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Sohal Ismail

Erasmus MC

Home-based Education Increases Knowledge, Communication and Living Donor Kidney Transplantations

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Home-based Education Increases Knowledge, Communication and Living Donor Kidney Transplantations

Thuisvoorlichting zorgt voor een toename in kennis, communicatie en het aantal nierdonaties bij leven

Sohal Ismail

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Chapter 1

General introduction.

General introduction

In the Netherlands the waiting time for a deceased donor kidney transplantation (DDKT) for patients with end-stage renal disease is three to five years starting from the first day of dialysis. At the moment there are approximately 750 patients on the wait list (1). While waiting for a DDKT patients are dependent on dialysis which is accompanied by substantially lower quality of life, increased morbidity and mortality and lower graft survival rates after transplantation (2-4). Eventually, only 40% of the wait listed patients are alive when a kidney from a deceased donor becomes available for them (5). While the incidence of end-stage renal failure is increasing, supply of deceased donor kidneys is failing to meet this demand. This shortage of deceased donors is caused by higher family refusal rates, lower traffic accidents, improved survival after (neuro-)trauma, and due to aging donors dyeing from diseases that makes them less suitable for organ donation (6). These circumstances along with the lower quality of life on dialysis has created the need for alternative treatment options.

Living donor kidney transplantation (LDKT) has been a successful treatment option in our center since 1981. The donor is often genetically related but can also be a partner, friend, an acquaintance or an anonymous donor (7). This has led to a widened range of potential living donors (8). Since the deceased donor kidney pool is not (and is not going to be) sufficient enough to provide all our end-stage renal disease patients with a kidney transplant, LDKT has become a popular and indispensable treatment option. Importantly, LDKT has major graft survival benefits compared to DDKT (5). Next to understandable concerns regarding the surgical procedure and the common misconceptions regarding lifestyle restrictions for the donor (9) most people hold a positive attitude towards living donation from family members and friends (10-12). Evidence on the impact of donation on living donors suggests that the vast majority do not experience negative consequences on long term health and quality of life (13, 14). There is some evidence of positive outcomes for the donor, such as enhanced self-esteem (15) and improved relationship with the recipients (16).

Living donor kidney transplantation rates are still increasing and now exceed those of deceased donor kidney transplantation in the Netherlands (17, 18). However, a recent paper on the figures of living donor kidney donation in North America shows a general decline in LDKT rates (19). A similar trend has been observed in some European countries as well (20). Internationally, non-European transplant candidates are substantially underrepresented in LDKT programs (21-23). Different educational interventions for patients and their family have been internationally implemented to promote LDKT (24-30). Yet, substantial increases in LDKT rates following a behavioral intervention have only been documented for home-based educational interventions (31). Such home-based educational interventions should target potential hurdles in the pursuit of LDKT (32). Ambivalence surrounding communication on renal replacement therapies, insufficient knowledge on LDKT and (religious) concerns regarding LDKT have been reported as some of these hurdles that hamper patients and their families in pursuit of LDKT (32-34).

The aims of this thesis were:

1) to identify which potential factors can promote the access to LDKT

2) to develop and test the effectiveness of a home-based interventional program aimed at promoting the access to LDKT.

Additionally, in line with the original motivation for this thesis, factors that may contribute to the inequality in ethnicity in access to LDKT was investigated and tested whether a home-based intervention can reduce that inequality. As the investigation progressed, the aim of the thesis was generalized to the two above standing aims.

In order to achieve the aforementioned aims the following research questions were answered in subsequent chapters:

1. Which psychosocial factors facilitate access to LDKT for renal transplant candidates. Do different factors play a role among non-European patients compared to European patients? (Chapter 2, 3)
2. To what extend does religion play a role in receiving and donating a kidney? (Chapter 4)
3. Which psychosocial factors are associated with having a potential living donor? (Chapter 5)
4. How can knowledge on kidney disease and renal replacement therapies be measured validly and reliably? (Chapter 6)
5. Would renal transplant candidates regard an home-based educational intervention as an appropriate solution for overcoming those hurdles? If so, are there any conditions that need to be considered? (Chapter 2, 7)
6. What are the potential theoretical, ethical and practical ‘hazards’ concerning home-based interventions? (Chapter 7, 8)

7. To what extend is a home-based intervention effective in facilitating the access to LDKT for transplant candidates? Is there a difference in effectiveness of such an intervention between European and non-European patients? (Chapter 8).

The final chapter (chapter 9) provides a general discussion and clinical recommendations.

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Chapter 2

Living donor kidney transplantation among ethnic minorities in the Netherlands: A model for breaking the hurdles

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Abstract

Objective: Despite living donor kidney transplantation (LDKT) being the optimal treatment option for patients with end-stage renal disease, we observed a significant inequality in the number of LDKT performed between patients of Dutch versus non-Dutch descent. We conducted a focus group study to explore modifiable hurdles to LDKT.

Methods: Focus group discussions and in-depth interviews were conducted among 50 end-stage renal patients. Analyses were conducted according to 'grounded theory' using Atlas.ti.

Results: We found nearly all patients to be in favor of LDKT (96%). However, multiple factors played a role in considering LDKT. Four potentially modifiable hurdles were derived: 1) inadequate patient education 2) impeding cognitions and emotions 3) restrictive social influences 4) and suboptimal communication. With regard to solutions, we found that our patients were open to home-based group education on renal replacement therapy options (88% in favor).

Conclusion: The study highlights the need for sensitivity and awareness of the influence of cultural factors on decision-making when discussing living donation with culturally diverse populations.

Practice Implications: Since the majority of our patients were open to a tailored group education in their own homes, we see this as an opportunity to address factors that influence equality in access to LDKT.

Keywords:

Kidney transplantation; Patient education; Ethnicity; Attitudes; Communication.

