating:

The lack of association between knowledge and having a potential donor suggests that more intensive education of transplant candidates will not increase live donor transplantation. On the other hand, self-efficacy may be an important target in designing interventions to help candidates find live donors. (p. 2792)

The literature suggests that targeted education, early intervention and support with self-efficacy may play an important role in transplant uptake, and that education may address the concerns of patients and ensure that they have accurate knowledge about living donation. When education programmes have been implemented internationally, the rates of transplant uptake appear to improve (Dageforde et al., 2014; Kucirka et al., 2012; Sieverdes et al., 2015; Tamura et al., 2014). There is no NZ research that examines the role of health literacy in LKD transplant uptake.

Transplant Preferences

Several articles examined recipient preferences or attitudes towards deceased kidney donation versus living kidney donation, and the prevalence of some transplant candidates to wait for a deceased organ to be made available rather than approaching family or friends for a kidney, or accepting an offer of a living kidney donation because of perceived risks to the donor (Bailey et al., 2015; Zimmerman et al., 2006).

Research conducted in the Netherlands by Kranenburg et al. (2005) found that 61% of the wait-listed recipients they interviewed would prefer a living kidney donation in preference to post mortal donation, believing that the LKD offered a better quality kidney. However, most studies highlighted patient preference towards waiting for a deceased kidney. Bailey et al. (2015) conducted interviews with 32 recipients of deceased–donor kidneys. They found that 25% of those participating had not been willing to accept an altruistic, or non-directed, living kidney donation. For those who were unwilling to accept an altruistic living kidney donation, they expressed concerns about the risks to the donor, fear of acquiring the donor’s characteristics, and issues of self-worth and reciprocity related to ‘gifting’. Conversely, those patients who had accepted an altruistic kidney donation stated that the anonymity of the gift freed the recipient from a feeling of obligation.

Understanding that there is a disparity between supply and demand of deceased organs suitable for transplant is important when considering the health literacy not only of renal patients, but the wider population. Cornwall et al. (2015) showed there was a high level

of support from young NZ adults for organ donation as a concept, however there was limited understanding of the restricted circumstances whereby organs might be retrieved after death. If this lack of clarity surrounding organ donation and receipt is generalised to the wider population, it is conceivable that many patients on the deceased donor list waiting for a transplant may have a poor understanding of the circumstances whereby they might receive a kidney transplant from a deceased donor.

Donor decision-making

While some recipients may find accepting the offer of a kidney difficult, conversely, living kidney donors generally reported being motivated by a desire to help a loved one who was suffering (Pradel et al., 2003). The donor might be motivated by the progression of the recipient's disease, or the prospect of impending dialysis or commencement of dialysis (de Groot et al., 2012). However, there might also be benefits to the donor, in that the recipient's health would improve post-transplant, the recipient would therefore be less dependent, and this would mean greater involvement in family life (de Groot et al., 2012). Whether the offer is altruistic, or whether the donor feels that they would benefit personally from the recipient receiving a transplant, most research points to the fact that donors are satisfied with their decision to donate (Jowsey & Schneekloth, 2008).

Gill & Lowes (2008) interviewed 11 families where a family member had donated to another within the family. They reported that most donors made quick, voluntary decisions about donating, and that they derived immense personal satisfaction from giving. They also found that transplant did not have a detrimental effect on donor-recipient relationships (p. 1612). Indeed, de Groot et al. (2012) reported that donors and recipients generally reported a closer relationship after transplantation (p. 109).

While many donors volunteer to donate, and converse with their recipients about donation, there is sometimes negative feedback from other individuals within the donors' social networks causing a cessation in communication about transplant with those individuals (Smith, Nazione, LaPlante, Clark-Hitt & Park, 2011). Smith et al. (2011) advocate that training should be given to donors and recipients on effective

communication with non-recipient individuals. This highlights the need for positive media messages about transplant, so that non-recipients have a better understanding of the risks and benefits involved in the transplant process, and why LKD is needed.

In NZ, Shaw & Bell's (2014) research examined financial hardship and expectations associated with 'gifting' a kidney as a barrier to transplantation from the perspective of 25 living donors. Their research supported the premise that many factors influence the donor conversation – such as socioeconomic matters – and that this is particularly relevant and topical in NZ at present with moves to redress financial burden as a barrier to transplant through the introduction of the 'Compensation for Live Organ Donors Bill' (2016).

Conclusion

Many of the articles in this literature review highlighted that there are a range of barriers to kidney donation. For the recipient, barriers may include difficulties with recruiting or self-advocacy; concern for the donor with regards to surgical risk, future health and financial burden; concerns that the person asked might say 'no' or that the relationship might change as a result of giving or not giving a kidney, or that the relationship might change if or when the kidney failed. In addition to the barriers faced by the recipient, the potential donor may face socio-economic constraints. Several articles recommended increased support and education for recipients, while other researchers advocated that both recipients *and* donors would benefit from tailored education programmes. Other studies proposed that family or friends should be the ones who recruit donors, not the patient. All these articles highlighted the difficulty that many patients have in communicating need, and for further research into the experience of patients as they wait for a transplant.

There is currently no research that specifically examines the conversation between those in need of organs, and those who may be asked, in a NZ setting. In an age when it is increasingly important to promote LKD as an option for ESRD patients who meet eligibility, local research is both topical and important in order to inform the development

of local kidney donation practice using empirically-derived, culturally and ethnically informed data in a way that is appropriate to patients and families in Aotearoa / NZ. The findings of this study will be important for health professionals and policy advisors to allow the development of strategies that might support patients to effectively recruit donors, facilitating the growth of living kidney donation in NZ.

Methods

Introduction

This chapter discusses the theoretical and methodological basis for the research methods employed in this thesis. Ethics approval, participant recruitment methods, confidentiality, data collection and analysis are also described.

Choosing an Appropriate Methodology

This project utilises a qualitative approach to examine the factors that influence decision-making amongst patients with ESRD who are encouraged to find living kidney donors from their social networks. Qualitative research is particularly useful when a researcher wishes to answer the *why*, *how* and *what* questions about participants' behaviour and motivations as well as perceptions and barriers. Several theoretical approaches were considered appropriate as potential candidates for undertaking this project, including approaches such as qualitative descriptive (QD) methods, gift theory and decision-making theory.

Qualitative Descriptive Methodology

Qualitative descriptive methodology is a stand-alone qualitative research method that differs from grounded theory, phenomenologic and ethnographic studies, although some cross-overs might exist between QD and these other qualitative methods. According to Neergaard, Olesen, Andersen & Sondergaard (2009), QD is the least theoretical of the qualitative approaches and is "founded in existing knowledge, thoughtful linkages to the work of others in the field and clinical experience of the research group" (p. 53). However, lack of commitment to a theory does not necessarily mean that it is not influenced by a theory (Sandelowski, 2010).

Qualitative descriptive studies present the research findings in everyday language, with rich data being gathered through interviews, interpretations being made during analysis, and themes identified. Because the participants experience of an event is described using

the participants own language, the reader might argue that this research method could be construed as being narrative. One might also argue that examining the experience of a population of patients with a common condition could be deemed phenomenological, but QD studies may comfortably incorporate elements of other qualitative methodologies while remaining a QD study (Caelli, Ray & Mill, 2008). According to Thorne, Kirkham & MacDonald-Emes (1997) qualitative descriptive research involves “description of and interpretation about a shared health or illness phenomenon from the perspective of those who live it” (p. 171).

Sandelowski (2010) states that “qualitative description is especially amenable to obtaining straight and largely unadorned answers to questions of special relevance to practitioners and policy makers” (p. 337). Considering there is a need to better understand how those with ESRD communicate their need for a LKD with a view to improving LKD rates in NZ, this method was determined to be a plausible choice for this project.

Gift Exchange Theory

Marcel Mauss first described Gift Exchange Theory in 1993 after researching the custom of exchanging gifts by tribal societies in the Pacific region. The exchange of gifts was thought to be the most ancient form of economy; to redistribute wealth, share good fortune, or to restore social order (Sque & Payne, 1994).

When applied to organ donation, Gift Exchange Theory might provide a suitable methodology, as the act of giving and receiving are the basis of this theory. Gifting an organ would usually elicit gratitude from the recipient, but for some, receiving a gift that the recipient feels cannot possibly be reciprocated can be a burden (Sque & Payne, 1994). However, many donors just want to help; common motivations for offering a kidney include “the desire to preserve a loved one’s life, the desire to share one’s resources, the desire to be of help, and the belief the experience will be beneficial” (Smith et al., 2011, p. 873).

In Gill and Lowes (2008) article on gift exchange and organ donation, they found that donors made instant and voluntary decisions to donate, and that they invariably derived immense personal satisfaction from this decision. However, Gill and Lowes reported that recipients often found accepting donors' offers difficult, because of concern for the donors wellbeing. This was a finding echoed in many studies (de Groot et al., 2012; Rodrigue et al., 2014; Waterman et al., 2006).

While gift theory might be an appropriate theory to underpin this research, the main aim of this research project is to examine the experience of asking, or not asking, for a kidney, rather than the experience of offering, or accepting/declining a kidney. In this regard, the theory would not adequately fit the question.

Decision Theory

Decision Theory, also known as Decision-Making Theory, is sometimes referred to as the Theory of Choice, and examines the reasoning underlying a person's choices. It is closely related to the field of Game Theory (Myerson, 1991). Decision Theory is divided into three main branches: descriptive, prescriptive, and normative (Dillon, 1998). Dillon describes these 3 branches in the following way:

- Descriptive: What people actually do, or have done (what people are observed to do).
- Prescriptive: What people can and should do.
- Normative: What people should do (in theory)

At the heart of decision making is the understanding that people make choices under uncertainty, weighing up available choices of action, each of which could give rise to more than one possible outcome. However, one criticism of Decision Theory is that it assumes there are 'known unknowns' that the person is able to factor in when they consider their options, but there are also unexpected variations, or 'unknown unknowns' that might occur. The online Business Dictionary describe 'unknown unknowns' as 'Future circumstances, events, or outcomes that are impossible to predict, plan for, or even to know where or when to look for them'. (BusinessDirectory.com, 2017)

Decisional conflict and choice can be stressful for patients at a time when they are also dealing with health concerns that might impact on their social and vocational life. Janis & Mann (1977) explored decision making after extensive research into the psychology of stress, and they describe patterns of coping with stressful decisional conflicts. They argue that there are four major types of decisional conflict: utilitarian gains and losses for self; utilitarian gains and losses for significant others; self-approval or disapproval such as (moral or philosophical distress); and approval or disapproval from significant others. The gains for a recipient are obvious when it comes to acquiring a new kidney, but there are trade-offs in undertaking an operation that carries a degree of risk, as well as concern for the donor in being subjected to similar surgical risk and the perception of risk to long term health. Some recipients express a feeling of guilt that they are in need, along with a sense of being indebted to the donor, while some worry that relationships might suffer, the kidney might fail, and how this might affect the donor/recipient relationship (de Groot et al., 2012; Waterman et al., 2006). Adding to these concerns is evidence that there is considerable financial burden for the donor in loss of earnings while undertaking both workup and surgery (Grace et al., 2012; Klarenbach et al., 2014; McGrath & Holewa, 2012; Rodrigue et al., 2016; Shaw & Bell, 2014).

Decision theory has ramifications for this research project, in that there are many factors that influence patients thinking when considering approaching friends and family to ask for a kidney. These include whether the patient decides to ask for a kidney, whom they choose to ask, in what circumstances they might ask, and the manner in which they might ask. It also has implications for considering the recipients' baseline knowledge and health literacy from which the recipient is expected to make informed decisions about whom, how and when they might ask for a kidney.

Adoption of Qualitative Description as Methodology

While Decision Theory and Gift Theory were interesting possibilities as the basis for methodological approaches to the project, the decision was made to approach this project free of underpinning theory and philosophies, and a QD method was determined to be the most appropriate method for this project. It was adopted to gain understanding

of the lived experience of participants, in order to identify themes from the data that allow insight into the experience of what it is like to ask someone to donate a kidney, and the reasons why patients might decline to approach friends and family for a kidney. Common themes that emerged from the data would allow the participants experience to generate theory rather than having theory imposed on the data collected.

In adopting QD as the principal methodology for this project, I was able to examine the data using straight descriptions of the phenomena – in this instance, the experience and perceptions of individuals who collectively are faced with the issue of needing a kidney transplant. Their descriptions helped to explain the ‘who, what, and why’ of experiences and events, with the outcome providing a summary of experiences that are shared by (or common to) individuals.

According to Polit and Beck (2014), QD research typically demonstrates an accurate portrayal of people’s characteristics or circumstances and/or the frequency with which certain phenomena occur. This straight description of experience is grounded within the naturalist paradigm of enquiry (Sandelowski, 2000) where data is viewed at ‘face value’, and experiences are described from the participant’s viewpoint within the context in which it occurs. Neergaard et al. (2009) state that QD research “provides a description of informants’ experiences in a language similar to the informants own language” while Chenail (2011) states that this “naturalistic, discovery-oriented descriptive research ... offers a comprehensive summary of an event in the everyday terms of event insiders” (p. 1180).

Use of QD methodology in this project is therefore appropriate for several reasons. The data is unique to each participant, but the methodology allows individual responses to be grouped to provide insight into commonality between the participants. This provides a descriptive summary of data that allows a ‘best fit’ so as to inform the question. QD relies on the participants’ beliefs, insights and lived experience to provide the data with meaning, and by taking the position of having no preconceived notion or paradigm, the analysis allows the data to identify new insights into established problems, as well as to identify new and emerging areas in need of investigation (Sandelowski, 2000).

Use of Quotations

In this thesis, verbatim quotations have been utilised to demonstrate the findings and to provide a 'thick description' of the participants' experience. Ponterotto & Grieger (2007) provide the following definition of thick description:

A thick description does more than record what a person is doing. It goes beyond mere fact and surface appearances. It presents detail, context, emotion, and the webs of social relationships that join persons to one another. Thick description evokes emotionality and self-feelings. It inserts history into experience. It establishes the significance of the experience, or the sequence of events, for the person or persons in question. In thick description the voices, feelings, actions and meanings of interacting individuals are heard. (p. 416)

Because straight experience is described, this is also a valid way of gaining valuable insight into participants' perceptions of a specific topic with a view to informing health services and improving the quality and delivery of services to this population.

Sample Criteria

Sample size is an interesting question when no theoretical framework is being utilised. How does the researcher gather sufficient information when their project does not serve to support a theory? How does the researcher know that their sample size is adequate enough to ensure the credibility of research findings? Sandelowski (1995) suggests that adequate sample size in qualitative research is "a matter of judgement and experience in evaluating the quality of the information collected against the uses to which it will be put, the particular research method and purposeful sampling strategy employed and the research product intended" (p. 179). However, this does not help the novice researcher answer the question "How many participants will I need?" Malterud, Siersma & Guassora (2015) suggest that the concept of 'information power' should be used to guide adequate sample size. They suggest that the size of a sample with sufficient information power depends on (a) the aim of the study, (b) sample specificity, (c) use of established theory,

(d) quality of dialogue, and (e) analysis strategy. Because the researchers are seeking maximum variation in their sample population, and because of the lack of underpinning theory, it was decided that in order to gather sufficient information power in order to identify enough themes and create theory, a slightly larger sample population might be required.

Ethics Approval

Ethics approval was sought from the Northern B Health and Disability Ethics Committee (HDEC), with concurrent applications made to HBDHB and HBDHB Māori Health Units requesting locality approval. The application was approved by the Northern B HDEC (March 2016), the decision being made through the HDEC-Expedited Review pathway (Appendix A). HBDHB approval (Appendix B), HBDHB Māori Health Service (Appendix C), and Victoria University of Wellington Graduate School of Nursing, Midwifery & Health approval (Appendix D) were also given. All approval committees were aware that my employment included working with patients who were potential participants in this study. Additionally, approvals were obtained in line with the requirements of the Victoria University of Wellington for the purposes of undertaking research involving human participants.

