
4.1 Let's Talk About Living Donor Kidney Transplantation: Breaking the passive deadlock on living donation

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Abstract

We have observed a significant inequality in the number of living donor kidney transplantations (LDKT) performed in our center between patients of Dutch versus non-Dutch descent. This difference has also been found in other European countries. This chapter presents a study that aimed to investigate the role that attitudes of patients and individuals from their community towards communication on LDKT may play in this discrepancy. This was done by interviewing patients on their own attitudes and those of individuals within their respective communities. Focus group discussions and in-depth interviews were conducted among 50 end-stage renal disease patients who were on the deceased donor kidney transplantation wait list. Although patients held favorable attitudes towards LDKT they reported a passive deadlock in the communication on this issue with individuals from their social network. This chapter provides insight into aspects related to this passive deadlock. Thoughtful translation of these insights into an intervention may pave the way for redressing the inequality in the number of LDKT. We describe a promising intervention in the form of a home-based group education programme which intervenes on family dynamics by promoting communication on LDKT as one of the potential intervention targets.

Current status of access to living donor kidney transplantation

Living donor kidney transplantation (LDKT) rates have been increasing and now exceed those of deceased donor kidney transplantation (DDKT) in the Netherlands (Roodnat et al. 2009). However, as found in other countries (Udayaraj et al. 2010), there is inequality in access to LDKT among ethnic minorities in the Netherlands. Rotterdam, in particular, is a multi-ethnic society with 40% of the inhabitants of non-Dutch origin. In our kidney transplant centre between 2006 and 2009, 44% of patients on the DDKT wait list were non-European, whereas, only 18% of the patients who underwent a LDKT were non-European (Roodnat et al. 2010). These authors recommended further investigation into the reasons behind this inequality.

Previous research among Dutch and non-Dutch patients, has shown that communication between patients and potential donors plays a role in the access to LDKT (Kranenburg et al. 2007). Results show that although patients on the wait list were in favor of LDKT (78%) that their reluctance to discuss LDKT with potential donor(s) prevents them from pursuing this treatment option. Moreover, 80% of patients stated that they (probably) would not actively approach a potential do-

nor to 'ask' for a kidney. Following this, a state of non-communication on the subject emerges and may be interpreted by the patients as a refusal of the potential donors to donate: a state of passive deadlock (Kranenburg et al. 2009). Besides ineffective communication (Kranenburg et al. 2007), research has also suggested that shortcomings in knowledge might also contribute to the low LDKT rates among ethnic minorities (Kucirka et al. 2012). Other factors suggested in the literature include: attitudes towards disease (Martinez-Alarcon et al. 2006), cultural factors (Purnell et al. 2012), and awareness of the religious viewpoint on living donation (Randhawa et al. 2010). In many countries medical and socio-economic factors also contribute to the aforementioned inequality (Roodnat et al. 2012; Tirapani et al. 2012). Costs should not play a role in equality in access to LDKT in the Netherlands given the Dutch social health insurance system which is accessible for each citizen. Neither should costs related to LDKT be an issue for recent immigrants, since they are also insured through a collective insurance arrangement. In this chapter we will focus on gaining in-depth insights into communication about LDKT and how a passive deadlock may contribute to inequality in access to LDKT. Lastly, we will also discuss a potential intervention to address this issue accordingly.

1 Conducting the investigation

We focused on those patients on the DDKT wait list with a non-Dutch ethnicity. Non-Dutch ethnicity was defined as the patient or at least one of the parents being born in a non-Western country (Central Bureau of Statistics Netherlands, 2011 <http://www.cbs.nl>). The non-Dutch populations immigrated to the Netherlands after the Second World War. Indonesians arrived in the 1950's, Moroccans and Turkish in the 1960's, Surinamese, Caribbean and Africans in the 1970's. During these decades many immigrants came to the Netherlands together with their families and friends. For this study we focused on the largest ethnic groups living in the Rotterdam area. The country of birth for the non-Dutch patients in this study was the same as their ethnicity. Our comparison group consisted of Dutch patients, also on the wait list for a DDKT. Table 1 describes some patient characteristics.

In current clinical practice at our transplant centre in Rotterdam, patients who wish to be wait-listed attend the pre-transplantation outpatient clinic. This clinic is staffed by 3 transplant nephrologists who screen and prepare their patients in a systematically protocolized way. Patients also receive consultations with a social worker and transplant coordinator. All patients visiting the pre-transplantation outpatient clinic receive education at the hospital consisting of verbal information, written educational material on kidney disease and the treatment options, and a DVD on donation and transplantation. The written information on donation and transplantation as well as the DVD has been translated into several foreign languages that are commonly spoken in the Rotterdam municipality. Additionally, patients are invited to attend informational meetings held in various regional hospitals four times per year.