1. Introduction

Living donor kidney transplantation (LDKT) is associated with significant patient and graft survival benefits when compared to deceased donor kidney transplantation (DDKT) (1). LDKT rates have steadily been increasing and now exceed those of DDKT in the Netherlands (2). Rotterdam is a multi-ethnic society with 40% of the inhabitants of non-Dutch origin. 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. An inequality in access to the LDKT program between Dutch and the non-Dutch patients has been observed in our center: 44% of our patients on the waitlist for DDKT are from non-Dutch descent (3). However, only 15% of the actual donors are from non-Dutch descent. This health care inequality needs to be addressed (4). In the present investigation we aimed to gain insight into factors that may play a role in the access to LDKT and whether more proactive educational efforts would be a solution for this inequality.

A recent study at our centre reported that medical, socio-economic and ethnic factors exert a significant independent influence on the chance of receiving a LDKT. This study shows that, due to an accumulation of unfavorable factors, the chance of undergoing a LDKT dropped to only 10% for the non-Europeans, compared to 69% chance in the reference population (5). Of the socio-economic hurdles, health insurance is less relevant in the Netherlands due to a health insurance system which is accessible to everyone. In this study we focused on potentially modifiable psychosocial and culture-specific factors that may form hurdles to LDKT. Previous research has suggested that shortcomings in knowledge might be one modifiable hurdle (6). Currently all patients visiting our 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 material contains pictorial as well as textual information on medical, psycho-social and practical issues. The written information on donation and transplantation as well as the DVD has been translated into several foreign languages that are commonly spoken in our municipality. Approximately four weeks after receiving the educational material the patients are invited back to the out-patient clinic for further consultation with a transplant physician. Additionally, patients are invited to attend our informational meetings held in various regional hospitals four times per year. Other hurdles suggested in the literature include attitudes towards disease and treatment in general (7), communication about LDKT (8) and cultural beliefs (9).

If such modifiable factors can be identified that may form hurdles to LDKT, a suitable intervention to remove these hurdles is needed. Consequently, it becomes relevant to investigate the acceptability of possible solutions which may address these hurdles. Therefore, we investigated patients' attitudes towards two different intervention methods reported in the literature. The first is the Norwegian approach whereby the physician contacts a potential donor by telephone to discuss LDKT options (10). The other intervention is the US home-based group educational intervention (4), (11, 12).

To summarize, the focus of this study was to investigate the psychosocial and cultural factors that may constitute hurdles to LDKT and the acceptability of additional educational efforts that may be a solution to these hurdles.

2. Methods

Participants: We recruited patients on the DDKT waitlist with a non-Dutch ethnicity and they were compared with a sample of Dutch patients. All patients without a potential living donor who attended their yearly check-up in the outpatient pre-transplantation clinic of the Erasmus MC, between August 1, 2009 to July 31, 2010 were asked to participate in the study (n=131). Of these 57 were willing to participate (response rate = 44%), however, 7 dropped out due to medical and/or logistic problems (participation rate = 38%). Consequently, fifty men and women from Moroccan, Turkish, Surinamese, Caribbean, Cape Verdean and Dutch origin participated (Table 1). These participants were grouped according to their ethnicity for each interview. Additionally, following the recommendations of an expert institute on ethnic minorities, the Turkish and Moroccan participants were further grouped by gender.

Table 1. Socio-demographic characteristics

Variable	Turkish (N = 10)	Moroccan (N = 7)	Surinamese (N = 10)	Caribbean (N = 7)	Cape Verdean (N = 6)	Dutch (N = 10)
Characteristics						
Gender (male/female)	6/4	5/3	5/5	1/6	3/3	6/4
Mean age (yrs)	55 (40-62)	45 (27-62)	54 (30-71)	53 (48-69)	54 (21-71)	58.4 (28-74)
Educational level (1-3)*	1.8	2.3	2.4	2.8	1.3	2.2
Working (Full/Part)	1 Full	1 Full	1 Full	1 Part	Non	3 Part & 1 Full
No Children	2	2	3	1	1	1
Religion						
Islam (N)	10	7	2	-	-	-
Christianity (N)	-	-	4	7	6	7
Buddhism (N)	-	-	4	-	-	-
None (N)	-	-	-	-	-	3
Months on dialysis (median range)	24 (9-84)	4.6 (0-13)	17 (6-84)	31 (12-48)	21 (5-60)	28.6 (0-84)
Knowledge on LKD**	4 (3-5)	4.4 (2-6)	4.6 (3-6)	4.7 (3-6)	4.2 (3-5)	4.8 (3-6)

Values in the table with the spread (lowest through highest value) in parentheses are means. * The educational level was valued at three levels; 1 = Low, 2 = Average and 3 = High. ** This refers to a short knowledge questionnaire of LDKT related questions which our patients answered at the end of the sessions. Higher scores relate to higher knowledge median (range).

Procedure: In preparation for the study, a number of experts were interviewed in order to develop a topic list for the study. The experts were: an advisor from a knowledge institute on ethnic minorities (Pharos), transplant coordinators of varying ethnic backgrounds, hospital faith leaders, experts from foundations for women's emancipation, a social worker, a representative from the kidney patient society and an expert from a platform for Islamic organizations (SPIOR). Topics in the resulting topic list included attitudes towards LDKT, (non-) communication on kidney disease and treatment options, attitudes towards hospital education and openness to additional education interventions (Table 2). We discussed patients' openness to two education options: 1) In Norway the physician discusses potential donors with the patient. If the patient agrees, the physician telephones the potential donors to invite them to the hospital for a consultation about living kidney donor transplantation [10]; 2) In a number of centers in the US, health care educators visit patients and their potential donors in their homes to inform them about LDKT [11-12]. In this way, various aspects of LDKT can be discussed in a non-hospital setting and the social network of patient is educated at one time.

Table 2. Interview topics and questions

Topic	Questions
Demographic characteristics	Which renal replacement therapy (RRT) are you undergoing? If you do have RRT, for how long? What is your highest level of education? What do you regard as your ethnicity? What is your religion?
Personal medical history	Could you shortly describe your kidney disease? Are you on the waiting list? If yes, for how long?
Attitudes towards kidney transplantation	If you would get a new kidney, how do you think this will influence you life? Could you name a couple advantages and disadvantages?
Attitudes towards LDKT	What is your personal stance towards getting LDKT from a family-member or a friend? Would you accept a kidney from a living donor? Why would you and why would you not? From who would you and from who would you not? Would you donate a kidney if the roles were the other way round?
Religion on LKDT	Does religion play a role in accepting and declining a living kidney? And is this culture specific?