Cultural and Social Considerations

Treaty of Waitangi

While undertaking this research, the Treaty of Waitangi principles of partnership, protection and participation were adopted and adhered to. By conducting qualitative research that examines the lived experiences of those with ESRD, the researcher engaged in partnership with those patients, and endeavours to support their efforts to recruit a kidney donor with successful transplant and a benefit to health outcomes being the ultimate goal. All interactions with participants took into account their ethnic, social, cultural and spiritual health and wellbeing.

Cultural Competency and Considerations

Cultural competency training is a nursing requirement at the HBDHB, while the Nursing Council of NZ competency 1.2 requires that a Registered Nurse demonstrates the ability to apply the principles of the Treaty of Waitangi to nursing practice. *Te Whare Tapa Wha* is a holistic model of care for engaging with Māori participants, and this model of care was observed while conducting this research. Examples of using this model of care are that research was conducted in a culturally competent manner with the participant choosing whether or not to participate, and if deciding to take part, choosing where and when they were to be interviewed, and whether they wanted to have support persons present with them.

The Victoria University Māori Health Committee provides guidelines around expectations for research undertaken within the NZ health sector and under the jurisdiction of the University. All research was undertaken within the University's guidelines to ensure protection of participants.

Study Participants

Purposeful sampling was used to select potential participants for this project. Potential participants were drawn from adult patients (in this instance, defined as those over 20 years of age) with ESRD who were registered with the HBDHB. Inclusion criteria were those patients who are currently listed on the DDL, with or without LKD options, and those patients who had active potential donors currently being worked up by me in my role as a living donor coordinator at the DHB. Exclusion criteria included post-transplant patients, those who were temporarily suspended from the DDL for medical reasons, and those ESRD patients who were ineligible for transplant. Those who already had a transplant date arranged were also excluded from the project, as it was felt that being given a date for transplant could influence the recipient's recall of their experience in recruiting a donor.

There were almost thirty patients who met eligibility criteria, and could potentially have been interviewed. Because there was a surplus of potential participants, I endeavoured to utilise a maximum variation strategy focussing on demographic variation: selecting a cross-section of ages, genders and ethnicities that might adequately represent different viewpoints within this sample population, but was also an attempt at representing the typical ESRD population within this DHB, and ensuring the sample was not subject to accidental random variation (Maxwell, 2013).

Sample size was ultimately decided by several factors: some patients declined to take part in the project, and the primary investigator's study and workload constraints were another factor which influenced sample size. Data saturation provided a guide as to the adequacy of the sample population size, as when no new information was forthcoming, the primary investigator deemed that viewpoints had been comprehensively represented.

Recruitment

A letter of invitation to participate in the study was sent to twenty-three eligible patients (Appendix E). The letter outlined the project and expected outcomes, invited the participant to take part, and acknowledged their right to decline to be interviewed. The letter advised that there would be follow up phone call in two weeks from a HBDHB employee who was independent of the research project. The letter identified who this person would be, and that they would ask the potential participant whether they had read and understood the letter, and whether they wish to take part in the project.

Attached to the letter was the Participant Information Sheet (Appendix F). This three-page document provided further in-depth information about the project was provided about confidentiality and access to information. It also outlined information about those involved (including contact information), and also provided contacts for persons independent of the project that the participants could contact if they were unhappy about any aspect of the research.

Two weeks following the mailing of the letter of invitation and Participant Information Sheet, all potential participants were phoned by the renal services secretary (protocol in

Appendix F). The renal services secretary was unable to contact three of the twenty-three persons on the list after three attempts (each person), and a message was left for those persons that outlined a process for their involvement in the study should they decide they wished to take part. These three persons did not make contact with researchers. From those contacted, four persons declined to take part when asked and one person became ineligible when they were temporarily suspended from the DDL. This left a pool of fifteen potential participants that indicated that they wished to be involved. The researcher contacted each individual and organised times and dates for the interviews to take place.

Interview protocol and data collection

A consent form was provided and signed by both the researcher and the participant prior to the interview. Participants were assured that personal data provided by them would not be publicly divulged (Appendix G). The agreement specified how that personal information would be gathered and stored, but also stated how the data would be used. The interview process and intent of the study was outlined verbally prior to written consent being acquired. The participant was informed that they could withdraw at any time without needing to give a reason, that if they withdrew, all documentation pertaining to their involvement in the study would be destroyed, and that there would be no consequence to their healthcare delivery should they choose to withdraw.

Interview

Face to face, semi-structured interviews were conducted using open ended questions for all interview participants. The researcher conducted all fifteen interviews. An interview protocol was used to ensure consistency in collecting information, with a coding spreadsheet noting the name of the participant as well as the presence of any support person who might have contributed to the interview, and the date and place of interview. An interview guide (Appendix H) was developed to provide an outline of the purpose of the research. Questions for the interview were developed in order to answer the main aim of the study, this being to examine the factors influencing decision-making amongst

ESRD patients considering asking family and friends for a kidney. The guide included sample open-ended questions with a format for how to ask the questions, prompts or probes to elicit more information.

The interview sought to find out: Who did the patient ask, and why? Who did they exclude from asking, and why? Who was perhaps in the back of their mind that they could have asked but didn't, and why? How did they ask? What were their reasons for asking in this way? If they could make any recommendations, what advice could they pass on to another person in a similar situation?

Interviews were recorded using two digital audio-recording devices (Digital Voice Recorder, Endeavour EN625, Guangdong, China). Recorded data was downloaded and stored digitally on a USB flash drive (Silicon-Power Computer & Communications Inc., Taipei, Taiwan). At the end of each interview, participants were thanked for their time. Immediately following each interview, I recorded (and subsequently typed up) a précis of the interview, reflecting on the key themes and issues that had presented during the interview. This action consolidated the primary issues raised by the participant during the interview, and identified themes that could be followed up in subsequent interviews. I felt the need to reflect on each individual interview as they were conducted, the précis supplementing field notes, and a useful aid in identifying emerging themes. This process assisted in being able to make comparisons between interviews, and helped to steer subsequent interviews.

Confidentiality

All printed and hard data was securely stored in a locked filing cabinet with access limited to myself. Digital data was stored on an external hard-drive, with log-in access restricted to myself and my supervisor (no shared access). When not in use, the external hard-drive was locked in a filing cabinet with print and hard data. Data will be securely stored for ten years as per the approved protocol in the ethics applications. After ten years, print and hard documentation will be destroyed using a document shredding service. Information held on the external hard-drive will be erased.

Interview Transcription and Analysis

Transcription occurred as soon as possible after interviews to minimise delays in checking for accuracy. The audio files of the interviews were sent for transcription to a private transcriber who was blinded to the participant's personal details, was independent of the study, and was not employed by HBDHB nor Victoria University of Wellington. Each interview was transcribed in a uniform manner. Transcription was supplemented by field notes taken by the interviewer.

Data analysis occurred both during the period of data collection and after all the interviews were completed. While it was important to avoid premature analytic closure (Sandelowski, 1995), it was also important to identify themes that were emerging as a result of the first few interviews, and then probe a little in subsequent interviews to see if there were similar issues being identified. Sandelowski (2000) describes this process as being 'reflexive' and 'interactive' (p. 338), where interviewers modify their treatment of the data to accommodate new data and insights. This is an inductive or 'bottom up' method of thematic analysis, whereby the themes that emerge are strongly linked to the data themselves rather than driven by the researcher's theoretical interest in the question (Braun & Clarke, 2006).

It was also important to recognise that the research question asks about the participant's experience of asking, or not asking, for a kidney. While anecdotally I frequently hear patients report that "it's hard to ask", this experience might not be true for all. Being open to themes that were emerging as the interviews went on, and avoiding an *a priori* opinion of what might emerge in the data, was important to the process. Data analysis is also important in order for the researchers to understand when data saturation might have been reached.

Coding the data

Transcripts and field notes were revisited after all the interviews were completed. The transcripts were examined and discussed by myself and supervisor, with decisions made about coding possibilities - how to code and what to code. Coding options were also peer

reviewed by researchers that have a background in utilising this methodology from the Graduate School of Nursing Midwifery and Health, Victoria University of Wellington, to ensure appropriate choices and categorization of themes or topics. Inter-rater reliability checks ensured consistency, and interpretation of themes was checked for thematic drift. By undertaking peer review of the data and emerging themes, with agreement on possible coding, researcher triangulation has been carried out. I believe research integrity has been maintained throughout this project through self-reflection, and by utilising a renal specialist nurse to conduct the interviews.

The finalised codes were entered into a computerized management programme (NVivo Pro software, Version 11, QSR, Melbourne, Australia), to support the description and arrangement of segments of text, thus aiding the primary investigator in the analysis and presentation of the data.

Results

Introduction

This chapter presents descriptions and analysis of the data gathered during interviews with the participants of this study. It incorporates participants' quotes that help to demonstrate findings as well as providing 'thick description' of the participants' experience. It is broadly organised into two sections, the first describing basic demographic and participant data, and the second detailing the thematic analysis of interview data.

Basic Demographic and Participant Data

Participants

A total of fifteen participants were interviewed. While no survey was conducted, the group interviewed demonstrated the following characteristics. Ages spanned from 23 years to 68 years of age, the average being 49.8 years (Refer Fig 1) and there were five women and ten men interviewed. This gender disproportion is consistent with the eligible population listed on the DDL for the HBDHB (Refer Fig 2). With regards to ethnicity, six participants identified as Māori, three identified as Māori/NZ European, five identified as NZ European, one identified as Other European (Refer Fig 3). In 2016, the Hawke's Bay DHB dialysis unit population identified their ethnicity in the following way: 63% Māori, 26% Pasifika, 2% NZ European, and 9% other.

In regards to treatment modality, five patients were pre-dialysis patients who were currently listed on the DDL or had living donors being worked up. There were ten patients already on dialysis, seven of these on haemodialysis and three on peritoneal dialysis. Transplant modality: Eight patients were listed on the DDL alone with no living donors being worked up. Three patients were DDL listed and had living donors being worked up. Four patients were not DDL listed, but had living donors being worked up.

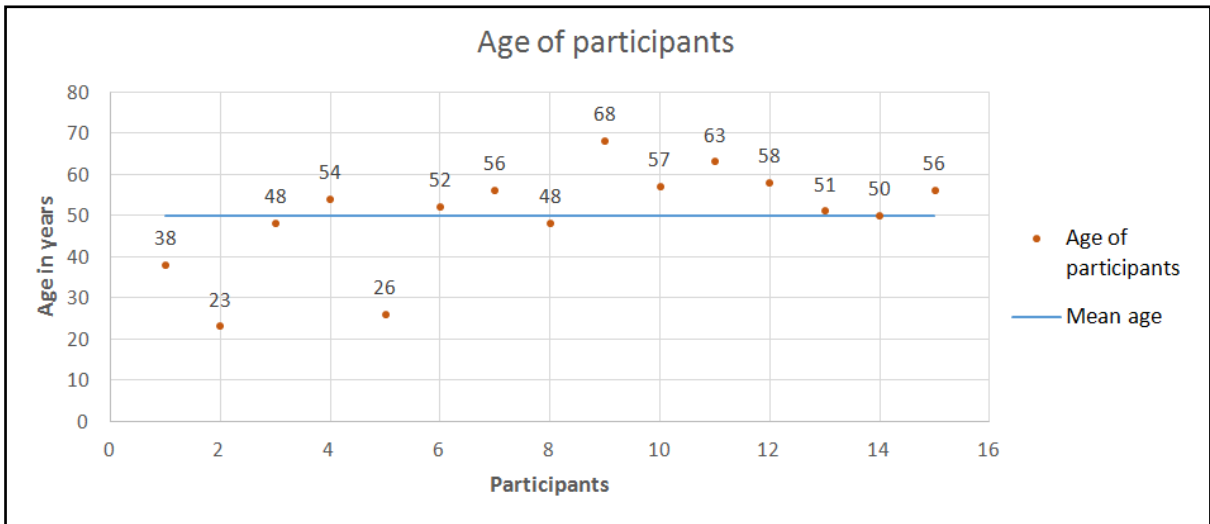


Figure 1: Age of participants

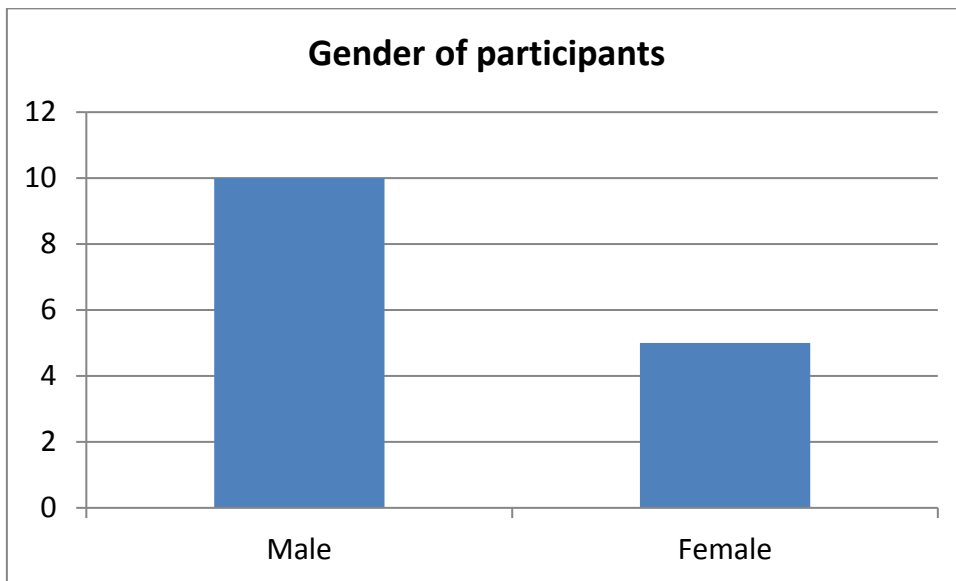


Figure 2: Gender of participants

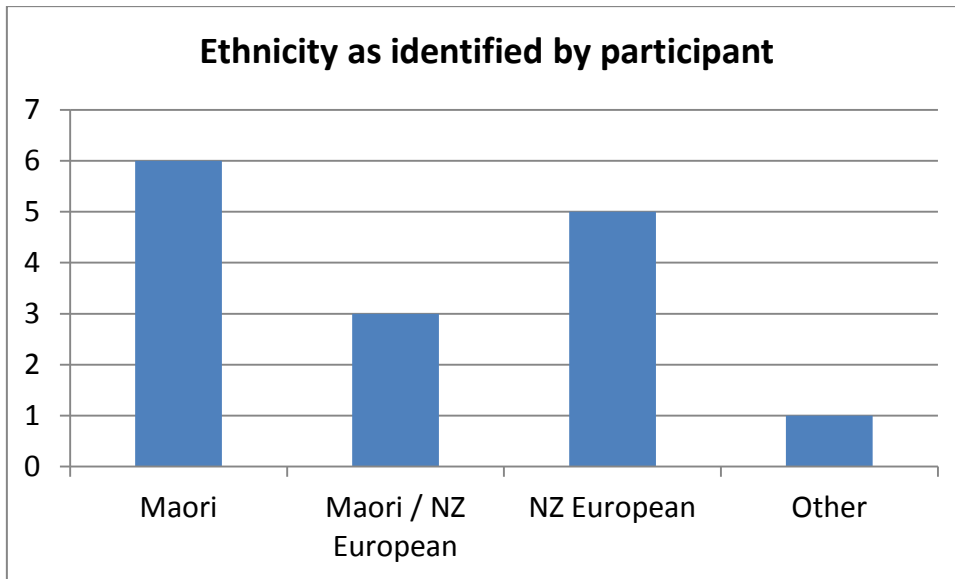


Figure 3: Ethnicity as identified by participant

Length of Interviews

A total of just over five hours and forty-five minutes was recorded for the fifteen interviews. The interviews ranged from just over eleven minutes to forty-five minutes in length. This variation was driven by the fact that the questions were open-ended, and if a participant had never asked anyone for a kidney, or had had no offers, then they were unable to recount their experience of this and the interview was moved on. The mean length of time for the interviews was just over twenty-three minutes with the median being twenty-one minutes.