We employed a focus group technique of group interviewing that generates data through people's sharing of knowledge and experiences. Focus groups have the advantage of making use of group dynamics to stimulate discussion, gain insights and generate ideas in order to pursue a topic in greater depth. Interaction between participants and exchange of experiences and views and comments was therefore encouraged (Kitzinger, 1995). Focus group discussions offer the particular advantage that individuals can participate who may be excluded from written assessments due to language or literacy barriers (Kitzinger, 1995). In our study sample 28% did not speak or had not sufficiently mastered the Dutch language. For this group, interpreters with the same ethnic origin as the group participants were recruited and trained to lead the focus group discussions to facilitate participation. The following topics were systematically discussed in each group: attitudes towards LDKT, attitudes towards acceptance of certain potential donors, patients' view on the attitudes of members from their community regarding LDKT, and attitudes towards (non-) communication on

LDKT. Per ethnic group 2-3 focus groups with 3-6 participants were held in a meeting room in the hospital. Most interviews lasted 2.5 hours. Twenty participants (1-3 per ethnic group) participated in an in-depth interview which lasted on average for 1.5 hours.

The interviews were taped and transcribed verbatim and if necessary translated into Dutch. Data from the focus groups were analyzed using the principles of the Grounded Theory (Glaser, 2002). The software package Atlas.ti was used to perform the analysis to maximize efficiency and reliability compared to paper and pencil analysis. Group and individual interviews were held until data saturation was reached. We have discussed the procedural details of our approach and analyses in greater detail in our technical report (Ismail et al. 2010).

Table 1: Patient characteristics

	Turkish (N = 10)	Moroccan (N = 7)	Surinamese (N = 10)	Caribbean (N = 7)	Cape Verdean (N = 6)	Dutch (N = 10)
Gender (male/female)	6/4	5/3	5/5	1/6	3/3	6/4
Mean age (range)	55 (40-62)	45 (27-62)	54 (30-71)	53 (48-69)	54 (21-71)	6/4
Median months on dialysis (range)	24 (9-84)	4.6 (0-13)	17 (6-84)	31 (12-48)	21 (5-60)	28.6 (0-84)

2 Attitudes towards LDKT

In general, patients held positive attitudes towards LDKT. Twelve patients did however say that they would only approve a LDKT if they could be guaranteed that it would not jeopardise the health of the donor. Only two patients reported an absolute negative attitude towards LDKT. They would not consider a LDKT because they could not live with the idea of ‘cutting’ into the body of their loved ones for personal health gain. Both were Cape Verdean patients:

- (1) a 53 year old female who had already undergone 3 DDKT and had two brothers who had offered her a kidney; and
- (2) a 58 year old male who had been on dialysis for 5 years and had no previous transplants or potential donors who came forward. He reported avoiding the issue of LDKT with his family members ever since being on dialysis. The specific circumstances of these two patients were not different from the other patients.

In all groups patients acknowledged that the graft survival rates in the case of a living donor are better compared to a deceased donor. Besides not going through with living donation if it would be harmful to the donor, the Surinamese patients had two reasons for accepting LDKT. Namely, the shorter wait list time for LDKT and the belief that preparatory examinations were better for LDKT compared to DDKT.

2.1 Conditional acceptance of LDKT

Almost everyone in each group reported that they would only accept a LDKT if donation would not harm the donor. Some Turkish patients reported: *“I do not want to lose someone in the process”*. *“I do not want the future health of the donor to be jeopardized”*. A Dutch patient said: *“I want a great deal of certainty that my donor is going to be ok”*. Another frequently reported conditional acceptance was related to partner donations. In this case patients reasoned that the kidney of the partner should be saved for their children in case they are ever faced with end-stage renal disease. For instance a Dutch patient said: *“My son is also having kidney problems therefore I will not accept*

a kidney from my wife". Even so, receiving a kidney from a direct family member was the most frequently mentioned source of potential donor. However, in all groups patients preferred not to receive a kidney from their children. These quotes illustrate potential reasons: "The children have their whole life ahead of them." "They have to take care of their own family." Lastly, some patients also said that they would rather not have a kidney from potential donors with a medical history or a history of unhealthy behaviours.