(Non-)communication on kidney disease	Do you talk to people in your social network about your kidney disease? Is this difficult? If yes, what makes it difficult? And is this culture specific?
(Non-)communication on LDKT	Do you talk to people in your social network about getting a new kidney? Is this difficult? If yes, what makes it difficult? And is this culture specific? Did you ever directly asked somebody to give you a kidney? Or did somebody ever offer you one? How 'should' it be: asking someone or getting an offer?
Attitudes towards obtaining and providing information	Are you satisfied about the given information on kidney transplantations and donation at your centre? Do you understand everything? Do you ask your physician questions?
Norwegian approach	In Norway the physician discusses potential donors with the patient. Afterwards, if the patient agrees, the physician telephones the potential donors to invite them to the hospital for a consultation about living kidney donor transplantation. What do you think of the Norwegian approach?
Home-based educational intervention	In America, health care educators visit patients and their potential donors at their homes, and inform them about living kidney donor transplantation. In this way, various aspects of living kidney donor transplantation could be discussed in a confidential setting. What do you think of this American approach? What would you like to discuss during such a meeting? Do you think that people in your community would be open for this intervention?

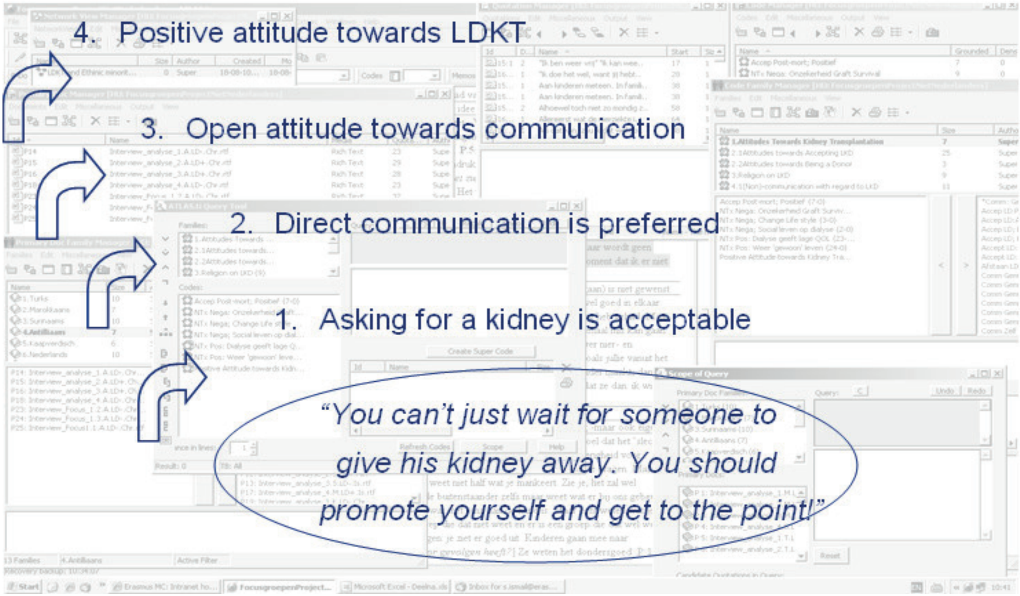
This table displays the topics and the questions we asked during the focus group discussions and the in-depth individual interviews. If a certain question was non-relevant for the group or interviewee it was left out and recorded as missing data.

Interpreters with the same ethnic origin as the group participants were recruited and trained to lead the focus group discussions to facilitate participation of those who do not speak fluent Dutch. Confidentiality among the participants was discussed extensively. Subsequently, permission was given for participation and audio recording the session. Interaction between participants and exchange of experiences and views was encouraged (13, 14). At the end of the session, participants received six general true/false questions on LDKT. All patients received a voucher for 20 Euros for their 2-3 hours participation. Ethical approval was sought but was deemed unnecessary for this kind of non-interventional research according to our medical ethical committee.

Data analysis: Interviews were taped and transcribed verbatim and if necessary translated into Dutch. Participants' names were replaced with identification codes. Data from the focus groups were analyzed using the principles of the Grounded Theory (15, 16). The software package Atlas.ti was used to perform the analysis to maximize efficiency and reliability compared to paper and pencil analysis. This focus group method was introduced in the field of transplantation by Randhawa and colleagues (17). We have discussed this method in greater detail in our technical report (18).

The analysis of the focus group transcripts was carried out in a similar manner to O'Brien (19). Firstly, we generated a grid according to Miles and Huberman's method in order to be able to compare the data between the groups (20). Two researchers read though the transcripts twice while listening to the tape recordings and organized them into a table. Figure 1 displays an example of this grouping process. Words or phrases were combined together in order to generate a covering category. This process goes on until the two researchers separately worked though the whole transcript and data saturation has been reached. The two researchers then jointly clustered the derived categories into themes. Thereby, they identified the underlying uniformities of the categories and further sharpened the conceptual structure of each theme. Finally, within each theme responses were evaluated across the different subgroups to search for similarities and differences.

Figure 1



Legend of Figure 1. A representation of the process in which the various patients' quotations were organized according to the principles of 'grounded theory' in Atlas.ti. (the program at work is vaguely displayed in the background).

3. Results

Attitudes towards LDKT

Almost all our participants held a positive attitude towards LDKT (96%). For instance, a Moroccan patient: *"Kidney transplantation would be a dream comes true for me!"* Despite their overall positive attitude the Dutch group demonstrated some skepticism regarding life after transplantation. For instance, a Dutch patient said: "*You have to take lifelong medication, you'll get spots on your face and your hair will fall out from the medication after transplantation."* The reasons given for preferring LDKT were: better graft survival rates, shorter waiting times for transplantation and the belief that the preparatory medical tests are better when undergoing a LDKT than DDKT. An illustration is a Moroccan patient who said: *"One can keep the kidney from a living donor longer than that of a deceased"*. Next to these reported advantages of LDKT, there were also twelve patients who explicitly stated that they would only approve a LDKT if it would not harm the donor. For instance, a Turkish patient said: *"I do not want the future health of the donor to be jeopardized"*. Ideally the living donor would be a direct family member (first and second degree family; parents, children and the siblings of the patient). However, children and co-parents were generally not regarded as acceptable potential donors. Patients viewed it as unjust to accept an organ from their children since parenting involves the protection of children from potential harm. For example a Caribbean patient said: *"I've told my two daughters that they should maintain their health so that they can take care for their own children"*. Co-parents should also preferably avoid undergoing LDKT since at least one parent should stay healthy for the child(ren) and therefore should avoid the risks associated with LDKT.