Thematic Analysis of Interview Data

The research question asks about the factors that influence the asking or not asking loved ones for a living kidney donation. From the interviews, five major themes arose, with subthemes identified (Fig 4). These major themes were: will ask; won't ask; offers; barriers to asking; advice to others.

Theme	Sub-theme	Topics
Will ask	Direct recruitment	<ul style="list-style-type: none"> – Asking friends and family for a kidney – “It’s hard to ask” – Anticipating rejection – Self-efficacy
	Indirect recruitment	<ul style="list-style-type: none"> – Sharing their story – Using social media – Family or friends recruiting on behalf
Won’t ask	Won’t ask and won’t accept an offer	
	Won’t accept offers	<ul style="list-style-type: none"> – Cultural or traditional values – Philosophical beliefs: Acceptance of how things are; Not wanting loved ones to donate; The anonymity of a deceased kidney
	Won’t ask but will accept an offer	
Offers	Waiting for offers from family or friends	
	Receiving offers	
	What it feels like to have people offer	
Barriers to asking	Managing risks	<ul style="list-style-type: none"> – Donor health risks – Financial impact on donor – Relationships
	“I don’t look sick”	
	Predetermining suitability	
	Limited recruitment opportunities	<ul style="list-style-type: none"> – Poor family health – Small social circle
	Waiting for a deceased kidney	<ul style="list-style-type: none"> – Availability – Legislation
	Misinformation	
Advice to others	Effective recruitment	
	Health literacy	
	Resources	
	Psycho-social support	
	Media focus	
	Raising awareness	
	Shock tactics	
Future technologies		

Table 1: Thematic analysis of interview data

Major Themes

Will ask

This major theme was subdivided into subthemes of direct recruitment and indirect recruitment based on the approach that the participants used to ask for a kidney. Both direct recruitment and indirect recruitment had different topics contributing to them, with four and three topics identified, respectively.

Direct recruitment

Direct recruitment describes how participants approached asking for a kidney and their attitude to asking. It also covers how participants dealt with being turned down. Along with examining how, and in what way, the participants asked for a kidney, the research asked those who had approached others about their experience of asking to enquire what it's like to ask. Four main topics were identified. These were:

- asking friends and family for a kidney
- it's hard to ask
- anticipating rejection
- self-efficacy

Asking friends and family for a kidney

More than half of the participants had at some point approached friends or family to ask for a kidney. Several of these discussed the manner in which they had done this. Some had used humour or “cheekiness”, admitting to trying to keep their approach light so that they might cope with an anticipated rebuttal more easily. The only difficulty with this approach was that some described getting responses from people that were either equally jovial or were bewildered, as the subject matter and style of delivery of information were at odds. A joking or throw away comment could result in confusion as to whether the person asked was serious or not. “I was actually cheeky...um...yeah, I asked one young lady, and she actually thought I was joking” (Mr J).

“It’s pretty hard, because ...it’s a pretty big step in somebody’s life to donate a kidney, so it’s pretty hard to ask for one” (Mr J)

Others were more direct in their approach. One participant described asking widely of family and friends, and that his friends had “looked at him sideways, like um, why do you need a kidney?” To his family, he stated “Hey, I’m on the scrounge – giz a kidney!” This invariably resulted in a positive response, but he states that when his whanau got more information, they were put off by the descriptions of extensive testing. He stated that they worried they might find out that they had something wrong with them. His reply to this was “What can you have worse than me?” (Mr L). Another described telling her family that she was sick, and that only a kidney could keep her alive (Ms D).

“It’s even hard to ask for help. But I think it might be a pride thing. I don’t know” (Mr F)

Most participants said that it was important to provide information about transplant and the workup process to friends and family before asking for a kidney. People might then offer spontaneously, or be able to go away and think about it before being followed up. Without a lead-in of information, many of those asked might have felt put on the spot, with little time to digest what was being asked of them.

“Yeah, and it’s hard to know who to ask, ‘cause you don’t know who’s willing and who isn’t willing...” (Mr J)

It's hard to ask

Most of those interviewed stated that there were difficulties with asking. Even those who said they had become good at asking “anyone and everyone” still stated that it was hard, but one suggested that perhaps the more they asked, the more desensitized they had become. When asked about their approach to asking, several participants discussed the need for humility.

“How can I ask for a kidney, when I can't even ask to borrow a chainsaw?” (Mr O)

Only one participant described early attempts at approaching others for a kidney as “demanding” and that “when I asked them, I used to swear a lot.” When asked about his success with this approach, he said it had not worked. “This time when I asked them, I did it without the swearing, and it kind of got through to them” (Mr E). Most participants said it was important not to demand.

*“Don't demand. You can't demand. You've got to be humble
and approachable, you know? Just...cap in hand.
And prepare yourself for a 'yes' or 'no'” (Mr F)*

The majority of participants stated that a direct approach was best, rather than ‘beating around the bush’, especially when talking with family/whanau. Two participants however felt that a direct approach might not be a suitable way to broach asking for a kidney from people who were not immediate relatives or close friends. One stated that “with strangers, it might be a different scenario” (Ms D). One participant stated that asking for a kidney was “not a woolly question” (Mr C) and yet, for many, being direct had not resulted in offers to donate.

*“It’d be like asking for money, in a way. It’s not an easy thing for a donor to do –
there is a risk to their health, there’s the surgery and recovery
that they have to go through, so it’s not...it’s not a minor request,
it’s...it’s pretty major” (Mr K)*

Many participants struggled with their perception of altered independence as a result of asking for a kidney. One stated “I’ve always been independent, and done everything myself, and not asked, so it’s really hard to ask. I find it hard to ask, yeah” (Mr J). Another participant felt that their pride made it hard to ask. Another stated that he felt too *whakamā* to ask people – explaining that this meant feeling shy or ashamed – and that it took a long time to bring the subject up when around other adults (Mr L). One participant felt even more strongly about it. She likened it to talking about death, or “planning someone’s funeral that’s not even dead. A lot of people don’t want to hear it.” She felt the subject was “quite taboo” (Ms I). A sense of guilt about the concept of asking was often expressed, with several participants indicating that it didn’t seem right to ask.

*“All the family know, eh. They all know that I’m in dire need of a kidney.
I haven’t the gumption to go up and say “Give us your kidney, mate?”” (Ms I)*

Anticipating rejection

Some donors anticipated who might or might not be approachable within their circle of friends and family, and therefore where they anticipated rejection, they did not even bother to ask.

One participant had approached two children but stated of his other children “the other two won’t give me nothing” (Mr L). Another participant described an early offer made by a friend. Sometime later when the participant’s health started to seriously decline, the participant raised the subject with the friend to see if their earlier offer still stood. He described his friend as “having a bad day” and answered “not now.” The participant stated he felt upset, and that he would never broach the subject with his friend again (Mr O). Another participant described getting initial interest from a potential donor, then having that person “go cold” on them felt “like being dropped into a big pit.” He stated “you’re up there, and then next minute, you’re down there” (Mr A).

“If they’ve got the courage to ask, then ask. It can either be a yes or a no, but just prepare yourself for a no answer.” (Mr F)

Only one participant described physical manifestations of anticipating rejection, stating “my heart was pumping, and I thought well, what if he panicked about it, you know? Like what would it do to our relationship, but...yeah, I got all sweaty, and thinking, well, I sort of have to tell him” (Ms B).

Self-efficacy

According to Albert Bandura (1996), self-efficacy is defined as "the belief in one’s capabilities to organize and execute the courses of action required to manage prospective situations." In the case of recipients, self-efficacy is described as a measure of belief that the patient has the ability to pursue live donor kidney transplant in difficult circumstances (Waterman et al, 2015). These beliefs are what Bandura describes as determinants of how people think, behave and feel (Bandura, 1977).

“Your confidence builds as you get more information” (Mr J)

While many participants stated that it was hard to ask, almost all of those participants who had asked friends and family for a kidney stated that being empowered with information was an important part of the asking process, both for themselves, and to be able to impart accurate information at the time of asking. It was felt that having information at the time of asking was important, to ensure that the opportunity was not lost. Several participants described knowledge as a means of empowerment and confidence. Knowledge enabled them to answer questions that potential donors might have, or to direct them to resources such as the Live Kidney Donor Aotearoa (LKDA) books and DVDs which were an important aspect of the approach for many.

Several participants stated that they had always found asking difficult, but they found that once the subject had been broached, people almost always wanted to know more. Several participants also advocated that ‘practice makes perfect’ and that, while it asking would never be easy, the more one approached others, the less difficult it became.

Indirect Recruitment

Rather than ask directly for a kidney, several participants described using social media as a general approach to asking for a kidney. Others preferred to share their story with friends and family in the hope that someone might offer a kidney. Others were grateful for their spouses, parents or friends who were actively recruiting on their behalf. Three main topics were identified:

- telling their story
- using social media
- family and friends recruiting on behalf

Sharing their story

For many of the participants, sharing their story was an effective means of communicating their need for a transplant, particularly if they felt uncomfortable with asking. Sometimes they used a combination of both, sharing their story in order to generate interest before discussing what was needed to address their renal failure. This combination of sharing their story and testing the response was described by many who had felt that asking was too difficult. Sometimes the story was told by a significant other, such as a spouse or parent, and this removed the responsibility of 'asking' from the participant altogether. Many participants felt that this was an ideal way to broach the subject of their renal failure, as many said that they didn't look sick to others. This raised the question of how you inform people of the need for a kidney when you look well.

Using social media

The use of social media, in particular Facebook, seemed to be an important means of getting the message out that a kidney is needed. More often than not, it was the family who posted information about the participant and a statement about the need for a kidney transplant.

"I think social media's the way to go now, 'cause it goes, it goes off! You just need to put something up...if anyone out there is willing to donate...please..." (Mr F)

Many of those who had used social media in an attempt to generate potential donors had found it an effective means of widening their reach. They either did this as a direct supplication for expressions of interest to donate, or generally addressed the need for living kidney donations and included the fact that their family member needed a kidney. This was reportedly quite successful for a number of families to get the information out there that a loved one was unwell or in need of a kidney, but also to provide information about where to go to find out more about the transplant process.

Family and friends recruiting on behalf

Most of the younger participants described the way family, especially parents, had recruited for them. This often involved family meetings or hui, where the health of the participant was discussed and requests for relatives to be worked up were common. Most of the Māori participants reported that it was important to involve family/whanau in discussions. A few others described the way that spouses or partners were instrumental in talking with others about the need for a kidney.

Won't ask

This section describes the following sub-themes and topics:

- Won't ask and won't accept an offer
- Won't accept offers (cultural and traditional values; philosophical beliefs – acceptance of how things are; not wanting loved ones to donate; the anonymity of a deceased kidney)
- Won't ask but will accept an offer

Won't ask, and won't accept offers

Almost half of all the participants interviewed stated that they had not asked friends or family for a kidney, had declined all offers for a kidney, and were preferring to wait for a kidney on the DDL as their preferred option for kidney transplant. Even although they were on the deceased donor list, and therefore met quite stringent criteria for health and wellbeing in order to be listed, they had declined to ask friends and family for a kidney.

"I've never felt comfortable to ask" (Ms M)

A few participants described both not asking, and not accepting offers to donate. One went as far as describing evasive tactics to avoid a person who had repeatedly offered

(Ms M). Some of those who refused to approach friends and family stated they would never accept a living kidney donation if one was offered.

“I’ve never asked anyone else for a kidney, I’ve never approached anyone” (Mr F)

Won’t accept offers

This sub-theme comprises two main topics:

- Cultural or traditional values
- Philosophical beliefs: acceptance of how things are; not wanting loved ones to donate; the anonymity of a deceased kidney

Cultural or traditional values

Several participants discussed their beliefs in the context of kidney transplantation, and whether their ethnicity, cultural or spiritual beliefs had a part to play in their decision-making around non-acceptance of a living kidney donation. Many of the Māori participants acknowledged traditional values and beliefs that the body should die intact, but also acknowledged a changing world that was mindful of the older generations’ beliefs, but also that attitudes needed to change with the times.

*“You can still belong to a church, and still happen to donate these things.
You can still belong to an Iwi, and still can donate their body parts” (Mr E)*

One participant stated that attitudes needed to change, because “your own people are needing those body parts” (Mr H). Another stated that they knew “a lot of Māoris that

don't believe in having someone else's parts or blood, yeah. But that never crossed my mind" (Mr F).

"Pacific Islanders and Māoris are probably the worst for actually giving up body parts...and yet we've probably got the biggest demand out there for it...a lot of that is our own cultural beliefs, you know, that you go into the earth all in one piece, and all that, but, yeah... probably need to do some more work around our people's beliefs. If I'm gonna get well, I gotta get (a kidney)... I'll do a karakia, and make use of the new one" (Ms D)

Most felt that cultural influences were not a major factor in their refusal to accept a living kidney donation, but concerns about the health and wellbeing of their whanau or loved ones that was the bigger determiner as to whether a participant accepted an offer from a living kidney donor.

Philosophical beliefs

Acceptance of how things are

Many of the participants who were already on the deceased waiting list, and had perhaps turned down offers of a living kidney donation, expressed their desire to hold out for a deceased kidney rather than accept an offer of a kidney from those close to them. They stated they were aware that waiting for a deceased kidney could take many years, and indeed, that they might die waiting for a kidney.

"If I get sicker, it's my time. And that's how I look at it. I can't cheat death" (Mr N)

Many stated that waiting for a deceased kidney donation was a bit of a lottery. One stated that he felt the allocation of kidneys was not particularly transparent, and that he questioned how the kidneys were allocated (Mr H). Several participants said that they had been on the waiting list for many years already. When questioned about what might make them change their mind and accept a living kidney donation, many were philosophical, and stated that neither a change in health, nor the prospect of dying would alter this decision.

*"I don't feel anybody should sacrifice anything of theirs for somebody else...
I mean...that's not something you do lightly, and it's not something I would
expect of anyone" (Ms M)*

Not wanting a loved one to donate

Most of the participants discussed their concerns regarding the impact donating a kidney would have on their loved ones, particularly regarding physical health both during surgery, and the perceived long term health risks of living with one kidney.

"If my Pa donates, and then he dies on the day, well then it's all on me" (Mr E)

Many also expressed fear that relationships might be affected by either asking or receiving a kidney. This might take the form of feeling obligated to the person donating,

and fears that the relationship might deteriorate because the participant had asked. Some expressed that they would never accept the offer of a donation from loved ones, and many valued the health and wellbeing of their loved ones more than they valued their own health.

"It just made me sad, 'cause...oh, I don't know. I just felt sad because they offered me something from their bodies to fix mine" (Ms G)

The anonymity of a deceased kidney

Many participants expressed the concept of anonymity of the deceased donor being important to them. They would be released from the burden of feeling obligated to the living and known donor, and would not worry about their known donor's wellbeing, particularly the surgical risks and then potential risks to long term health as a consequence of donating.

"I don't want to know who the person is" (Ms D)

Several participants stated that the deceased donor was already dead, and while this loss of life appeared to sadden the majority of participants, it was felt that the deceased donor's organs were benefitting others after death and this was preferable to putting a loved one through the stress and physical discomfort involved with workup and operation.

Won't ask, but will accept offers

For those participants who had never asked anyone for a kidney, several described the fact that while they would not ask for a kidney, they might accept a kidney that was offered if they felt there was no other option, and if they thought that the donor's health would not be compromised.