2.2 Influence by family members

Many familial reasons for not going through with a potential living donor were mentioned by Turkish patients. Some examples are: "The husband of my sister discouraged her to donate a kidney to me". "My sisters said that they do not want to have family problems in the future because of the donation". Also in the Moroccan group a patient reported that a potential donor was discouraged by other family members: "My mother was ready to donate before she was influenced by my sister". Both Turkish and Moroccan patients were confronted with the fact that potential donors will not donate because they fear familial problems. A typical quotation was: "Let's just say 'family problems', I don't want to talk about that". The group of Caribbean patients reported familial influence towards potential donors most often. Some quotes were: "His wife said: 'Why would you give to your sister you might end up being sick yourself!'" "His kids told him that he was too young to donate and that they want him around for a long time".

3 Communication on LDKT

In all groups the majority of all patients were in favour of a passive communication style with respect to pursuing a living donor. They all reported that as a kidney patient they should wait for a kidney offer from a potential donor. One third of the patients said that they would indirectly communicate about LDKT. They do this by cautiously discussing the topic and making their preference for LDKT known. A minority was in favour of asking directly for a kidney. The main reason for preferring a passive communication style was fear of anticipated rejection and regret. All the non-Dutch patients who had an opinion on this matter stated that their community would appreciate a passive approach towards the issue.

Almost all Turkish, Moroccan, Caribbean and the Cape Verdean patients were in favour of a passive approach. Some examples were: "A person should be able to decide for himself if he wants to donate a kidney", a Turkish patient. "I am not going to beg for a kidney", a Moroccan patient. "I would never ask. I would wait for that miracle to happen", a Caribbean patient. "I would be emotionally overwhelmed if I asked for a living donor kidney. No I would never do such a thing", a Cape Verdean patient. A minority would prefer a more indirect style of asking. "I cautiously dropped the subject when I met up with my friends, hoping that some of them would offer me a kidney", a Cape Verdean patient. However, none of the patients in these groups would approve a direct communication style.

A Turkish patient mentioned that as a recipient you have no right discussing someone else's body. Another patient said that he would have discussed the subject with potential donors if he had more information on LDKT. Fear of anticipated rejection and regret were other common reasons in the Turkish group for not actively pursuing a kidney: "I would never forgive myself if something goes wrong with the donor". "If I would get a 'no' from a potential donor I would be devastated. You cannot imagine how much that would hurt". The Caribbean and Cape Verdean groups stated something similar: "I am afraid that the donor someday will ask for his kidney back and that therefore I would regret asking for his kidney in the first place", a Cape Verdean patient. A Cape Verdean

patient also said that asking would inevitably lead to rejection of the request. He would rather use an indirect style of asking. The Moroccan patients did not report any reasons for favouring a passive approach.

The Surinamese and the Dutch patients held similar views on this topic. The majority was in favour of waiting for a kidney offer to be made by the potential donor. *"I actually would not know how to ask such a thing"*, a Surinamese patient. *"I would not expect someone else to ask me such a question, so I would not ask anybody either"*, a Dutch patient. In most cases the passive attitude was also fed by their fear of anticipated rejection and regret. Roughly half of the patients from both groups also favoured an indirect approach. *"I would discuss the subject of needing a living donor but I would never ask for a kidney"*, a Surinamese patient. *"I would make a joke about it: if I for example pick your name you will lose a kidney!"*, a Dutch patient. The Surinamese patients who used the indirect approach reported that they are still waiting for a response. A minority of the Surinamese and Dutch patients also exclusively and in equal proportions reported to approve of a direct approach. *"You cannot just wait for someone to give his kidney away. You should promote yourself and get to the point!"*, a Surinamese patient. *"You should come up with a really good story, so that they cannot turn down your request"*, a Dutch patient. Half of the Dutch patients who asked directly for a kidney got a negative response from their potential donor. *"The people I asked do not want to put their life in the firing line"*, a Dutch patient.

4 From problem to solution: where can we go from here?

In general, patients were in favour of LDKT. This finding could be accounted for by feelings of reciprocity. Research indicates that a patient's need for a LDKT independently increases their likelihood of being in favour of LDKT by ten fold (Rios et al. 2009). Only two patients could not live with the idea of 'mutilating' a beloved one in order to gain health status for themselves. No further specific differences were found in the reasoning between these two patients and those in favor. However, we found evidence for a passive deadlock (maintained by both recipients and potential donors) that appears to transcend ethnicity.