Hurdles to LDKT

Using the Grounded Theory, we have built-up from the patients' quotations four themes that may form hurdles to LDKT namely: 1) inadequate patient education, 2) impeding cognitions and emotions, 3) restrictive social influences and 4) suboptimal communication.

1. Patient Education

Firstly, Table 1 shows that patients from various ethnic groups had comparable levels of knowledge on six basic LDKT knowledge questions. Forty percent of our waitlist patients were satisfied with the hospital information provided in our center, an equal number were unsatisfied, and twenty percent had no opinion. The dissatisfaction was related to a need for more tailored information. A Turkish patient phrased it as follows: *"The collaboration between the hospital and foreign people is bad; they do not give us all the information we need"*. Moreover, except for the Surinamese patients, two third of the non-Dutch patients reported that they did not completely comprehend the hospital information. For instance, a Cape Verdean patient said: *"I did not get sufficient information and could not understand the rest of it"*. Approximately a quarter of the non-Dutch patients stated that they were not active information seekers. This group, who do not actively seek information, also reported that their passive approach is typical within their community (a group of people with the same ethnic origin). For instance a Caribbean patient said: *"Yes, especially the older Caribbean people just say 'yes' to everything and never dig any further for information"*. In contrast, Dutch patients stated that their community is actively involved in searching for information. A typical quote of a Dutch patient was: *"We just ask questions if we don't understand something"*.

2. Cognitions and Emotions

Patients showed serious concerns, fears and anxieties, some of which were based on incorrect cognitions about transplantation. We observed factual information being misinterpreted and risks associated with transplantation and dialysis being misjudged. For instance, a Caribbean patient said: *"My daughter said that she heard on the television that you can't have any alcoholic drinks after donating a kidney"*. Almost all the patients in this study mentioned at least one cognitive and one emotional hurdle towards LDKT. Cognitive hurdles include: the believe that the graft survival for LDKT and DDKT is the same, unfamiliarity with the donation process, risk of donor developing kidney disease/failure, lifestyle changes after transplantation for the donor, the donor not being able to have children afterwards, and expected debt / regret towards to the donor and/or his/her family. A Turkish patient: *"My brother's kidney won't work because he drinks a lot of alcohol '….' I am afraid that the donor someday will ask for his kidney back"*. Beside these cognitive hurdles, we could also distinguish some emotional hurdles including (fear of): surgery, death (own or donor), potential harm to the donor, anticipated rejection by potential donors, and anticipated blame if something goes wrong with the donor. A Surinamese patient illustrates this: *"I'm afraid that I will get to live and the donor will die, I heard that it already happened once, so I've heard"*.

3. Social influences

With the exception of Cape Verdean patients, all patient groups mentioned restrictive social influence of other family members regarding the choice of LDKT. Restrictions were set for some family members to prevent them from being regarded as a potential donor by the patient. For instance, a Caribbean patient said about her brother: *"His kids told him that he was too young (40 years) to donate and that they want him around for a long time"*. Social influence was seen most often in relation to acceptability of the patient's partner as a potential donor: other family members believed that one parent should stay healthy and therefore should avoid the risks associated with donation. A frequently heard quote is from a Moroccan patient: *"Just the fact that they have two children. At least one of them should stay 100% healthy"*. Other interpersonal issues include: anticipated family conflicts after the donation and anticipated blame of the patient if the graft is rejected. For instance, a Turkish patient said: *"My sisters said that they do not want to have family problems in the future because of the donation"*. Lastly, there were also cases in which our patients reported social influence from other family members without any further elaboration. A Moroccan patient's quote illustrates this: *"Let's just say 'family problems', I don't want to talk about that"*.

4. Communication

We investigated the communication patterns with respect to pursuing LDKT. We found that in each ethnic group almost all patients were in favor of a wait-and-see attitude. They reported that as a kidney patient they should wait for an offer of a kidney from a potential living donor. For instance a Caribbean patient said: *"I would never ask. I would wait for that miracle to happen"*. The main reasons for upholding a wait-and-see attitude was the fear of rejection and ensuing emotions and anticipated regret after the donation process. For instance, a Turkish patient said: *"If I would get a 'no' from a potential donor I would be devastated. You can not imagine how much that would hurt"*. Additionally, all the non-Dutch patients, who answered or had an opinion on this matter, stated that their community would also appreciate a wait-and-see attitude on this matter. A Caribbean patient: *"It is still a taboo to talk about your illness in the Caribbean community"*. Nevertheless, thirty percent said that they would indirectly 'ask' for a kidney. For instance a Cape Verdean patient said: *"I cautiously dropped the subject during a meeting with friends, hoping that some of them would offer me a kidney"*. A minority (8%) of the Dutch and Surinamese patients was in favor of directly asking for a kidney from a potential donor. A Surinamese patient: *"You can not just wait for someone to give his kidney away. You should promote yourself and get to the point!"*