"Probably if I'm lying in bed, and I'm...I've had a gutsful of it, and there's nobody else around, and I'm at my last...last resort...probably then" (Mr C)

Offers

Waiting for an offer

Almost half of the participants stated that they had not asked friends or family for a kidney. Some of those who had never asked friends or family for a kidney had received offers, but had declined them for various reasons. Often the offers were deemed inappropriate, from persons who might not have good health themselves, or had weight or lifestyle factors that might rule them out as donors. Some participants appeared physically uncomfortable when stating that they had no family or friends who would offer.

"No-one's offered...like I'm from a family of nine, and none of them have offered me a kidney. So if they're not gonna offer, I'm sure as heck not gonna ask" (Ms G)

Receiving offers

Just over half of the participants talked about their experience of receiving offers. Of this group, most stated that their family or friends had come forward and freely offered a kidney. Several participants stated that they didn't get to ask before the offers were made.

"I've had a lot of offers" (Mr F)

One person talked about his wife offering a kidney as being a "little bit different" from others who had offered as it seemed to be what was expected, but that her offer was appreciated just as much (Mr O). Another stated that his wife "volunteered" to be tested (Mr C). Several participants described feeling that offers had been made lightly, or when drunk, and were therefore turned down as not having been offered in a serious manner.

"Some of them, you know it's all drunk talk, and I don't take no notice of that" (Mr F)

Two participants stated that they had turned down multiple offers when they believed they had a donor who was about to start workup. This also had the potential to cause angst that they had done the wrong thing in declining offers in case the person being worked up was not a suitable donor. One participant felt that having had a friend or family member offer in the past might make it easier to broach the subject with that person again in the future (Ms B).

"I don't want to do that to my kids. And plus, they've got kids.

So they've still got a life to live" (Ms G)

Many worried about receiving offers from younger persons, feeling that young adults were potentially sacrificing their health and ability to lead a full life by donating. Often offers from younger adults were refused in favour of offers from older adults.

What it feels like to have people offer

For those participants who had received offers of a kidney, most described feeling happy that friends or family had offered to donate, with one participant stating that he felt “chuffed”. Two participants stated it “felt nice”, one further qualifying the offer as “noble”, while another stated they “felt glad”. Another participant described feeling “quite proud”, while other participants stated they felt “lucky” and “humbled”.

“It’s a pretty humbling experience, you know?”

It’s...you get a little bit emotional about it” (Mr F)

For most participants, having offers come forward from family and friends provided a sense of feeling loved. However, while offers touched their hearts, receiving offers could also cause concern, one participant expressing her worry that it appeared that she was valuing some family member’s lives over others if she accepted a donation from her daughters but not her granddaughter. She worried that her granddaughter was too young, and had not had children yet (Ms I). Many participants expressed worry about the perceived risks to their loved ones. One participant cried when she described how it felt to have her daughters offer to donate. She stated it made her feel sad to think that they were offering a part of themselves in order to “fix” her (Ms G).

Barriers to asking

In this section, barriers to asking are described under the following sub-themes:

- Managing risks (donor health risks; financial impact on donor; relationships)
- “I don’t look sick”
- Predetermining suitability
- Limited recruitment opportunities (poor family health; small social circle)
- Waiting for a deceased kidney
- Misinformation

Managing risks

Donor health risks

Most of the participants perceived potential health risks to the donor as a barrier to them proactively asking for a kidney. Several participants stated they had declined offers, reasoning that the person who had offered might need the kidney themselves, or need to donate to their own children or whanau in the future. One participant described several of his whanau offering their kidneys, and then when they had read about all of the testing and the transplant procedure itself, they had become scared about proceeding (Mr L). Another described her son withdrawing an initial offer after considering that his kidney might be needed for his own son in the future (Ms D).

“I wouldn’t be able to cope if something happened to her” (Ms M)

Yet another participant stated that she understood what it was like to feel sick and did not wish this to be inflicted on another person (Ms G). The majority who had turned down offers had turned them down because they perceived the person offering to be too young with a full life ahead of them, especially in the case of offers from the children of participants. Only one participant stated that they understood that there would be no

major health problems following donation (Mr K), while another acknowledged that transplant is major surgery, but the donor can survive with one kidney (Ms B).

“Cause if anything happens to them, I’ll think ‘Oh heck, she’s in that situation because of me’” (Ms I)

Financial impact on donor

Only a few participants raised the issue of financial impact on the donor. One participant stated that once a donor is being worked up, they worried “about the ins-and-outs of it, what their circumstances are” (Mr O). Another worried that because their family was so far away, there were “a hundred practical reasons why you can’t do it”, and went on to name flight costs and loss of income for the donor, then the added burden of looking after, feeding and housing them (Mr C).

Relationships

Some participants worried about altered relationships that might ensue from them asking their loved ones for a kidney. Several stated that they tried to turn their approach into bit of a joke. This approach was not deemed to be particularly successful, as the persons approached had not taken the participants seriously. One gave an example of saying to a friend “Giz your kidney, mate?” and then laughed when their friend laughed (Ms I).

Two participants felt that they would feel more connected with the donor after the transplant, and would need to take great care of the kidney. One of these participants felt the donor would say “you look after that, that’s mine, that’s still mine.” (Mr F). One participant stated that she felt her whanau “tip-toed around” her once they knew she needed a kidney (Ms D), but three other participants felt that their relationships had not been altered at all by family or friends declining to donate.

“I would feel obliged to them forever, really. And then, you know, you’d have to – you’d want to – look after it even more, because it came from a friend. You know. I looked after this one quite well, and it came from a stranger. But, you know, from a friend, you’ve got to be more, sort of...buy-in there” (Mr C)

“I don’t look sick”

Nearly half of the participants talked about the fact that they did not appear sick to others, and that this was a barrier to people knowing, or having some understanding of, what they were going through.

“I’m not a typical dialysis patient, really. I’m not overweight, I’m not diabetic. I look reasonably healthy, you know...I don’t look like a dialysis patient” (Mr C)

Some described going off to dialysis three times per week, or managing their peritoneal dialysis at home at night, and carrying on with work or other commitments. They felt that the people they interacted with had no idea, unless they had seen the participant sick.

“I don’t talk about my sickness. I don’t want everybody to know that I’m sick. A lot of people, they look at me and still think I’m fit as, you know?” (Mr N)

Several also said that people did not see their tiredness, or that they tired easily. One participant stated that because they looked well, then others around them decided that the participant was alright, and that therefore there was apathy towards offering a kidney. Another participant stated that she had difficulty getting people to understand her need for a new kidney because she looked so well to them (Ms B).

*“People see people with kidney failure all the time in the community,
but they may not know that they’re doing dialysis overnight,
or three times a week in the hospital” (Mr F)*

Predetermining suitability

Almost half of the participants discussed incompatible blood group, age (perceptions of a donor being too young, or too old), recreational drug or alcohol use, health concerns or family responsibilities as a reason that they had not asked certain family members or friends for a kidney.

“He wasn’t the right blood type” (Mr A)

The most common factors discussed were age, health and weight, with participants predetermining whether a potential donor might be accepted for workup or not based on their own understanding of what might make for a suitable candidate.

“She’s too young, she’s only 25, or 26 actually. She’s too young, she hasn’t had children, hasn’t travelled. She’s really career-driven. She loves, you know, exercising, and things like that. And so I don’t want her to have to give up a lot of that...just for me” (Ms B)

Several of the participants ran through lists of their siblings citing medical conditions that the participant felt would rule their siblings out as potential donors.

Limited recruitment opportunities

Poor family health

Nearly half of the participants belonged to larger families where chronic medical conditions were common. These families were predominantly Māori. Several participants stated that their siblings all suffered from high blood pressure or diabetes, or that renal disease was commonplace in their family. Some cited high cholesterol or cardiac issues as reasons they had not approached family members.

“I feel lucky, I suppose, that they offered, but then none of them can give me their kidneys, cause they’ve all got some sort of illness” (Ms D)

This subgroup of participants were often the ones who had not asked family for a kidney as they had pre-determined that the health of their whanau would be a barrier. When discussing potential recruits who might have been considered, several participants stated that their wider community of friends and neighbours were distantly related, too. This was especially so in rural or geographically remote locations.

*“We’re a pretty sick bunch out here. You know, we’re all connected –
somewhere along the line we’re all sick.
We’ve all got something wrong with us” (Ms G)*

One participant stated that he had never approached anyone in his mother’s family, because the same problem that caused his renal failure ran in her side of the family (Mr F). Another stated that all of his cousins, first and second, were all descended from the same grandparents, and that those same grandparents had what he has got. Therefore, he had ruled these family members out as potential donors (Mr L).

*“My cousins, first and second, are part of my family, and they all came from the
same grandparents, and the same grandparents have got what I’ve got,
so you know... the pool might be big, but the net’s only small” (Mr L)*

Small social circle

This subgroup was typically NZ European and consisted of three participants. Two participants were geographically isolated from their social network. One of these participants had come from Europe and he felt he only had his wife and children available to him as potential donors. Only one child was of eligible age to donate, but was still under 20 years of age. Childhood friends that could have been approached were now too distant. Newer friends were felt to be more acquaintances than lifelong friends that the participant felt he could have approached (Mr C). The other participant had moved from another remote part of the NZ to a remote part of Hawke’s Bay, and his social circle was limited (Mr H).

“I’ve got my one sister, and like, two cousins, kind of thing” (Ms B)

Another participant was a second generation NZer with only two children, one of whom was under eighteen. Her parents had health issues and two siblings were reluctant to come forward (Ms M).

Waiting for a deceased kidney

Availability

Almost half of the participants discussed availability of deceased kidneys. Several of those participants on the DDL expressed frustration about the limited number of kidneys available, and the growing number of people requiring kidneys on the list.

*“It’s grown faster. I think when I went on the waiting list
there was only 150 on it” (Mr H)*

One participant felt that if he had remained in his country of birth, he would almost certainly have had a kidney transplant by now (Mr C). Another expressed frustration that he had been told several years ago that by the time that he needed dialysis, he would be given a kidney from the DDL. However, the number of patients waiting for a deceased kidney had grown, and despite the fact that his ESRD had been stable for a number of years, he felt he was less likely to receive a kidney. He felt let down and angry with regards to the information he had been given in the early stages of his disease. Because of this advice, he had also not been as proactive with seeking out living donors (Mr H).

Those participants who discussed being registered as an organ donor on one's drivers license also expressed frustration at the low numbers of organs that were actually available to be procured in this manner.

"I think about all these other people dying from crashes, and what's wrong with their kidneys? How come I haven't been rung up to say I've got a kidney?" (Ms D)

Legislation

Several of the participants expressed frustration that NZ does not have an 'opt-out' system of compulsory organ donation for persons who die in circumstances that would allow for deceased organ donation. They mentioned other countries where the opt-out system was working well such as Spain, Germany and Wales, and that these countries had better deceased organ rates as a consequence.

"I reckon the biggest thing we've gotta get under control is how many kidneys that you hear of that are lost all the time, because the patient wants to donate, and the family stop it" (Mr H)

Several participants also raised concern that families were able to override a person's wishes upon death when that person had indicated their wish to be a donor. Those participants that raised this issue universally felt that this was wrong, and that the NZ government should legislate to uphold the wishes of the deceased person, despite family wishes, in order to procure better rates of deceased organ donation.

“See, one law says that the transport department says you can put on your license, but then another law is contradicting itself saying, well, the family can overturn it” (Mr A)

Misinformation

One participant felt that giving a kidney was a major issue, and that the donor suffered more than the receiver. This participant felt that this was common knowledge and the reason that a lot of people get “too scared” to proceed with transplant (Mr E). Another thought that the personality of the donor might be carried through with the donated kidney, and that it wouldn’t be good to have a grumpy person donate (Mr J).

“Well, you have to open up and willingly give it, not be pressured into it, and then you don’t really want to, and then the kidney will just die” (Mr E)

Several participants believed that because their family members lived overseas, that this excluded them from being worked up as donors. Another discussed the fact that they had heard other patients talking in renal clinic waiting rooms about transplant failures and that there had been a lot of misinformation from other patients. Once this participant had talked with renal specialists, their attitude had changed (Mr J).

“A lot of my relations live in Australia now. And I haven’t asked them because I haven’t got there, or they haven’t come home” (Mr L)

Advice to others

This section includes some of the participant's comments with regards to advice that they might give to others who are about to approach friends and family to ask them to donate a kidney. It also includes additional topics that did not fit under the main themes.

Effective recruitment

Most participants stated that empowering themselves with information, and ensuring the potential donor had information was essential to the recruitment process. This involved talking about the process, and also the risks. Almost all of the participants also felt that talking about it either through asking directly, or through telling your story, was important to communicate need. Some participants felt that the whole whanau should be involved – the donor and their family.

“If they don't know what they're getting themselves into, later on they're going to not want to go through with it anyway” (Mr H)

While most agreed that asking was indeed hard, a person needed to have courage, and ask, being prepared for either a yes or no response. If a person did not feel they could do this, then involving family or friends to ask on behalf of the person was a good idea. Social media was seen as a good tool to tell one's story, enabling indirect requests for offers. It was universally felt that requests should be humble, never demanding. One participant stated that the more he asked people the less of a struggle it was. Over time, he had learnt what sort of questions would be asked, so had learned to prepare better answers with practice (Mr J).

Improving Health literacy

Nearly half of the participants felt that knowledge was power, and that through being better informed, they were better able to inform and educate potential donors. It was also generally felt that if recipients were better informed, then they were more likely to convert enquiries into actual workups through being able to answer questions as they arose during the initial conversation.

Several stated that they hadn't wanted to know about their condition earlier on, or that they had been oblivious to others in the family who had renal disease or were on dialysis. One participant stated that she wanted to bury her head in the sand, while another participant stated that they now wished that they had known what their renal disease would escalate into. This was especially apparent where diseases such as polycystic kidneys ran in families.

"Talk about it earlier, and look at it earlier" (Mr O)

Two participants also described how they had delayed their renal failure from progressing towards dialysis through being well informed and trying to manage their dietary intake, medication and weight while in the pre-dialysis stage.

Resources

Participants were generally positive about the LKDA resources that were available, including booklets and video clips on the LKDA website. They stated that the resources were extremely useful for both donors and recipients. Most felt that the language used was accessible, and that the images represented people that they could relate to. One Māori participant was happy to note that "there's a lot of Māori people on there" when talking about the video resources (Mr N).

“One lady was out there fishing, and she had her bag just bloody hooked up over here while she’s having her PD, you know? She actually having it while she’s fishing. You know, I thought that was great. I’d never hop in my togs and go fishing with the bloody thing hanging off me, but yeah!” (Ms G)

Another participant stated that their donor found it “hard to get his head around medical talk”, but that after reading the booklets felt quite confident that he “understood what was going on” (Ms B). This participant also felt that more emphasis should be put living well with one kidney after donation, and “the fact that you’re not actually going to miss out too much in life.”

Two of the participants stated that they had deliberately not read any of the resources by choice. One of these participants felt that information books were “probably not as useful as actually meeting with someone to talk about it” (Ms D). The second of these participants stated that there “was nothing really there that gives guidance” on approaching potential donors (Mr C). Another participant felt that getting potential donors to view the videos might be difficult, and that she doubted it would lead to someone saying yes when you asked for a kidney (Ms G). One donor said that the books had informed his whanau well, but had made them too scared to proceed. Instead of opening up offers to donate, it had “shut them up” (Mr L).

Psycho-social support

A quarter of the participants discussed the need for some form of professional support. Two participants felt that professional support might be useful to help raise the topic of asking for a kidney. Several participants felt that having someone coach recipients in how they could ask would be useful.