4.1 Patients' acceptance of LDKT

Despite the positive attitude towards LDKT we identified psychosocial factors which withhold patients from pursuing LDKT: fear of social rejection, fear of anticipated regret, negative familial influence and anticipated familial problems after a LDKT. The quotes highlight the emotionally laden nature of this topic. This finding is also reported in another transplant centre in the Netherlands (de Groot et al. 2012). In that study, potential donors had significantly fewer negative expectations regarding LDKT than patients. In addition to this, the patients in our study precluded certain potential donors based on their characteristics such as, being a child of the patient or being a co-parent. Ideally these predetermined beliefs and exclusions should at least be discussed with relevant others before reaching such conclusions. The Gift Exchange Theory as applied to the field of LDKT provides additional support for this statement (Gill et al. 2008). As patients are very much concerned with the future health of the potential donors, they are only able to accept the donor's gift after a solid discussion on LDKT. The fears and social influence were also reported by both Dutch and non-Dutch patients in our study. This similarity of attitudes towards LDKT between different ethnic groups has been reported elsewhere in the literature (Rios et al. 2009).

4.2 Patients' preferred communication style on LDKT

The majority of the patients preferred a passive communication style towards communicating with potential living donors about LDKT. Some patients (Dutch and non-Dutch) adopted an indirect communication style. However, half felt that they had been ignored. The patients interpreted this latter reaction as a refusal which was obviously painful and precluded any further communication. This passive deadlock needs to be addressed from both the angle of the patient as well as the angle of the potential donors.

In addition, non-Dutch patients perceived that their communities would also approve a passive communication approach regarding LDKT. The main reasons behind this passive attitude were: anticipated rejection, anticipated regret and the belief that no one has the right to discuss issues regarding someone else's body. We already know from previous research that initiating discussions on such delicate issues with loved ones may be very difficult for patients (Kranenburg et al. 2009). This group of patients would benefit from professional assistance aimed at enhancing the level of understanding and knowledge on LDKT while taking the personal stances, feelings and relationships into consideration in an emotionally secure environment. Mediation by a health care educator may alleviate the responsibility of initiating a discussion on living donation from both the patient and their loved ones.

We also consider group education to be essential in order to promote effective communication on living donation given the substantial influence of family members on the knowledge and attitudes of both patients and potential donors. The importance of such influence or support from significant others during decision-making processes has been reported in a metasummary on patients' and donors' experiences (Ummel et al. 2011). It is therefore of utmost importance that these influential family members are acquainted with accurate and accessible information on LDKT. Group education offered to the patient and their extended social network may be an effective way to achieve this. The geographical availability of kin is less problematic when arranging a group education with family members in a small country like The Netherlands. However, in big countries this point may be an issue. Yet, our experience is that ethnic minorities in Western countries tend to live close together in line with their cultural values of group cohesiveness and social support.

4.3 A way forward

Special attention should be paid to patients' personal circumstances, involvement of the social network and making the information about LDKT more easily accessible (e.g. using an interpreter). An intervention meeting these interrelated and complex requirements is the home-based education intervention developed and advocated by Rodrigue et al. (2008). His research has proven to be successful at reaching out to those patients who have difficulties discussing LDKT with significant others. Following his example we have developed such a home-based educational intervention to address potential hurdles to LDKT in the European context (Ismail et al. 2012). The content of the intervention was adapted according to the current findings and is currently being testing in a randomized controlled trial (Netherlands Trial Register, NTR2730). Previous research has already described the dangers to consider when intervening in patients' health behaviour. They have argued that the intervention should be restricted to patient empowerment (Hilhorst et al. 2007).

In conclusion, the attitudes towards LDKT and hurdles to communicating about living donation were found to transcend ethnicity. We found some subtle differences between ethnic groups however similar concerns were held by all patients. Nonetheless, educational programmes should be tailored according to patients' knowledge, concerns and social circumstances. The number of non-Western patients who could benefit from such a tailored intervention is larger than the number of Western patients. Therefore, this may in turn reduce the inequality in access to LDKT. This chapter

provides some insights into patients' perceptions on family dynamics which may contribute to the development of an intervention for improving communication and knowledge on LDKT.