Intervention options

The Norwegian approach

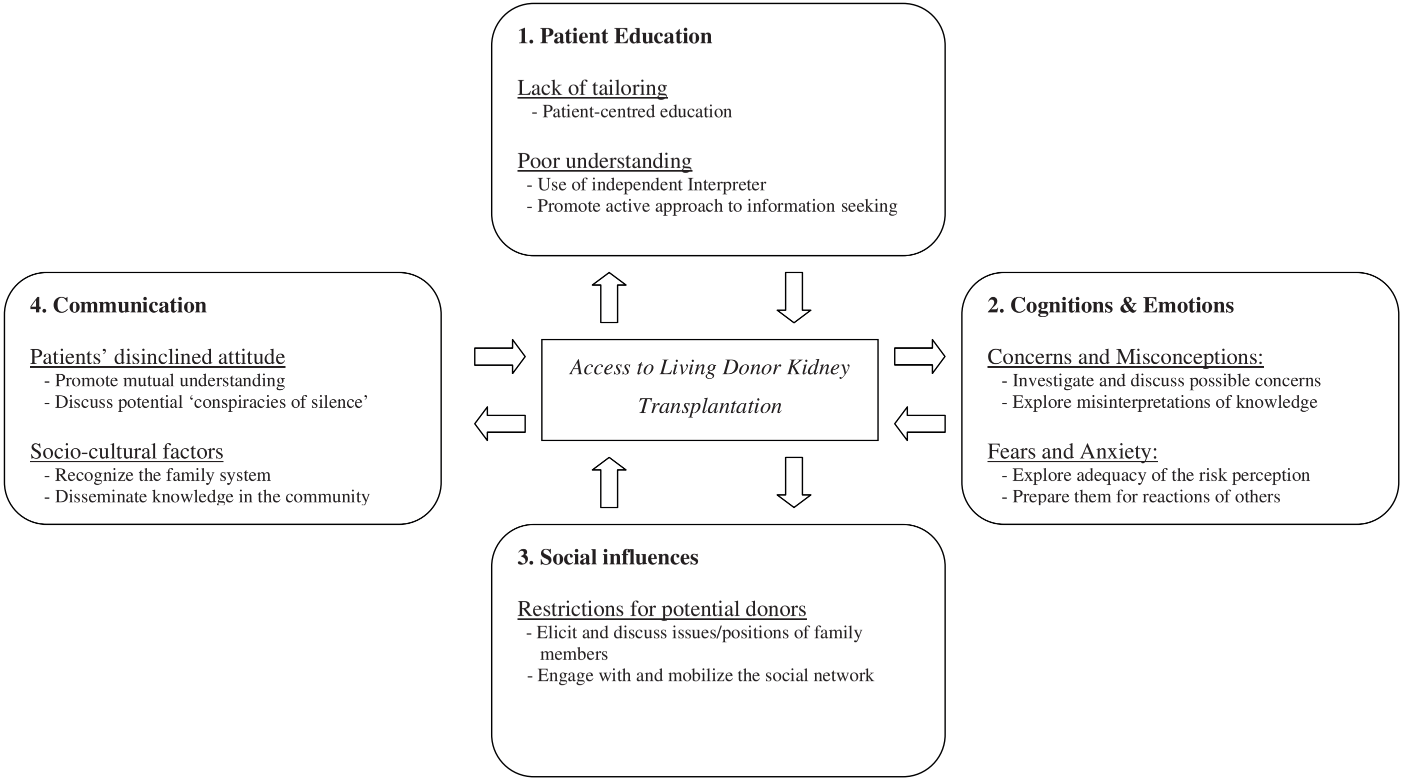
Nearly half of our patients approved this way of stimulating living donation. For instance a Moroccan patient said: *"I would love it if my doctor would put such an effort into helping me"*. Those in favor reasoned that a legitimate person (a physician) will be able to 'get through' to the potential donor. A Surinamese patient said: *"It would be wonderful if that an objective person would ask for you. It would actually work if the doctor contacts the donor. The donor would see the urgency of the situation"*. Patients also reported an additional advantage namely, that the physician could also directly respond to the questions of the potential donors. On the other hand, a group of similar size disapproved of this idea. They reasoned that the potential donors have a will of their own. Therefore, it would be unjust to impose an idea on them that they did not ask for. For instance a Moroccan patient said: *"I think that everyone has the right to decide for himself what to do. I would prefer that the information was given in a written form and that the donor can decide to go to the doctor in his own time"*. However, regardless of their personal stance on this approach, all patients did agree that the physician should not be persuasive. For example a Turkish patient said: *"It is a good option, but the donor must not feel pressured"*.

The US approach

Finally, we investigated patients' attitudes towards home-based group education. This form of intervention was favored over the Norwegian intervention. Eighty-eight percent of our patients (distributed over all groups) were in favour of this home-based approach. For instance a Turkish patient said: "*We have a big family and therefore it would be good if everyone could get the information in this way"*. However, several conditions were set by the patients before implementing such an intervention: provided information should be of value to the patient, the intervention should not be persuasive, and the non-Dutch groups stated that an independent interpreter is highly recommended. A Surinamese patient said: *"It is really nice to let the information come to you. But people are principally against pushy behaviour, especially in your own house"*. Most non-Dutch groups reported that their community would also welcome this idea. For instance, a Caribbean patient said: *"The community would appreciate it!"* A minority (12%) had no opinion on this approach. This group had some hesitations towards home-based education. A Dutch patient said: *"I do not want to bother my family with this; it would feel like I want to bring them together to show them how sad I am"*.

As the focus groups generated a lot of rich qualitative data, we generated a model of the results in Figure 2 to ease interpretation and practical use of the findings. Access to LDKT is placed in the middle of the figure and the arrows going and coming from the hurdles indicate the mutual interaction between the access to LDKT and the hurdles.

Figure 2



Legend of Figure 2. A summary model of the psychosocial and cultural hurdles to living donor kidney transplantation (LDKT). In the center one can see the access to LDKT which is influenced by four potential hurdles. In the four outer boxes we have noted the hurdles in bolded headings. The underlined subheadings show the respective issues reported. Below each underlined heading we present our recommendations on how to address these hurdles.

4. Discussion and Conclusion

This focus group study investigated the psychosocial and cultural factors that may constitute hurdles to LDKT. Four major themes emerged which may play a role when a patient is considering LDKT: 1) inadequate patient education 2) impeding cognitions and emotions 3) restrictive social influences 4) and suboptimal communication. Additionally, we investigated openness to possible educational approaches to tackle these hurdles. Results showed that the majority of the patients were open to home-based group education.