*"I think kidney disease is probably the worst disease you can have.
If you've got a heart problem, they go in for surgery straight away and fix it;
anything else, they go in and fix. But a kidney, they just..." (Mr H)*

One participant felt that he had heard some worrying things in clinic waiting rooms, and this made it hard for him to ask friends and family members, but once he had talked with specialist, his viewpoint changed (Mr J).

Media focus

One third of the participants felt that renal disease was the poor relation of the chronic diseases family when it came to media coverage. They stated that cancer and heart disease received lots of attention, but that renal disease was "quiet", one describing it as being "behind closed doors."

*"...cancer and that, they all do it...the Heart Foundation...why not renal?
And actually, renal is actually one of the quietest things, eh?
Kidneys and things, it's the quietest thing of all" (Mr N)*

Several participants talked about the impact that Jonah Lomu's transplant had in raising awareness for living kidney transplants, and that positive media stories, especially with high profile NZers, helped generate discussion about the issue. One participant expanded on the topic of Jonah Lomu's transplant, stating that his death had created fear for her partner that the same thing could happen to her (Ms B). Stories about notable persons

with renal disease or having transplants were seen as equally important in generating conversations about the need for organ donation.

Raising awareness

Several of the participants felt that raising awareness of kidney disease and the need for transplant should be talked about in schools. They thought that talking with kids about renal disease and the correlation of unmanaged diabetes and poor diet was a good message to get across.

“For me it would be classroom presentations at school for senior students, and so that they’re aware that they’ve heard someone talk about donating a kidney, or receiving a kidney, so that in the next ten years, if they have a close family member or friend that’s suffering renal failure, they’ll remember hearing about that, and...removing the fear, I suppose” (Mr K)

Participants also talked about using social media to promote positive stories about transplants on anniversaries of successful transplants. One participant felt that people were better informed than they were perhaps twenty years ago, and that there was a lot more awareness or such things as dialysis now (Mr F).

Shock tactics

A few participants observed that shock tactics are utilised for certain medical conditions, such as photos of diseased lungs, gums and coronary arteries on cigarette packets. One also talked about the healthy food pyramid graphic published by the NZ Heart Foundation (Mr E). They felt that similar initiatives could be used for renal disease awareness and

prevention of diabetes, using items like cardboard milk cartons to advertise health messages.

Another participant discussed television media campaigns for accident and falls prevention, and that similar campaigns could be adopted for preventable medical conditions. One participant felt that film footage of life inside a dialysis unit would provide greater public understanding of both the disease and the need for transplant (Mr A). This related well to another participant's viewpoint that renal disease was seen to be quiet, and that the public had limited understanding and exposure to its presence (Mr N).

Future technologies

One participant had heard about cloning ears, and was excited about the prospect that kidneys might one day be able to be cloned (Mr F). Another participant discussed the possibility of being able to manufacture 3D printed kidneys in the future, doing away with the need for human kidneys to be sourced for transplant (Mr H).

Discussion

Introduction

This research was undertaken to explore the factors influencing decision-making amongst ESRD patients as they consider asking family and friends for a kidney. The aim was to better understand the challenges of asking, or not asking, for a kidney which has important implications for policy makers and health providers at a time when they seek to improve rates of LKD in NZ. The discussion chapter is divided into five sections: the first section examines the main findings, providing a discussion centering on each area and concluding with a brief statement as a summary. The second section considers the implications of these findings, assimilating the main findings into a discussion that explores potential solutions with respect to improving the likelihood of positive responses to requests for a kidney donation. The third section in this chapter explores future directions for research. Following this, the limitations of this research are discussed, while the fifth and final section provides an overall conclusion on this thesis.

Main findings

This study set out to explore why patients with end-stage renal disease choose to ask, or not to ask, family or friends for a kidney. This section discusses the main findings and uses subheadings that group the main themes:

- communicating need (asking or not asking for a kidney, or that of waiting for an offer)
- barriers to asking
- advice to others

It concludes with a summary of the main findings.

Communicating need

The data gathered in this research project indicated that most participants struggled with communicating their need for a kidney, many of the participants refrained from asking

friends and family at all, and even those who were practised at asking for a kidney still admitted that it was difficult for them to approach others to ask them to donate. Some participants who approached friends and family favoured a direct approach, but for those who found it too difficult to approach friends and family directly, many preferred to share their story about their illness rather than ask for a kidney. Participants hoped that this indirect approach might engender offers to donate. Several participants and their families were turning to social media to help them do this, while others had never thought of doing this. Several participants stated that they would never ask a loved one for a kidney, however some agreed that they would accept offers of a kidney donation, while other participants had turned down all offers of a donation, preferring to wait until a deceased kidney became available.

Many participants in this study felt that understanding the transplant process, and what makes for a suitable donor, was important information to have *before* approaching potential donors, as participants stated that being prepared to answer any questions their friends and family might have was an important part of recruitment. Being able to provide information at the time of discussion about the participants need for a kidney means that an opportunity is not lost; whereas if the participant sent friends or family off to independently gather information, the potential donor might forget, or lack motivation to pursue information. Delays in imparting information to a potential donor might also cause apprehension for the participant, and several participants expressed reticence with following up potential donors, as follow up contact could be perceived as coercion, or putting pressure on the potential donor.

The majority of participants who had approached friends and family to ask for a kidney, or wanted to ask but felt that they couldn't, stated that "it's hard to ask", and this finding is consistent with Martin's (2013b) findings in her thesis entitled 'Increasing the rate of living donor kidney transplantation in NZ: developing an evidence base'. Chapter three of Martin's thesis focussed on barriers to transplant, both deceased and living kidney donation, and in this chapter, Martin states that "the general impression was everyone found approaching potential donors difficult" (p. 100). Martin's mixed methods research examined attitudes to LKD by patients who had already been accepted on the DDL. As well as highlighting the multiple barriers patients face, it also provided an overview of

fiscal and legislative constraints to LKD in NZ as told by both patients and health care providers, with view to proposing strategies that might increase rates of LKD in NZ. The contrasting research methods and the close examination of one significant barrier during this thesis project - that being "it's hard to ask" - were the main differences between the studies of Martin and myself. My qualitative research focussed solely on donor recruitment for LKD, in order to specifically examine the experience of the recipient; who, how and why were potential donors approached, and what were their reasons for choosing to approach some persons and not others. Some of the recipients were not eligible to be listed on the DDL, which left LKD as their only transplant option. I wanted to know whether potential donors were being lost to recruitment because recipients struggled to approach others for a kidney, and whether there was a way that health providers could assist recipients with communicating their need for a kidney.

Barriers to asking

Reluctance to accept or ask for a kidney is fashioned by many factors. Barriers from previous research have been identified, and may include lack of confidence or poor self-efficacy, inability or non-willingness to communicate need, fear that their request for a kidney may be declined, or worry that the donor might need to give their kidney to a more 'deserving' family member in the future (Hanson et al., 2015; Pradel et al., 2003; Rodrigue et al., 2014). Other barriers may include poor health literacy of the donor or the recipient (Barnieh et al., 2011; Dageforde et al., 2014). Additionally, patients may worry about relationship changes; that the donated kidney might be rejected; or be concerned about surgical risks or risks to the future health of the donor (de Groot et al., 2012; Gordon, 2001; Pradel et al., 2003; Siegel et al., 2011). Cultural, ethnic or socio-economic factors may also have a bearing on willingness to approach potential donors (Davison & Holley, 2008; Grace et al., 2012; Sieverdes et al., 2015; Waterman et al., 2010).

All of the participants in this research project experienced one or more of these barriers, with the most universally expressed barrier being concern for the health and wellbeing of the potential donors. According to Siegel et al. (2011), recipients typically overestimate the level of discomfort and time that it takes for a donor to recover. Indeed, only two of

the fifteen participants in this study stated that being a kidney donor would not potentially cause long term harm to the donor. Few understood that the donor workup was designed to screen the donor to ensure that they would be considered safe to donate and live with one kidney, indicating that health literacy is a factor that created a potential barrier to asking for a kidney for some participants.

Several of the participants in this study had poor health literacy, with an example being that some participants were surprised to learn that a donor did not have to be a blood relative. Poor health literacy has an impact on decision-making and informed choice, in the ability to weigh up available options, to identify suitable potential donors, and to problem-solve. This finding is similar to other overseas studies that have examined health literacy in communities where living kidney transplant uptake is low (Rodrigue et al., 2014; Skelton et al., 2015; Tamura et al., 2014). The participants in this study who had a good understanding of their renal disease, and what treatment options were available to them, were more likely to discuss ways that they had managed their condition and appeared to take more proactive role in their health management. This is also seen in international studies that examine the correlation between good health literacy and improved transplant uptake (Kucirka et al., 2012; Tamura et al., 2014).

Approaching others to request a kidney donation was a highly emotional experience for several participants in this study, many using words such as worry, anxiety, and sadness when they described their experience of asking or accepting offers. Some participants talked about anticipating rejection and others disclosed how it felt when their request for a kidney had been rejected. Other participants perceived a change in their relationship after a request has been made. Several participants in this study discussed being negatively influenced by waiting room conversations about transplant complications or failures, or that they had been told they wouldn't have to wait long for a transplant from a deceased donor. Others stated that family or friends had negatively influenced their decision-making, or had changed the decision of a potential donor to proceed with workup. This finding was also seen in the study by Smith et al. (2011) where negative feedback about donation within the donors' social networks had caused communication to break down, and the authors recommended training for recipients and donors on effective communication about transplant.

In her thesis examining barriers to transplant in NZ, Martin (2013b) found that patients often perceive asking for a kidney as difficult to do, undermining the 'voluntary' nature of donation and putting pressure on the potential donor (p. 84). Many participants in this study stated that they would prefer to wait for offers rather than ask for a kidney, avoiding the possibility of placing the potential donor in a position of psychological discomfort. The findings in this study also highlighted the fear that several recipients' had that their request might be refused, with several participants describing the effects asking for a kidney had had on their relationships. While the question was not asked during interviews, two of the participants in this study stated that they believed they would have a closer relationship with the donor after transplant. This finding is consistent with research by de Groot et al. (2012) and Gill & Lowes (2008) who state that donors and recipients generally reported a closer relationship after transplantation.

For some recipients in this study, the concept of reciprocity was also an issue; this concept is especially important in Māori culture. The donation of a living kidney from a family member or friend is, for some recipients, too big to be considered a gift, and difficult to accept. Several participants expressed a burden of responsibility when they talked about caring for a living kidney donation, but that the burden did not exist with a deceased kidney, because the person donating was already dead. Two participants talked about the fact that the living kidney could not be given back; it was not like a favour that can be returned at some point. Patients may feel that they have nothing of value that can be given in return to compensate the donor, and no gift that they could give could ever match the generosity of giving back the recipient's quality of life. Māori traditional beliefs are further discussed under the sub-heading *Cultural Support*.

Advice to others

All participants were asked about what advice they may give to other people in similar situations. Interestingly, several participants in this study expressed regret that they had not been aware of ways that they might have slowed progression of their kidney disease to delay dialysis, and only one participant felt that they had done this well. Poor awareness of modifiable health conditions that might lead to kidney disease, such as

diabetes and hypertension, can lead a patient to feel inadequate to self-manage their care, and cause distrust of health professionals, along with loss of confidence and disengagement with pre-dialysis decision-making. Disengagement with health services was a finding also echoed by Walker et al. (2017) who found that “many Maori patients with CKD experienced marginalisation within the NZ healthcare system due to delayed diagnosis” (p. 1), and represents a missed opportunity to engage in preventive care.

Conclusion

When considering whether to approach someone to donate a kidney, the data from this research project demonstrated that participants were not motivated by thoughts of improved health for themselves. This is supported by other international research that suggests that participants are willing to deny themselves improved health outcomes in order to avoid perceived health risks to a donor, feeling an obligation for a ‘gift’ that could not be reciprocated, or guilt should the kidney be rejected (Kranenburg et al., 2005; Pradel et al., 2003; Zimmerman et al., 2006). Reluctance to approach or recruit donors from within the patient’s family or social circle is a barrier to transplant. This is of importance to policy makers because while the aim is to increase LKD rates in NZ, recipients strive to protect their friends and family from perceived potential health risks, and in doing so protect valued relationships. It is also apparent that encouraging patients to consider the possibility of improved health outcomes as a result of transplant is not enough of a motivating factor to override the value that recipients place on the relationship with the donor or the donor’s health.

Implications of the findings

In this section, the main findings of this research are assimilated into a discussion that explores both the implications, and the potential solutions, with respect to improving the likelihood of positive responses to requests for a kidney donation. Subheadings include: health literacy; psychosocial support; relationship management; cultural support; deceased organ donation; consistency on transplant messages; and peer support after engagement.

Health Literacy

Fundamental to understanding the motivations and influences of the recipient as they consider asking someone to donate, is being mindful of the needs of the patient as they make decisions about who they might ask and how they might approach the subject, or whether they might allow others to do this for them. Integral to this decision-making is the existing health literacy of the recipient and their ability to make an informed choice.

An important aspect of ensuring that the patient with ESRD can make informed choices is early engagement with health services. This study showed that early engagement with health professionals was meaningful, with participants who engaged with renal services early in their disease progression demonstrating reasonable understanding of their renal disease and treatment options. Several participants discussed their disease progression in terms of what they learnt along the way, or what they hadn't known but wished they had. The benefits of early interaction with renal health professionals are many. First, early education allows patients time to be exposed to information from a variety of sources (brochures, books and digital) and for this information to be absorbed and understood. Improved recipient health literacy means that the recipient is more likely to make informed decisions, incorporating an understanding of the disease process and treatment options while encompassing personal values and preferences. Early engagement encompassing shared decision-making is associated with improved patient outcomes, such as pre-emptive transplant (Ghahramandi, 2015). Second, early engagement allows patients time to identify persons within their social networks who could potentially

donate a kidney, and to consider possible barriers that might impede transplantation. Early engagement means that there is a higher likelihood of accessing specialist support along with initiation of planned renal replacement therapy and, ideally, pre-emptive transplant (Martin, 2013b).

Another important factor in relation to recipient education is willingness to approach donors. The literature review found research demonstrating that there is a correlation between low rates of offers to donate and recipients failing to discuss living donation with friends and family (Barnieh et al., 2011; Rodrigue et al., 2014; Weng et al., 2010), and this research project identifies similar findings. Participants in this study who chose not to talk with family or friends about their need for a kidney, or had turned down offers, were invariably (or by choice) waiting for a deceased kidney donation. Those participants who were actively engaged in talking about transplant were more likely to have living donors being worked up. These findings imply that talking about transplant might result in higher transplant numbers, and suggests that some patients may need support in the form of tailored education strategies to assist them to talk about their need for a kidney (Pradel, et al., 2009; Skelton et al., 2015; Waterman et al., 2010).

In support of tailored education strategies, Skelton et al. (2015) proposed that best practice for education programmes for ESRD patients should be (1) individually tailored, (2) understandable for patients with low health literacy, (3) culturally competent, and (4) helpful in showing patients how to navigate the complex healthcare process. They state that “transplant education needs to be clear, comprehensive, understandable and motivating” in order to facilitate patients to successfully “complete the clinical steps necessary to be evaluated for transplant” (p. 78). This best practice should be incorporated into every encounter with recipients and their potential donors. My research demonstrated a wide range of health literacy within the sample population, suggesting a need to tailor education to meet the needs of the individual, providing information for those who have little knowledge about transplant, and dispelling any misinformation that patients might have been exposed to during their decline into ESRD, thus helping the patients to navigate their options in an informed way.