References

- Central Bureau of Statistics Netherlands (2011) <http://www.cbs.nl>.
- de Groot, I.B., Schipper, K., van Dijk, S., van der Boog, P.J., Stiggelbout, A.M., Baranski, A.G., et al. (2012). Decision making around living and deceased donor kidney transplantation: a qualitative study exploring the importance of expected relationship changes. *BMC Nephrol*, 13, 103.
- Gill, P., & Lowes, L. (2008). Gift exchange and organ donation: donor and recipient experiences of live related kidney transplantation. *Int J Nurs Stud*, 45, 1607-1617.
- Glaser, B. G. (2002). Conceptualization: On Theory and Theorizing Using Grounded Theory. *Int J of Qual Meth*, 2.
- Hilhorst, M.T., Kranenburg, L.W., & Busschbach, J.J. (2007). Should health care professionals encourage living kidney donation? *Med Health Care Philos*, 10, 81-90.
- Ismail, S.Y., Luchtenburg, A.E., Boonstra, A.C., Zuidema, W.C., Weimar, W., Busschbach, J.J., et al. (2012). Multisystemic engagement & nephrology based educational intervention: a randomized controlled trial protocol on the kidney team at home-study. *BMC Nephrol*, 13, 62.
- Ismail, S.Y., Luchtenburg, A.E., Massey, E.K., Claassens, L., Busschbach, J.J., & Weimar, W. (2010). Living kidney donation among ethnic minorities: A Dutch qualitative study on attitudes, communication, knowledge and needs of kidney patients. http://repub.eur.nl/resource/pub_20862/index.html.
- Kitzinger, J. (1995). Qualitative research. Introducing focus groups. *Bmj*, 311 (7000), 299-302.
- Kranenburg, L.W., Richards, M., Zuidema, W.C., Weimar, W., Hilhorst, M.T., JN, I.J., et al. (2009). Avoiding the issue: patients' (non)communication with potential living kidney donors. *Patient Educ Couns*, 74, 39-44.
- Kranenburg, L.W., Zuidema, W.C., Weimar, W., Hilhorst, M.T., Ijzermans, J.N., Passchier, J., et al. (2007). Psychological barriers for living kidney donation: how to inform the potential donors? *Transplantation*, 84, 965-971.
- Kucirka, L.M., Grams, M.E., Balkara, K.S., Jaar, B.G., & Segev, D.L. (2012). Disparities in provision of transplant information affect access to kidney transplantation. *Am J Transplant*, 12, 351-357.
- Martinez-Alarcon, L., Rios, A., Conesa, C., Alcaraz, J., Gonzalez, M. J., Ramirez, P., et al. (2006). Attitude of kidney patients on the transplant waiting list toward related-living donation. A reason for the scarce development of living donation in Spain. *Clin Transplant*, 20, 719-724.
- Purnell, T.S., Hall, Y.N., & Boulware, L.E. (2012). Understanding and overcoming barriers to living kidney donation among racial and ethnic minorities in the United States. *Adv Chronic Kidney Dis*, 19, 244-251.
- Randhawa, G., Brocklehurst, A., Pateman, R., Kinsella, S., & Parry, V. (2010). Religion and Organ Donation: The Views of UK Faith Leaders. *J Relig Health*, 59, 161-165.
- Rios, A., Martinez-Alarcon, L., Sanchez, J., Jarvis, N., Guzman, D., Parrilla, P., et al. (2009). Factors that influence the attitude of East European residents in Spain towards living kidney donation. *Transpl Int*, 22, 707-716.
- Roodnat, J.I., Kal-van Gestel, J.A., Zuidema, W., van Noord, M.A., van de Wetering, J., JN, I.J., et al. (2009). Successful expansion of the living donor pool by alternative living donation programs. *Am J Transplant*, 9, 2150-2156.
- Roodnat, J.I., Laging, M., Massey, E.K., Kho, M., Kal-van Gestel, J.A., Ijzermans, J.N., et al. (2012). Accumulation of unfavorable clinical and socioeconomic factors precludes living donor kidney transplantation. *Transplantation*, 93, 518-523.

- Roodnat, J.I., van de Wetering, J., Zuidema, W., van Noord, M.A., Kal-van Gestel, J.A., Ijzermans, J.N., et al. (2010). Ethnically diverse populations and their participation in living kidney donation programs. *Transplantation*, *89*, 1263-1269.
- Tirapani, L.S., Rodrigues, C.A., Marsicano, E.O., Braga, L.S., Grincenkov, F.R., da Silveira, S.T., et al. (2012). Social diagnosis of chronic kidney disease patients in preparation for living donor renal transplantation. *Transplant Proc*, *44*, 2341-2343.
- Udayaraj, U., Ben-Shlomo, Y., Roderick, P., Casula, A., Dudley, C., Johnson, R., et al. (2010). Social deprivation, ethnicity, and access to the deceased donor kidney transplant waiting list in England and Wales. *Transplantation*, *90*, 279-285.
- Ummel, D., Achille, M., & Mekkelholt, J. (2011). Donors and recipients of living kidney donation: a qualitative metasummary of their experiences. *J Transplant*, *2011*, 626501.