4.1. Discussion

The following points should be taken into consideration when interpreting these results. Firstly, the Moroccan group was less likely to elaborate on topics. This observation is not unique in this study and has already been noted among middle-eastern patients consuming heath care in other western societies (21). It may be that unfamiliarity with the Dutch health care system and socio-cultural values of modesty, honor and shame among patients of Moroccan descent account for this observation. Secondly, an interpreter was used in approximately a third of the focus groups: Potential benefits of a translator include having an individual from their own community with whom the patients identify and with whom they can easily communicate. Using trained translators adds the certainty that the information given is translated accurately and not filtered which is the worry when using family members to translate. Potential difficulties include cultural norms (such as modesty) which may inhibit exchange of information. By using professional translators, doubts regarding the trustworthiness of the data were minimized and we were able to incorporate to some extent the views and experiences of those who otherwise would not be represented if translators were not used. Thirdly, the factors we have identified as potential hurdles are a result of the topics we discussed with our patients. Therefore, there may be additional hurdles which we did not touch upon in our interviews. Factors such as, mastery of the Dutch language, socio-economic status (22), and familiarity with the Dutch health care system undoubtedly also play a role. However, the factors identified in this study are more easily modifiable with targeted intervention strategies.

Firstly, patients identified issues with education on LDKT: it was either insufficient, incomprehensible or not tailored enough. These issues with patient education are reflected in the room for improvement seen in the basic knowledge level of the participants. Possibly, as a consequence, patients may lack input and/or confidence to ask important questions in order to fully understand the material and become satisfied. This is in line with the concept of health literacy – the ability to read and comprehend essential health-related materials, the application of information, doctor-patient communication and confidence– (23). The varying experiences and opinions in the group demonstrate that one size does not fit all and a tailored approach to education is required. Possible solutions could be found in providing tailored information, translated materials and using independent interpreters when necessary. In this way, passive information transfer could be replaced with a more interactive transfer.

Secondly, we found cognitive and emotional factors that may impede our patients from pursuing a LDKT. Such cognitive and emotional dilemmas regarding LDKT have also been reported elsewhere in the literature (24). One way to interpret this is that our patients experience some level of ambivalence/dissonance (25): while being positive towards LDKT they hold at the same time cognitions accompanied by emotions which prevent them from pursuing this treatment. Discussing cognitions and emotions that form a hurdle to LDKT may help transform this state of dissonance into a state of consonance.

Thirdly, we found that there were restrictive social influences with regard to who would be an acceptable potential donor. Often these restrictions were based on fears and assumptions. This highlights the necessity of educating not only the patient but also those in their environment. Such familial influences in complicated health problems have been recently described in a study (26). The study by Rohrbaugh and colleagues also reported on resolving such interpersonal communication difficulties. Following their recommendations, a way forward could be that health care professionals discuss the reasoning behind possible oppositions and should encourage the patient's social network to communicate their mutual fears and concerns.

Fourthly, we found that sixty percent of patients approved a wait-and-see attitude towards communicating with potential donors and that this approach is commonplace and accepted in their own communities. This finding has been highlighted by a recent study (27). Ethnic minorities were found to be leading in this passive attitude regarding communication on LDKT. This may be due to cultural norms. Personal factors such as lack of confidence and education, and cultural norms such as maintaining personal relationships and autonomy may also serve to promote this wait-and-see attitude. For instance, patients hold and communicate justifications for non-donation to potential donors which may further impede communication with a potential donor. It is not surprising that this passive deadlock leads to little or no communication on the issue of LDKT. This needs to be addressed from both the angle of the patient as well as the angle of the potential donors.

The themes which we describe are likely to be interrelated. For instance, an attitude towards LDKT may be based on inaccurate information, this attitude may influence others, which may lead to negative emotions which in turn may feed fears and a reluctance to communicate. We believe that the presented concepts are highly interrelated and should be treated accordingly (i.e. a holistic approach).

4.2. Conclusion

It becomes evident from our findings that several psychosocial and cultural hurdles play a role in the discussion of and the choice for LDKT. We regard these hurdles as potentially modifiable and, therefore, we present possible solutions for tackling these hurdles in our model (see Figure 2). A promising way of tackling these hurdles, which was found to be acceptable by these patients, is home-based group education. The core feature of such an intervention is educating patients and their social network in a safe and familiar environment outside the hospital. Such a patient-centered, ‘house-call’ approach reaches out to those patients for whom the doctor-centered, hospital-based approach is not enough.

4.3. Practice Implications

Following our findings and other studies on home-based education, we propose arguments for further testing and implementing of a home-based education intervention to address hurdles to LDKT. Our findings are in line with the content of the US home-based educational model (11). In order to translate this intervention to the Dutch population and tailor it to the specific ethnic groups found in the Netherlands (or other European countries), additional attention should be paid to communication, social influences, in addition to knowledge, cognitions and emotions. Contact with cultural and familial values is inevitable when providing health care to culturally diverse populations (28). Thus there is a need for sensitivity and awareness of how such cultural factors influence decision-making (e.g. patterns of familial power) when healthcare professionals engage with culturally diverse populations. We are currently testing such a home-based educational intervention in a randomized controlled trial (29). By educating the social network together with the patient, everyone receives the same correct information. Indeed, research has shown that patients with higher knowledge on LDKT are more likely to favor living donation (6). Moreover, the responsibility of addressing this sensitive subject is removed from the patient and handed over to a professional. This offers the social network the opportunity to ask questions immediately and address and share their fears. Of course, as highlighted by the patients themselves in this study and by other authors (30), any intervention of this kind should be voluntary and non-persuasive.

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Chapter 3

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 invention targets.

Keywords:
Attitude to health, Cultural Diversity, Communication, Living Donors, Patient education

1. 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 (1). However, as found in other countries (2), 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 (3). 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 (4). 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 donor 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 (5). Besides ineffective communication (4), research has also suggested that shortcomings in knowledge might also contribute to the low LDKT rates among ethnic minorities (6). Other factors suggested in the literature include: attitudes towards disease (7), cultural factors (8), and awareness of the religious viewpoint on living donation (9). In many countries medical and socio-economic factors also contribute to the aforementioned inequality (10, 11). 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.