Tailored support for patients, such as that which could have been useful to several participants in this study, can be offered through providing education on ways that recipients might approach donors, and reinforcing information that the recipient needs to know to be able to answer questions that might arise in response to the approach. Strategies such as role playing could be offered, exploring different approaches to ask for a kidney. While asking others for a kidney donation might continue to be difficult, through improving the recipient's health literacy and knowledge the recipient might be better prepared to answer the type of questions that could arise. Failing that, the donor coordinator or educator could provide support to the recipient by facilitating home-based family/whanau meetings to provide information about the transplant process and workup, and answer questions that arise. If the patient is comfortable with family members or friends being present in clinical or education sessions, this is also a valuable way of introducing the concept of transplant as a treatment option, without the patient needing to initiate a direct request for a donation. Addressing health literacy for patients with ESRD is an important issue, because the findings in this study indicate that recipients find it difficult to approach potential donors. This creates a barrier to transplant, and has implications for policy makers and health providers at a time when NZ is seeking to improve rates of LKD.

Psychosocial support

This study found that many participants would like more support with the act of approaching or engaging with potential donors (i.e. the 'donor' conversation). The majority of participants in this study tended to be more comfortable with *accepting offers* of donations than with initiating discussions about donation with their loved ones, and this is consistent with other research (Martin, 2013b; Siegel et al., 2011; Skelton et al., 2015). However, if a patient does not disclose that they need a kidney, many potential donors may not even know that a kidney is needed. For those patients who prefer an indirect approach, or those who have poor self-advocacy, confidence, or communication skills, assistance with finding ways to talk about their condition or their need for a kidney should be given. For those with poor literacy skills, assistance with wording a social media

post might assist. Several of the participants in this study had written their own donor requests on Facebook; there are some generic templates available internationally which patients or their family can access to frame a donation request on social media. A similar template could be developed for NZ patients, and perhaps translated into a variety of languages to assist patients from different ethnic or cultural backgrounds.

It is also important for health professionals to revisit the transplant conversation with the patient at different points of their journey to see whether their situation or viewpoint might have altered, understanding that preferences can change with time. Several participants in this study stated that they were not willing to consider LKD, and yet when asked what might make them reconsider this stance, some flexibility was evident. A recipient who is reluctant to discuss transplant at the beginning of their ESRD journey might change their mind further down the track when health or social circumstances change.

Many participants in this research project stated that they felt nervous, anxious, or shy when it came to approaching friends or family to ask for a kidney. By gaining knowledge of what is involved with both workup and the transplant operation, the recipient may feel greater confidence in their ability to answer questions that the potential donor may have. Gaining knowledge may help a recipient with low self-efficacy, or belief that they have the ability to pursue LKD. Reese et al. (2009) proposed that intensive education alone does not influence living kidney donation rates, but that interventions should target greater self-efficacy for recipients looking to recruit a donor. A patient may have great health literacy and accurate information, but if they are too reticent to approach others to ask for a kidney because they feel their life has less value than the persons that they might approach, then the information serves little purpose.

Participants in this project identified several barriers, such as struggling to accept offers from loved ones because of perceived health risks, struggling to revisit an offer that had been made years earlier, or refusing to ask family members for a kidney because family don't offer first. Some participants displayed distress when recounting their efforts to approach others, while others were saddened by the lack of offers to donate. Several of the participants interviewed may have benefitted from psychology input. However, the

psychosocial support that is offered to recipients in NZ is variable, and is largely dependent on the resources available at each DHB. Some recipients may not have access to a psychologist or social worker until they and their donor have been worked up for transplant. Moreover, there is no formal screening process that examines unmet psychosocial needs for recipients before they approach donors. In NZ, some transplanting centres require recipients and donors to be assessed by a psychologist prior to transplant, but not all. Furthermore, not all DHBs employ renal psychologists to assess the transplant candidates. If all DHBs employed dedicated renal psychologists, then recipients could have skilled support to address issues, such as relationship tensions or guilt that may act as barriers to transplant at any stage of their journey (Hanson et al., 2015). If psychological support was available to all recipients, such issues could be addressed by a skilled professional who could reflect the participants fears back to them in order for the participant to perhaps consider a different viewpoint.

Another benefit to offering all potential recipients the opportunity to talk with a psychologist before they approach potential donors is that the psychologist can gauge whether the recipient is willing to consider LKD at all, how confident they are with broaching the subject with their networks, and their understanding of what is required of them post-transplant. The patient may have sat with a nephrologist and been encouraged to think about potential donors within their networks but, ultimately, not want to commit to this journey. In recent research examining renal patients' motivation to pursue living donor kidney transplant (LDKT), Waterman et al. (2015) argued that:

Having the ability to accurately assess individual patients' readiness to pursue LDKT, weighing the risks and benefits of LDKT, and confidence in their own ability to find a living donor is very important. (p. 211)

In order to assess the recipient's motivation and willingness to pursue transplant, a screening tool could be developed; at present, no such tools exist for the purpose of examining the health literacy of recipients. Suggestions to develop screening tools to assess health literacy (Dageforde et al., 2014) and self-efficacy (Reese et al., 2009) have been advocated in other research. However, the tool could be used to assess many factors, including health literacy, emotional wellbeing, self-efficacy, cultural and spiritual

beliefs, and attitudes towards transplant that might hinder progression to a successful transplant. Screening results could be used by both the transplant coordinator to help tailor resources and information for the recipient, but also by the renal service psychologist and social worker who could meet with the patient to discuss any psycho-social concerns. The tool could also have inbuilt algorithms that flag the need for community, peer, spiritual or cultural supports. For those patients who identify health literacy needs or communication barriers, a tailored support plan could be developed in partnership with the patient, including an action plan that may address who the patient might approach to ask for a kidney donation, how they might approach the subject, and what they might say. Coaching and support in the form of role play could also be offered, with renal health professionals coaching the patient's approach and rehearsing different ways to start a conversation about transplant. Implementing a screening tool early in the eligibility assessment of the recipient could identify barriers that might delay or hinder the patient from progressing towards transplant. Through identifying barriers and providing early support from a renal psychologist or social worker, psycho-social barriers could be addressed.

Relationship management

Almost all of the participants in this study stated that LKD should be voluntary, not an obligation, indicating that it was unethical to put pressure on a donor, or make them feel obligated to go ahead with surgery that they may not have wanted, but felt obligated to proceed with. This finding is consistent with Gordon's (2001) research that explored the differences between asking for a kidney and voluntary offers to donate organs.

The opportunity for recipients to discuss interpersonal dynamics with trained professionals such as a psychologist prior to approaching friends or family might address some of the concerns the recipient might have about perceived changes to relationships, while preparing recipients emotionally for what lies ahead, including the possibility of setbacks. Most participants in this study voiced concerns for the health and wellbeing of their loved ones with regards to surgery, but many also worried that the donor might need two kidneys in the future, or need to give a kidney to another family member, such

as a child. The age of the potential donor and their relationship to the recipient also had an influence on the recipient's decision to accept or decline an offer to donate. For some, accepting the gift of a kidney came with a degree of guilt for the recipient of the gift. There were also concerns voiced that accepting the gift might place a sense of obligation towards the donor.

Finally, transplant professionals need to consider the importance of relationships, and might consider placing more emphasis on the potential positive benefits to relationships as a result of organ donation. This may, in turn, encourage the patient to pursue LKD, and support the growth of kidney donation in NZ.

Cultural Support

For the purposes of this discussion, I have chosen to focus on Māori culture with regards to exploring the concept of cultural support, as Māori were the dominant ethnicity within the sample population, with this population reflecting the dominance of Māori patients being treated within the researcher's DHB renal service. Māori also dominate the DDL, with many of the Māori participants in this study having fewer available options to recruit donors from their whanau, due to co-morbidities within their families.

The NZ Public Health and Disability Act (2000) legislates that health providers recognise the principles of the Treaty of Waitangi (1840) in their decision-making and priority setting. Because of the Treaty and health disparities, NZ's Ministry of Health afford Māori greater funded supports that are not afforded other non-indigenous groups, such as funded GP visits, or home-based personal care being available 10 years earlier for Māori than non-Māori (Durie, 2003). Despite these supports, health disparities are significant for Māori. According to statistics from Te Puni Kokiri (1999), Māori are four times more likely to die from renal disease than non-Māori, and are more likely to need kidney donations than non-Māori, while according to Walker et al. (2017), Māori are 3.5 times more likely than NZ Europeans to start dialysis as their primary treatment for ESRD, and have a very low likelihood of receiving pre-emptive kidney transplantation or home-based dialysis.

Such figures are consistent with the experience of the researcher in her DHB, and likely reflect potential outcomes for the participants in this study.

In 2014 there were 138 kidney transplants in NZ. Those recipients who identified as Māori numbered 22 patients, or 15.9% (ANZDATA, 2016). However, if all 1628 functioning kidney transplants across all ethnicities in NZ up until 31 Dec 2014 are considered, 158 recipients identified as Māori, which is 9.7% of the total recipient population in NZ (ANZDATA, 2016). In 2014, Māori recipients numbered 15.9% of all kidney transplants. This represents a shift in the numbers of Māori accepting transplants, and may signal a shift in attitudes towards organ donation. No cultural viewpoint is uniform, and beliefs are seldom static, but it is never the less important to reflect on historical beliefs which are an important aspect on NZ Māori culture.

Spirituality is viewed by many Māori as an essential aspect of their health. Traditional values maintain the spiritual importance at death of burying a body complete in order to return life to Papatuanuku (Lewis & Pickering, 2003). However Māori participants in this study invariably agreed that there was a need for organ donation, and that traditional attitudes are changing. Indeed, of the six participants in this study who identified as Māori, three of the participants stated that cultural traditions were not the reason that they had chosen to decline offers of a kidney. For these participants, they were doubtful that anyone within their whanau would be medically suitable to donate, or they did not want their loved ones to donate. Another two participants, who were actively asking and would accept offers of a kidney, also stated that they had no-one in their family who would be a suitable donor. Only one participant stated that she could not accept a living kidney donor due to traditional Māori values, LKD contravening the spiritual necessity of dying with the body intact, but that she would accept an offer of a deceased kidney.

As well as talking about their spiritual values, the Māori participants in this study also discussed whanau in relation to their discussing their treatment options. One participant in this research stated that whanau should always be involved in decision-making about transplant, and most of the Māori participants interviewed stated that whanau meetings or hui were the most appropriate way to address transplant education. This view is consistent with Beechey's (2012) view that health for Māori is a whanau (rather than an

individual) concern (p. 55), while Durie (1985) states that within Māoridom, the whanau remains the major support system, and that 'full appreciation of health requires an understanding of a particular culture, rather than an assumption that health principles are equally relevant to all situations' (p. 483). This finding is further strengthened in the research article by Walker et al. (2017), where thirteen Māori patients with ESRD were interviewed. The participants valued including whanau in their early care and decision-making, and where patients had their families actively involved both care and decision-making, there appeared to be better understanding and support. Walker's (2017) research is congruent with my research where participants highlighted the need for greater whanau-focussed education and opportunities for informed choice with regards to transplant options.

Deceased organ donation

Deceased organ donation was a topic brought up by many participants in this study. In NZ in 1994, 80% of all transplants were from deceased donors. With the spotlight now focussed on increasing LKD rates in NZ, the number of living kidney transplants has grown. In 2015, there were 147 kidney transplants in NZ: 73 were deceased donations, and 74 were live donor transplants (ANZDATA, 2017). While NZ's transplant figures are basically an even split between DDL and LKD, some countries have been actively increasing the rate of deceased organ and tissue donation in the last five years. This came about following a joint initiative between governments and professional organisations called the Resolution of Madrid (2010) that challenged countries to aim for self-sufficiency through increasing organ donation activity, while attempting to reduce the burden of end-stage organ failure. Legislation reforms, provision of appropriate healthcare infrastructure and workforce, and engendering a progressive approach to organ donation within those societies have all had an impact (Australian Government Organ & Tissue Authority, 2016). Countries that have increased their rate of deceased organ donation include Spain, Portugal, Croatia, Australia and the United Kingdom. A common factor to their success in raising deceased organ donation rates is that they have utilised champions within Intensive Care settings; doctors and nurses who are skilled at

talking with families about organ donation upon death, and how this benefits others by giving new life, or quality of life. Another factor is that there have been positive media campaigns featuring high profile transplantations, and highlighting awareness of organ and tissue donation.

In this study, there was a general perception that if a person is registered as an organ donor on their drivers' licence, then those organs should be available for distribution on death; however there was a poor understanding of the limited circumstances whereby this might happen. Some voiced frustration that although people might have 'organ donor' printed on their drivers' licence, the organs may not be removed upon death. These participants were generally those who felt that a deceased kidney was the only option available to them, participants with limited recruitment options as is the case where there are genetic predispositions in a family, and those who culturally or ethically reject living kidney donation as an option. In order to help those who do not have access to suitable living donors, deceased kidney donation fulfils a need. The participants in this study generally also had little knowledge of the circumstances whereby organs could be harvested. It is evident that there is a need to educate the wider public regarding procurement of deceased organs in the event of accidental death or brain injury. These findings were similar to recent NZ research by Cornwall et al. (2015) that highlighted university students' limited understanding of the circumstances in which deceased organ donation could occur.

While it is generally agreed that NZ has a shortage of available organs from deceased donors, debate continues about developing a consent register in NZ as advocated by GiveLife NZ (2016), or following international leads in adopting an opt-out system, where organ donation will occur automatically unless a specific request is made, before death, for organs not to be taken (McIntosh, 2014). Additionally, campaigns that raise awareness of the need, or that encourage people to talk with loved ones about their wishes to donate should they die in circumstances that might mean they could donate their organs, are tactics that could be employed. In NZ, such campaigns could be guided by ODNZ, the aim being to get people talking about organ donation in general, with anticipated improvement in the rates of both LKD and deceased donation in NZ.

Consistency in transplant messages

Participants in this study discussed accessing transplant information from websites and from printed resources. As patients' access information from different sources, using a wide range of media to reach patients and their potential donors is important. Support groups and blogs may provide information for patients, but may not always carry consistent messages about transplant. Negative transplant experiences within a family/whanau may also have a discouraging effect on the patient with ESRD who has transplant offered as a treatment option. Indecision about whether to progress with transplant options, or fears about surgical risks for both recipient and the donor, can arise when the information provided across different sources is inconsistent, or a poor outcome is sensationalised. Consistency in the use of language and positive messages is desirable when seeking to increase enquiries about living kidney donation.

In the community, patients with ESRD ideally receive early assessment and are given information about treatment options from their nephrologist, transplant coordinator, pre-dialysis nurse, or other renal health professional. Just as important, however, is that primary health care providers such as GPs and practice nurses are well informed with regards to living kidney transplant being the 'gold standard' option for those who meet criteria in order to deliver a consistent message about transplantation and the processes involved. This would alleviate some of the confusion about transplant processes that was evident in participants in this study. Primary health care providers should be made aware of the benefits that having a living kidney transplant can bring to a recipient. Community health professionals could be asking their patients to start thinking earlier about possible potential donors and, more importantly, to make timely referrals to the renal team.

Another important facet of ensuring consistency in transplant messages is making sure that health professionals who work in smaller referring centres have access to current practices and information. This could happen through maintaining effective channels for communication with larger centres, provision of funded study days, educational meetings or teleconferencing to assist in maintaining accuracy in transplant information and processes. This keeps the conversations about transplant in the forefront of clinicians' minds when considering renal replacement options and, according to Martin (2013b),

sharing best practice strengthens the common goal of increasing rates of LKD in NZ (p. 253-256).

A simple strategy used at HBDHB is that the clinician discusses transplant options with the patient during renal clinic, also identifying whether the patient is suitable for LKD and if they are accepted for listing on the DDL, or have LKD as their only option. All clinic letters to the patient's GP (which are copied to the patient) also state the patient's transplant status. If the patient's family/whanau is present during clinic, they also hear about the benefits of transplant to the patient. However, if the patient's family is not present at the clinic visit, they might enquire about the transplant status on reading the clinic letter, and this might initiate a conversation about transplant. Although a search of literature found no NZ guidelines or references to support this strategy, personal communication with clinicians indicates that this is clinical or anecdotal best practice (C. Hutchison, Nephrologist, personal communication, May 23, 2017; A. McNally & N. Cross, Nephrologists, personal communication, June 6, 2017). Further research centred on this strategy is required to confirm its potential usefulness.

It is also important that there is congruence in the messages that health professionals impart regarding living kidney donation in order to provide consistent support to the recipient and hopefully lead to a successful transplant for the recipient. In international research, Gordon's (2001) study demonstrated that transplant professionals' opinions and attitudes influenced the uptake of living kidney donations, and that positive opinions lead to positive results (p. 256), while in NZ, Martin (2013b) found that 'positive attitudes are more likely in nephrologists who are younger, have been in practice for less than ten years, work in transplantation rather than dialysis, and work in larger urban renal centres' (p. 51). Finally, health professionals need to understand the potential benefits of LKD for their patients in order that they can feel comfortable with initiating a conversation about transplant, as talking positively about the benefits of transplant with their patient might be the first step for the patient in talking with their family/whanau about LKD.

Peer support after engagement

Several participants stated that it would be good to talk with people who had previously received a transplant. Studies have reflected on the benefits of peer support (Ghahramani, 2015; Hughes et al., 2009), but these studies examined peer support between the donor and potential donor; there is scant research that examines the value of peer engagement between recipients. Having someone to talk with who might understand the recipient's concerns, and allay specific anxieties, may help to build confidence and reassure the recipient as they make treatment decisions. This is congruent with Walker et al. (2017), whose research into the experiences of Māori patients with ESRD concludes that "potential areas for development and evaluation include enhancing peer support and health literacy" (p. 7).

Talking with a person who has previously donated could also be of benefit to a recipient who is worried about the health outcomes for a donor. It might reassure patients who have heard of failed transplants or complications arising from surgery, or who have preconceived ideas about LKD that hold them back from being open minded about live transplant. Peer support for donors was established by the LKDA scheme several years ago and administered under the umbrella of the Auckland Kidney Society, but unfortunately, the peer support programme no longer exists. Rather, DHBs are arranging informal peer support for potential donors, asking previous donors who are willing to make contact with those potential donors who indicate that they would like to talk with someone. A similar informal scheme could be taken up by each DHB for recipient peer support. Such meetings between persons who have experienced transplant and patients who wish to have first-hand information about the transplant experience are valuable. Meetings may take place between individuals in a home setting, or in a group meeting such as a hui, or patient support group, or education session. Ultimately, through providing peer support to recipients as well as donors, the recipient may be better informed to make a decision to proceed with living kidney donation.

Future directions for research

Reflecting on the findings from this study, it would be logical to examine what research might be considered following on from this project. In order to determine whether a screening tool would be useful to examine willingness and motivation to proceed with LKD as well as identify potential barriers, such as health literacy, a systematic review might explore whether tools have been developed in other centres. Their effectiveness and limitations could be evaluated, and a draft screening tool that has relevance to NZ patients could then be developed, then trialled in a single-centre pilot study. Development of a screening tool also has implications in the development of tailored education strategies.

Research that examines use of psychologists attached to renal services could also be reviewed. It would be interesting to explore whether psychological support given to recipients assists them with donor recruitment and results in greater numbers of potential donors being approached. In addition, there is no NZ evidence that provides clinicians with best practice regarding written communication with patients and GPs about transplant modality. Research into the practices of clinicians around NZ might help to formulate a best practice guideline.

There is also scant research available on the effect of peer support for recipients, with most research focussed on providing support for donors. A pilot programme might be designed that provides peer support for recipients from those who have already received a kidney, with view to supporting the recipient as they approach potential donors.

Finally, in an effort to improve health outcomes for Maori, more research could be conducted into what Maori patients deem culturally competent approaches to LKD education and support.

Limitations

There were several limitations to this small study. Only a small number of participants were interviewed (n=15), however as this project was a 90-point research thesis there were resource and time constraints, and it was not possible to have a higher number of participants. It is also possible there was some selection bias with participants; being employed by the HBDHB as a donor liaison coordinator, and prior to that, a haemodialysis nurse, many participants were known to me, however some were met for the first time at interview. Having a dual role as a renal services nurse and interviewer was identified on the Participant Information Sheet (Appendix E) so that participants were made fully aware of who would be conducting the interviews in order to alleviate any surprise and potential discomfort for participants.

The sample population were all directly involved in transplant as ESRD patients registered with the HBDHB Renal Service. In this regard, they were a homogenous group that reflected the renal population awaiting transplant in one geographical region of NZ. However, within this sample population there were subgroups. The first sub-group had living kidney donors currently being worked up; the second sub-group were patients who were active on the deceased kidney donation list, and this sub-group could be further divided into those with, or without, living donors being worked up. There were no interviews conducted with patients who *might* have been eligible to receive a kidney, but who weren't on the DDL *and* had no living kidney donors being actively worked up. While the sample population reflected the HBDHB renal population demographically, this has the potential to be perceived as introducing an element of selection bias. However, having a demographically transferable sample group ensured generalisability to the wider population with ESRD within our renal service, and certain trends might be generalisable to other NZ regions such as Northland, who have similar renal population demographics to Hawke's Bay.

Conclusion

This is the first study in NZ where the sole focus was to examine the decision-making of patients with ESRD as they seek to recruit living kidney donors or wait for offers of a kidney donation. All of the patients in this study either stated that it was hard to ask family or friends for a kidney donation, or described difficulty with asking, many stating that 'it's hard to ask'. In an age where LKD is encouraged as the gold standard for renal replacement therapy, it is important to identify barriers to transplant in order for health services to attempt to address those barriers. For many patients, being expected to recruit kidney donors is a barrier in itself. Almost half of the participants in this study had never asked anyone to donate due to concerns for the health and wellbeing of the loved ones, or limited potential donors available in their social networks, or due to poor communication skills, health literacy, or self-efficacy.

Some patients are lucky enough to receive offers when they are diagnosed with renal disease, and sometimes those offers will result in a transplant. However, many of the renal patients in this study had relatives who were well intentioned, but were ineligible to donate due to chronic health conditions. Many of the Māori participants in this study were from large families, but because co-morbidities are a prevalent finding in Māori health, just as they are in other indigenous cultures, they struggled to identify suitable donors.

Support was a key theme identified by many participants, with almost all desiring more support in order to be able to approach potential donors. Some participants were distressed at not being able to find a suitable donor, while others were distressed thinking they might cause harm to a loved one by accepting a kidney. This suggests that counselling, cultural or spiritual support should be available to recipients. In addition, patients felt that having accurate information about the transplant process *before* they approach potential donors was paramount, in order to be prepared to answer questions as they approached others to ask for a kidney. Findings from this research therefore indicate that psychosocial support could be routinely offered to all recipients, ideally before the patient has approached any potential donor, addressing concerns such as self-efficacy, reciprocity, and relationship management, as well as providing skilled

counselling for depression or negative quality of life, or distress that may arise as the result of being diagnosed with a chronic, life-limiting disease. Development of a screening tool to assess specific recipient needs is recommended, and further NZ-centred research is required to determine how such a tool can be developed to best serve NZs unique cultural and ethnic profile.

Māori patients in this study stressed that there was a need to involve whanau in decision-making when it comes to treatment options, and this is congruent with other NZ research (Durie, 1985; Walker et al., 2017). More research into streamlining care pathways for Māori may support more Māori to choose transplant options. Māori face significant disparities in LKD transplant with low likelihood of receiving pre-emptive kidney transplantation (Walker et al., 2017). Further investigation examining whether this is because the recipient has not approached whanau regarding transplant, or whether there is a challenge in conversion rates from starting donor workup through to successful transplant might give an indication of challenges many Māori face in recruiting suitable donors.

With the increasing use of social media sites, such as Facebook, some patients and their families in this study were turning to such sites in an attempt to recruit donors. Potential areas for development might include development of sample social media templates sharing the patient's story and providing information about how to make contact with the patient's donor coordinator. These could be developed in a variety of languages and be able to be customised according to the patient's needs.

Revisiting the transplant conversation regularly throughout the patient journey is important, as attitudes towards transplant and circumstances can change. Ensuring transplant eligibility is included on clinical letters to the patients and their GP helps to consolidate the transplant option. Educating GPs about the benefits of transplant and early referral to renal services, as well as up-skilling clinicians working in smaller referring centres, helps ensure clinicians have current/best practice information. Gordon's (2011) study demonstrated that transplant professionals' opinions and attitudes influenced the uptake of living kidney donations. She found that positive opinions lead to positive results, while Martin (2013b) stated that talking about transplant generally results in

higher transplant numbers. These statements do not solely relate to patients and their families, but highlight the need for positive media stories about organ donation, and also the need for health professionals to communicate similar positive messages. Conversations regarding positive outcomes for patients between transplanting centres, renal service staff, general practitioners and community health workers are also important, as a positive culture between health professionals leads to congruent messages being relayed to the patient.

Campaigns that raise awareness of the need for organs, or that encourage people to talk with their families about their wishes to donate in the event of death, are important for keeping the donation topic alive. There is generally a poor understanding of the circumstances whereby organs can be procured in the event of death in NZ, and more work needs to be done to educate the public. Internationally, the use of Intensive Care champions in organ donation has seen a rise in the rates of deceased organ donation, and greater support for this initiative could be provided to each hospital in NZ.

Lastly, some patients may never pursue, or be successful in, recruiting live donors. Until artificial kidneys can be grown in a petri dish or 3D printed, there will continue to be a need for deceased kidney donations. Where organ transplant conversations are promoted, the rates of transplantation have been seen to increase (Australian Government Organ & Tissue Authority, 2016). Talking about transplant and keeping the media focus on positive stories, helps both living and deceased donation rates as families discuss their viewpoints on organ donation research that evaluates the effectiveness of media or public education campaigns would be useful. Increasing public understanding about how donation benefits recipients lives may lead donors to feel more comfortable with donation as an acceptable way to help those in need and may make the task of trying to recruit donors easier for recipients who find that it's hard to ask.

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Appendices

Appendix A	HDEC approval
Appendix B	Hawke's Bay DHB locality approval
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Appendix I	Hardware / Software

Appendix A – HDEC approval



Health and Disability Ethics Committees

Ministry of Health
Freyberg Building
20 Aitken Street
PO Box 5013
Wellington
6011

0800 4 ETHICS
hdccs@moh.govt.nz

21 March 2016

Ms Merryn Jones
5 Haumoana Rd
Haumoana
Hastings 4102

Dear Ms Jones

Re:	Ethics ref:	16/NTB/3
	Study title:	Examining the factors influencing decision-making amongst End-Stage Renal Disease (ESRD) patients considering asking family and friends for a kidney

I am pleased to advise that this application has been approved by the Northern B Health and Disability Ethics Committee. This decision was made through the HDEC-Expedited Review pathway.

Conditions of HDEC approval

HDEC approval for this study is subject to the following conditions being met prior to the commencement of the study in New Zealand. It is your responsibility, and that of the study's sponsor, to ensure that these conditions are met. No further review by the Northern B Health and Disability Ethics Committee is required.

Standard conditions:

1. Before the study commences at any locality in New Zealand, all relevant regulatory approvals must be obtained.
2. Before the study commences at a given locality in New Zealand, it must be authorised by that locality in Online Forms. Locality authorisation confirms that the locality is suitable for the safe and effective conduct of the study, and that local research governance issues have been addressed.

After HDEC review

Please refer to the *Standard Operating Procedures for Health and Disability Ethics Committees* (available on www.ethics.health.govt.nz) for HDEC requirements relating to amendments and other post-approval processes.

Your next progress report is due by 20 March 2017.

Participant access to ACC

The Northern B Health and Disability Ethics Committee is satisfied that your study is not a clinical trial that is to be conducted principally for the benefit of the manufacturer or distributor of the medicine or item being trialled. Participants injured as a result of treatment received as part of your study may therefore be eligible for publicly-funded compensation through the Accident Compensation Corporation (ACC).

Please don't hesitate to contact the HDEC secretariat for further information. We wish you all the best for your study.

Yours sincerely,



Kate O'Connor
Chairperson
Northern B Health and Disability Ethics Committee

Encl: appendix A: documents submitted
appendix B: statement of compliance and list of members

Appendix A
Documents submitted

<i>Document</i>	<i>Version</i>	<i>Date</i>
PIS/CF: PIS	1	06 January 2016
PIS/CF: Consent Form	1	06 January 2016
Covering Letter: Introduction Letter	1	06 January 2016
CV for CI: CV for Meryn Jones	1	06 January 2016
Protocol: Research Proposal	1	06 January 2016
CVs for other Investigators: CV Jon Cornwall	1	06 January 2016
Evidence of scientific review: Research proposal, including literature review & background. Proposal has been accepted by the Vic Uni GSNMH research committee in Nov 2015	1	06 January 2016
Evidence of scientific review		
PIS/CF: Updated consent form using HDEC template	Consent Form V3	09 March 2016
Protocol	Appendix 1 - working Safely in the Community	09 March 2016
Evidence of scientific review	Appendix 2 - Peer Review Dr Hutchison	09 March 2016
Evidence of scientific review	Appendix 3 - Peer Review Dr McNally	09 March 2016
Protocol	Appendix 4 - Interview Guide	09 March 2016
Covering Letter: Response letter to HDEC re: provisional approval dated 21 Jan 16, responding point by point to each item raised	Provisional Approval Response	09 March 2016
HBDHB Locality approval letter	Institutional Approval	09 March 2016
Updated Research Proposal Final	V2	09 March 2016
Covering Letter	Introduction Letter V2	09 March 2016
Response letter to HDEC re: provisional approval dated 21 Jan 16, responding point by point to each item raised	HDEC Review Response Letter	09 March 2016
Approval for research proposal from Maori Health Unit at HBDHB	Maori Health Approval	09 March 2016
PIS/CF	Participant Information Sheet V3	09 March 2016

Appendix B
Statement of compliance and list of members

Statement of compliance

The Northern B Health and Disability Ethics Committee:

- is constituted in accordance with its Terms of Reference
- operates in accordance with the *Standard Operating Procedures for Health and Disability Ethics Committees*, and with the principles of international good clinical practice (GCP)
- is approved by the Health Research Council of New Zealand's Ethics Committee for the purposes of section 25(1)(c) of the Health Research Council Act 1990
- is registered (number 00008715) with the US Department of Health and Human Services' Office for Human Research Protection (OHRP).

List of members

Name	Category	Appointed	Term Expires
Mrs Malaga Erick	Lay (consumer/community perspectives)	01/07/2016	01/07/2018
Mr John Hancock	Lay (the law)	14/12/2015	14/12/2018
Mrs Phyllis Hutema	Lay (consumer/community perspectives)	19/05/2014	19/05/2017
Dr Nora Lynch	Non-lay (health/disability service provision)	24/07/2015	24/07/2018
Miss Tangihare Meclarlane	Lay (consumer/community perspectives)	19/05/2014	19/05/2017
Mrs Kate O'Connor	Lay (ethical/moral reasoning)	01/07/2012	01/07/2018
Mrs Stephanie Pollard	Non-lay (Intervention studies)	01/07/2015	01/07/2018
Mrs Loesa Russell	Non-lay (Intervention studies), Non-lay (observational studies)	14/12/2015	14/12/2018

Unless members resign, vacate or are removed from their office, every member of HDEC shall continue in office until their successor comes into office (HDEC Terms of Reference)

<http://www.ethics.health.govt.nz>

Appendix B – Hawke’s Bay DHB locality approval

Health Services



26 February 2016

Institutional Approval

Merryn Jones
Living Kidney Donor Coordinator
Renal Service
c/- Ballantyne House
HB Hospital
Hawke's Bay District Health Board

Dear Merryn

RE: Hawke's Bay District Health Board Research Application - Reference 16/02/229

Thank you for your application to conduct research within the Hawke's Bay District Health Board. The Research Office has had the opportunity to review your study and has given approval for your research project to be conducted within HBDHB. This approval has also been completed via the Health & Disability Ethics Committee on-line form process.