2. 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 (12). 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 waitlisted 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 (13). Focus group discussions offer the particular advantage that individuals can participate who may be excluded from written assessments due to language or literacy barriers (13). 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 (14). 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 (15).

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)	58.4 (28-74)
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)

3. 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.

3.1. 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 received 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.

3.2. 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”.*

4. 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.

5. 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 tenfold (16). 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.

5.1. 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 (17). 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 (18). 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 non-Dutch patients in our study. This similarity of attitudes towards LDKT between different ethnic groups has been reported elsewhere in the literature (16).

5.2. 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 (5). 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 (19). 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.

5.3. 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 (20). 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 (21).

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.

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Chapter 4

Religious attitudes towards living kidney donation among Dutch renal patients

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Abstract

Introduction: Terminal kidney patients are faced with lower quality of life, restricted diets and higher morbidity and mortality rates while waiting for a deceased donor kidney transplantation. Fortunately, living kidney donation has proven to be a better treatment alternative (e.g. in terms of waiting time and graft survival rates). We observed an inequality in the number of living kidney transplantations performed between the non-European and the European patients in our center. Such inequality has been also observed elsewhere in this field and it has been suggested that this inequality relates to, among other things, attitude differences towards donation based on religious beliefs. In this qualitative research we investigated whether religion might indeed (partly) be the explanation of the inequalities in living donor kidney transplants (LDKT) among non-European patients.

Methods: Fifty patients participated in focus group discussions and in-depth interviews. The interviews were conducted following the focus group method and analyzed in line with Grounded Theory. The qualitative data analyses were performed in Atlas.ti.

Results: We found that religion is not perceived as an obstacle to living donation and that religion actually promotes helping and saving the life of a person. Issues such as integrity of the body were not seen as barriers to LDKT. We observed also that there are still uncertainties and a lack of awareness about the position of religion regarding living organ donation within communities, confusion due to varying interpretations of Holy Scriptures and misconceptions regarding the process of donation. Faith leaders play an important educational role and their opinion is influential.

Discussion: This study has identified modifiable factors which may contribute to the ethnic disparity in our living donation program. We argue that we need to strive for more clarity and awareness regarding the stance of religion on the issue of living donation in the local community. Faith leaders could be key figures in increasing awareness and alleviating uncertainty regarding living donation and transplantation.

Keywords: Attitudes, Communication, Ethnicity, Kidney transplantation, Organ donation, Religion

Introduction

Living donor kidney transplantation (LDKT) is associated with significant patient and graft survival benefits when compared to deceased donor kidney transplantation (DDKT) (1). Furthermore, undergoing LDKT can avoid or minimize the negative physical, social and emotional consequences of long term dialysis. However, there is evidence to suggest disparities in access to LDKT programmes among diverse ethnic groups (2).

As disparities in access to living donor kidney transplantation may translate into higher morbidity and mortality for patients from ethnically diverse backgrounds, an important line of investigation is exploring possible factors that play a role in this disparity. In kidney patients various factors are likely to contribute to this disparity including a higher susceptibility to renal disease due to high levels of diabetes and blood pressure (3) and allocation rules based on Caucasian blood distribution and HLA makeup (4). In addition psychosocial and cultural factors may also be of influence. How do patients from ethnically diverse backgrounds view living donor transplantation? Our aim was to gain insight into why we have observed disparities in the number of patients being transplanted with a living donor kidney.

Research into attitudes towards deceased organ donation has highlighted many potential barriers to organ donation such as cultural rituals surrounding death, alienation from or distrust in the health care system, discrimination and exclusion from mainstream society, and lack of awareness of the organ shortage issue and donor registration (5-9). Although the various religions do not appear to prohibit the giving and receiving of living or deceased donor organs, objections to both are often made on religious grounds (10). Some of these objections relate to sacredness of the body, desecration of the body after death, trusteeship of the body from God, fatalism towards the issue of illness and death, the body remaining intact for resurrection, organs acting as witnesses on Judgement Day and concerns regarding the conduct and religion of the recipient (5, 10). One source of difficulty is that organ transplantation is not explicitly discussed in holy scriptures such as the Bible or the Qur'an, which has resulted in varying opinions on the issue among scholars, faith leaders and their followers.

Although previous studies give insights into attitudes within ethnically diverse communities towards organ donation *after death*, there is little research on attitudes towards *living donation*. The study by Alkhawari and colleagues describes their participants voicing 'great disquiet' about living donation, although these concerns were quantitively fewer than for deceased donation. Religious issues among ethnic groups hindering the LDKT process need to be sorted out, so that tailored interventions could be offered to these groups, which are –as research has shown- overrepresented on the deceased donor waiting list (2). The main aim of this study was to investigate the attitudes of End Stage Renal Disease (ESRD) patients regarding living donor transplantation and religion. This paper focuses specifically on the role of religion in attitudes towards LDKT; other barriers to LDKT are discussed elsewhere (11).

Methods

Participants: We included patients from the largest ethnic groups in the Netherlands, and specifically in the Rotterdam area: Turkish, Moroccan, Surinamese, Dutch Antillean and Cape Verdean populations. Participants were required to be over 18 years of age and to be on the waiting list for deceased donor transplantation with no living donor. No restrictions were set as to gender or type of dialysis.

Procedure: Focus groups were used to collect data on attitudes towards living donor transplantation. When the patient was not able to travel or if they preferred not to participate in a group discussion an in-depth interview was conducted. In the focus group discussions as well as in the in-depth interviews, the patients were free to mention anything on the topic at hand. Focus group discussions have the additional advantage of stimulating a group discussion on the topic compared to the individual interview. Thus we chose not to ask our patients about their attitude towards predefined barriers. Consequently all the results are generated by a bottom-up process and may (widely) differ across patients or not be addressed to by all patients. The procedure is discussed in greater detail elsewhere (11) and is based on the methodology of Randhawa and colleagues (12).

Preparation: An expert steering group was established and consulted on how to optimally conduct the focus groups and development of the topic list. The steering group consisted of physicians, transplant coordinators, social workers, psychologists, and experts from organizations who work with immigrant groups and dialysis patients from the target ethnicities. After consultation the definitive topic list was tested during a practice focus group session.