This Institutional Approval is dependent on the Research Office having up-to-date information and documentation relating to your research and being kept informed of any changes to your study.

It is your responsibility to ensure you have kept Ethical Committees (as required) and the Research Office up to date and have the appropriate approvals. HBDHB approval may be withdrawn for your study if you do not keep the Research Office informed of the following:

- Any amendment to study documentation
- Study completion, suspension or cancellation

Conclusion of your Research

At the conclusion of your research you will be required to provide a written report of your research findings to the HBDHB Research Office.

Should you have any queries during your research, please do not hesitate to contact me during normal working hours.

Regards



Sally Houlston RN, BN, MN
Nurse Consultant Workforce Development
On behalf of the
HBDHB Research Office and Chief Medical Officer

RESEARCH OFFICE
Hawke's Bay District Health Board
Private Bag 9014, Hastings, New Zealand
Telephone: 06 878 8109 Extn: 4505 Email: research@hbdhb.govt.nz

Appendix C – Maori Health Services (HBDHB) approval



Wednesday 10th February 2016

Tēnā Koe Merryn,

RE: **Ethics ref:** **16/NTB/3**
Study title: Examining the factors influencing decision-making amongst
End-Stage Renal Disease (ESRD) patients considering asking
family and friends for a kidney

Thank you for the opportunity to review your application for the above clinical research trial.

The Maori Health Service is happy to support the research above. If you require any assistance in regards to engagement with Maori participants, then please contact Denal Meihana, Service Manager Maori Health Service on (06) 878 1654 extn: 2887.

We look forward to receiving a copy of your research findings.

Noho ora mai rā



Denal Meihana
Kaiwhakahaere
Māori Health Services
Hawke's Bay Hospital

Document

Appendix D - Graduate School of Nursing, Midwifery & Health (VUW) approval



FACULTY OF HUMANITIES & SOCIAL SCIENCES TE WĀHANGA ARONUI
VICTORIA UNIVERSITY OF WELLINGTON PO Box 600, Wellington 6140, New Zealand
Phone +64 4 463 5745 Email free-enquiries@vuw.ac.nz Website www.victoria.ac.nz

27 November 2015

ID: 300177029

Merryn Jones
5 Haumoana Rd
Haumoana
Hastings 4102

Dear Merryn,

RE: Confirmation of Master's Thesis Research Proposal

We are pleased to advise you that your Master's Thesis Research Proposal has been approved by the Graduate School of Nursing, Midwifery and Health. This decision has been noted on your record by the Faculty of Humanities and Social Sciences.

Best wishes for your study.

Yours sincerely



Dr Kristina McGuinness-King
Manager, Student & Academic Services / Kaiwhakahaere
Faculty of Humanities & Social Sciences
kristina.mcguinness-king@vuw.ac.nz
Ph 64 4 463 5192

Appendix E – Letter of Invitation



March 24, 2016

Dear

We are undertaking research into the decision-making process and motivations behind who, why and how people with end stage renal disease might ask, or not ask, their family and friends to donate a kidney. We are interested in understanding more about the factors that contribute to why some people ask family and friends to donate a kidney, and why some people do not. The study is part of a Victoria University of Wellington project involving Merryn Jones, a registered nurse who works in the field of organ donation, and Dr Jon Cornwall, a university academic who studies tissue donation.

This research will help us understand what factors contribute to the difficulties that people may encounter in attempting to ask for a kidney, or the reasons for them not asking. We are hoping the project provides insight into kidney donation processes so we can help improve the chances of those needing kidneys successfully asking family and friends to donate.

We are seeking up to fifteen people from the Hawke's Bay region to interview in a one-on-one situation as part of this study. The interviews are expected to take up to 45 minutes. There are no right or wrong answers, and your views and experiences will provide information that will help to build a picture of the decision-making processes involved in kidney donation.

Please read the Patient Information Sheet attached to this letter for more information about the project. Heather Nicholas from the Hawke's Bay District Health Board Renal Service (where the study is based) will be contacting you by telephone in approximately two weeks to ascertain whether you may be willing to participate in this study. If you are not willing to participate, you are welcome to inform her of this decision with no adverse consequences to you or your healthcare.

Yours sincerely,

Merryn Jones
Hawkes Bay DHB
Ph. 027.449.4610
Merryn.Jones@hbdhb.govt.nz

Dr Jon Cornwall
Victoria University of Wellington
Ph. 04.563.6650
jon.cornwall@vuw.ac.nz

Appendix F – Participant Information Sheet

Participant Information Sheet



Study title: Examining the factors influencing decision-making amongst End Stage Renal Disease (ESRD) patients considering asking family and friends for a kidney.

Locality: Hawkes Bay DHB Ethics Committee ref.: 16/NTB/3

Lead Investigator: Merryn Jones Contact phone number: 0274494610

You are invited to take part in a study on decision-making in relation to recruitment of living kidney donors. The study would involve you being interviewed by a member of the study team. Whether or not you take part is your choice. If you don't want to take part, you don't have to give a reason, and it won't affect the care you receive. If you do want to take part now, but change your mind later, you can pull out of the study at any time.

This Participant Information Sheet will help you decide if you'd like to take part. It sets out why we are doing the study, what your participation would involve, and what would happen after the study ends. We will go through this information with you and answer any questions you may have. You do not have to decide today whether or not you will participate in this study. Before you decide you may want to talk about the study with other people, such as family, whānau, friends, or healthcare providers. Feel free to do this.

If you agree to take part in this study, you will be asked to sign the Consent Form on the last page of this document. You will be given a copy of both the Participant Information Sheet and the Consent Form to keep.

This document is 3 pages long. Please make sure you have read and understood all the pages.

WHAT IS THE PURPOSE OF THE STUDY?

The information that you provide in the interview will be used to look at the decision-making factors that contribute to deciding who, how and why some family and friends are asked to donate a kidney, or why they are not asked.

It is expected that the interviews will provide the researchers with a better understanding of the decision-making processes of patients with ESRD when they choose to ask, or decline to ask, others for a kidney.

Approval has been received from the Health and Disability Ethics Committee (HDEC).

The lead researcher for this project is Merryn Jones. Merryn is completing her Masters Thesis in Post-Graduate Nursing through Victoria University of Wellington (VUW). She is a Renal Nurse and transplant coordinator at Hawkes Bay DHB. Dr Jon Cornwall is Merryn's

academic supervisor at VUW. He has an interest in the processes involved in tissue donation. Both Merryn and Dr Cornwall's contact details can be found on the last page of this document should you wish to contact them about this study.

WHAT WILL MY PARTICIPATION IN THE STUDY INVOLVE?

You have been chosen to receive an invitation as a person who has renal disease and who is either eligible to receive a kidney transplant through the deceased donor list, or has a living kidney donor who is being actively worked up at present.

Heather Nicholas, a HBDHB Renal Service employee who is independent of the research, will contact you within two weeks of you receiving this letter to ask if you would agree to participate in the study.

If you have consented to participate and are selected to be interviewed, Merryn Jones will contact you by phone and arrange a time to come and interview you. It is anticipated that up to fifteen people will be interviewed. Interviews will be face to face. The interview would usually be in your home, but it could also take place somewhere else should a home interview not suit you. The interview will take approximately 45 minutes, but the time taken will be flexible. You will need to allow 1 hour for the interview process.

A set of open-ended questions will be asked during the interview in order to better understand what patients consider when thinking about asking family or friends to donate a kidney. There are no right or wrong answers. Questions might also explore the reasons for not asking friends and family for a kidney.

If you are interviewed, a code number will be applied to all personal and interview information to make sure you are unable to be identified. The interview will be recorded and typed either by Merryn Jones, or by a professional typist, and the code number will be used to protect your identity. All information will be confidential, with identifying information removed from the final research document.

WHAT ARE THE POSSIBLE BENEFITS OR RISKS OF THIS STUDY?

The interviews will provide information about the factors that influence who, why and how donors are selected by participants, and who is not approached from a participant's network of family and friends. This information will help those who work in the field of kidney transplant to gain a better understanding of these factors. It is hoped that the information provided will help transplant coordinators to identify common themes with a view to developing support and education strategies in the future to assist others with their decision-making process. We acknowledge that given the sensitive nature of the topic some participants could find the content may cause concerns or uneasiness, however all participants have the right to terminate the interview at any time should they feel the need.

WHO PAYS FOR THE STUDY?

Study participants will incur no costs, other than time given to be interviewed. For participating in the interview, a \$20 grocery voucher will be provided as koha or for costs associated with participation.

WHAT ARE MY RIGHTS?

Agreeing to be a part of this study is voluntary. You are free to decline to participate, or to withdraw from the research at any time up until the end of your interview being conducted, without experiencing any change in the care that you receive.

You have a right to access your own personal information that has been collected as part of the study. Your transcribed interview will be available for you to read and the research will be available to participants on request once the project has been completed.

Your private information will be stored by the lead researcher in a locked filing cabinet, and only Merryn Jones or Dr Jon Cornwall will have access to your information. All information will be securely stored either by password protected hard drive (digital) or locked cabinet (hard copy). Information will be stored for ten years then destroyed using Docushred (hard copy) or wiped from hard drive (digital).

WHO DO I CONTACT FOR MORE INFORMATION OR IF I HAVE CONCERNS?

If you have any questions, concerns or complaints about the study at any stage, or wish to withdraw from the study, you can contact:

Merryn Jones, Lead Researcher
0274494610
Merryn.Jones@hbdhb.govt.nz

Dr Jon Cornwall, Academic Supervisor
Victoria University of Wellington
04 5636650
jon.cornwall@vuw.ac.nz

If you would like to talk to someone who isn't involved with the study, you can contact an independent advocate:

Health & Disability Advocate
Phone: 0800 555 050
Email: advocacy@hdc.org.nz

Brian Murphy
Community Health Advocate
Kidney Society of NZ
Phone: 0800235711
Email: brian@adks.co.nz

For Maori health support please contact :

Sheyne Te Hau, Kaitakawaenga
Phone: 06 8781654 ext 2885
Email: Sheyne.TeHau@hbdhb.govt.nz

You can also contact the health and disability ethics committee (HDEC) that approved this study. The approval number to quote is: 16/NTB/3

Phone: 0800 4 ETHICS
Email: hdecs@moh.govt.nz

Consent Form



Examining the factors influencing decision-making amongst End-Stage Renal Disease (ESRD) patients considering asking family and friends for a kidney

If you need an INTERPRETER, please tell us.

Please tick to indicate you consent to the following

I have read, or have had read to me in my first language, and I understand the Participant Information Sheet.	Yes <input type="checkbox"/>	No <input type="checkbox"/>
I have been given sufficient time to consider whether or not to participate in this study.	Yes <input type="checkbox"/>	No <input type="checkbox"/>
I have had the opportunity to use a legal representative, whanau/ family support or a friend to help me ask questions and understand the study.	Yes <input type="checkbox"/>	No <input type="checkbox"/>
I am satisfied with the answers I have been given regarding the study and I have a copy of this consent form and information sheet.	Yes <input type="checkbox"/>	No <input type="checkbox"/>
I understand that taking part in this study is voluntary (my choice) and that I may withdraw from the study at any time without this affecting my medical care.	Yes <input type="checkbox"/>	No <input type="checkbox"/>
I consent to the research staff collecting and processing my information, including information about my health.	Yes <input type="checkbox"/>	No <input type="checkbox"/>
I understand that the interview will use an open-questioning technique. The questions will relate to kidney donation. The precise nature of the questions which will be asked have not been determined in advance, but will depend on the way in which the interview develops and that in the event that the line of questioning develops in such a way that I feel hesitant or uncomfortable, I may decline to answer any particular question(s) and/or may withdraw from the project without any disadvantage of any kind.	Yes <input type="checkbox"/>	No <input type="checkbox"/>
I understand that personal identifying information such as contact details, audio files, and interview transcripts will be destroyed at the conclusion of the project, but any raw data on which the results of the project depend will be retained in secure storage for ten years.	Yes <input type="checkbox"/>	No <input type="checkbox"/>

I understand that reimbursement (\$20 grocery voucher) will be provided to compensate interview participants for any costs associated with participation in the semi-structured interview.	Yes <input type="checkbox"/>	No <input type="checkbox"/>
I know who to contact if I have any questions about the study in general.	Yes <input type="checkbox"/>	No <input type="checkbox"/>
I understand my responsibilities as a study participant.	Yes <input type="checkbox"/>	No <input type="checkbox"/>
I wish to receive a summary of the results from the study.	Yes <input type="checkbox"/>	No <input type="checkbox"/>
The results of the project may be published and will be available in the Victoria University of Wellington library, but every attempt will be made to preserve my anonymity.	Yes <input type="checkbox"/>	No <input type="checkbox"/>

Declaration by participant:

I hereby consent to take part in this study.

Participant's name: _____

Signature: _____

Date: _____

Declaration by member of research team:

I have given a verbal explanation of the research project to the participant, and have answered the participant's questions about it.

I believe that the participant understands the study and has given informed consent to participate.

Researcher's name: _____

Signature: _____

Date: _____

Appendix H – Interview Guide

Questions the researchers may ask as part of their study include:

1. Who did the patient ask and why?
2. Who did they exclude, and why?
3. How did the patient approach the request?
4. What were their reasons for asking in this way?
5. Has anyone offered a kidney, but the patient turned them down?
6. What were the patient's reasons for doing so?
7. Can they identify any other strategies which might have been useful but were either not considered, or not available?
8. If they chose NOT to ask anyone, what were their reasons for doing so?

Questions are to be tailored according to whether the information sought has already been provided by the participant. If the participant has covered the information in a previous answer, the next question will be asked.

Examples of open-ended questions/prompts that may be used:

Section A – Examples of questions if participants have previously asked someone for a kidney:

I'm interested in the processes involved in asking for a kidney. Can you tell me who the people you asked were?

How did you choose those people?

I'm interested in why you chose to ask your (brother/friend, etc). Can you tell me more about the reasons why?

Can you tell me about how you approached the subject of donating a kidney?

Can I ask you to describe what it felt like to ask?

Looking back on that time, can you think of anything that might have helped you to ask that either was not available, or that you hadn't considered?

Sometimes friends or family might offer a kidney but a person might turn it down. If you have had experience of this, would you be able to describe this for me?

Sometimes people have family members or friends that perhaps they could have asked, but chose not to. I am interested in the reasons why people chose NOT to ask. Can you think of anyone in your circle who you might have asked, but didn't?

Section B - Examples of questions if the participant has never approached anyone for a kidney:

"I'm interested in the reasons people chose NOT to ask for a kidney as much as those who DO ask".

Can you tell me about the reasons you chose NOT to ask friends or family for a kidney?

Sometimes friends or family might offer a kidney but a person might turn it down. If you have had experience of this, would you be able to describe this for me?

Can you think of any circumstances that might lead you to change your mind about either accepting or asking friends or family for a kidney in the future?

Section C - General questions for all participants

If you could go back and undertake the process of acquiring a kidney again, what might you do differently in order to make the process better (more successful)?

If you could give advice to another person who was about to approach family or friends to ask for a kidney, what advice might you give them - either to do (things to help get a kidney), or not to do (things that may make it harder to get a kidney)?

Appendix I – Hardware/Software

Hardware/Software - Tools Used				
Item	Version	Model	Manufacturer	Country
USB flash drive	128 GB	Silicon Power	Silicon-Power Computer & Communications Inc	Taipei, Taiwan
Digital Voice Recorders x 2	4 GB	EN625	Endeavour	China
Nvivo software	11	NVivo Pro	QSR	Melbourne, Australia
Word	2007	Microsoft Office	Microsoft	Washington, USA
Excel	2007	Microsoft Office	Microsoft	Washington, USA