Moderator recruitment: Moderators were recruited from local hospitals or local immigrant organizations. All had experience with leading group discussions. We aimed to recruit moderators from the same ethnic background for each focus group. The purpose of this was to put participants at ease, to optimize open discussion of the issues and to allow participants to communicate in their mother tongue if desired (all moderators were also fluent in the Dutch language). Group sessions were co-moderated by a researcher (SI, EM, or LC). Moderators were trained by the researchers in the aims of the study and use of the topic list.

Participant recruitment: The deceased donor waiting list was reviewed and patients from Turkish, Moroccan, Surinamese, Dutch Antillean and Cape Verdean origin were approached preferably during their regular visit to the out-patient clinic. A comparison group of patients with a Dutch origin was also invited to participate. All patients invited to participate received written information on the study via the post in Dutch plus Turkish or Arabic for the respective groups. This was a convenience sample and may not be representative of all opinions, particularly of those we were unable to contact and those who did not want to participate. Patients were contacted within one week of receiving the study information pack to ascertain participation. Those who chose to participate were sent written confirmation of the appointment along with logistical information such as location. To maximize attendance all participants were contacted by telephone on the day prior to the interview.

Data collection: Focus groups were held in a classroom or meeting room at the hospital. On the advice of the steering group discussions were held separately for men and women of Turkish and Moroccan origin but this was not felt to be necessary for the other ethnicities. The patients were allocated to a focus group with patients from the same ethnic background. First names only were used to protect anonymity. All participants gave written informed consent. The interview commenced with a description of a case study and the questions then followed a pre-devised topic list. The hypothetical case study was used as a less personal spring board to get the discussion started. Participants were encouraged to be honest, to react to each other’s answers and to discuss any disagreements or inconsistencies if they arose. Techniques that were employed during the focus groups included five-second pauses, probing, playing devils advocate and asking questions by proxy (13). The meetings lasted between one and two hours. All participants received a €20 voucher and travel expenses were reimbursed or the transportation was arranged by the researchers.

Analysis: All interviews were audio recorded and transcribed verbatim. Sections of the interviews spoken in languages other than Dutch were translated immediately into Dutch by the respective moderator during transcription. Data were analysed in the Atlas.ti software package using the principles of Grounded Theory (14). Words or phrases were combined together in order to generate categories. This process continued until all transcripts were analysed and no new categories emerged. Subsequently, the content of the categories was analysed for overlapping or linking content. The categories were then compressed and clustered together into themes. Finally, the themes were evaluated across the different ethnic groups to search for similarities and differences in these themes.

Results

In total 50 patients participated in the study (26 males; 25 females). Age ranged from 21 to 74 (M = 54.2, SD = 12.2). Muslim patients were included in 3 groups: Moroccan (n = 7), Turkish (n = 10) and Surinamese (n = 2). Christian patients were included in 4 groups: Surinamese (n= 4), Antillean (n = 7), Cape Verdean (n = 6) and Dutch (n = 7). Four Surinamese patients were Buddhist and 3 Dutch patients were Atheist (coded as no religious affiliation).

Patients' perception of religion and LDKT

Nearly all our patients with a religious affiliation reported that their religion is in favour of living donor transplantation (41/47). This holds for all faith or belief groups (Muslim, Christian and Buddhist), and European as well as non-European patients. A Muslim Moroccan patient said: *"I know Islam quite well and I know what the principles are. Islam is not against it."* Some patients not only refer to just the accepting but also to the giving of organs. A Muslim Turkish patient: *"According to our beliefs you can become a donor, and you can also accept."* Three patients did report not having a religious affiliation (all 3 European) and therefore did not have an opinion on the viewpoint of religion on this issue. Other patients mentioned not knowing what their religion would have to say on this matter. A Turkish patient said that the viewpoint of the religion towards living donation was dependent on the culture rather than religion (i.e. depending on the geographical area; West versus East). Data on the opinion of the remaining other patient was missing. According to the patients, the most common reasons for adopting a positive attitude towards living donation were 1) that religion promotes helping others and 2) to save someone's life when possible. In addition, possible objections based on religious grounds were discussed. We discuss these issues in more detail below.

Helping others: Nearly half of our Turkish and Moroccan patients (all Muslim) stated that their religion would support living donation based on the reasoning that their religion promotes helping others (see Table 1), although donating a kidney may be an extreme form of helping. Islam regards it as helping and therefore would promote living donation, the other non-European patients (Surinamese, Antillean and Cape Verdean) did not offer this reasoning.

Our European patients reported that also in Christianity people cherish the idea of helping others. Consequently, this groups' religion supports living donation.

Table 1

Reasons to donate a living kidney – Helping one another

"From a religious perspective it's a good thing to help somebody. Living donation would help you to do good."	Muslim, Moroccan
"I think it's a noble act. It's the highest thing you can offer, that you can do. It's proof that you are a good person if you do that."	Muslim, Moroccan
"We are all people and should help each other, if it helps to save the life of another then I don't have any objections. It's universal. We live together and should help each other. It's a connection with your fellow man."	Muslim, Moroccan
"Regardless of one's religion I would help my people. No, religion wouldn't make a difference, people are people, and they help each other."	Christian, Dutch

This table displays patients' attitudes with regard to living kidney donation from a religious perspective.

Save a life: According to non-European patients, all religions (Islam, Christianity and Buddhism) are in agreement that a legitimate reason to donate a kidney should be that of saving a persons' life (see Table 2). According to the patients their religion states that it does actually not matter in what way you save a life. Therefore, donating a (living) kidney (with the motive of preventing the recipient from dying) would be supported by the religion of our patients. This point was exclusively shared by the non-European patients whereas none of the European patients spontaneously reported this rationale.

Table 2

Reasons to donate a living kidney – Save a life

"Saving one life is saving a thousand lives."	Muslim, Turkish
"Saving someone means saving everyone, according to our prophet (peace be upon him). And the other way round, if you let someone die, it means letting everyone die."	Muslim, Turkish
"The Islam is for the improvement of people's lives. If kidney transplantation or transplantation in general can contribute towards this then it's also welcome!"	Muslim, Moroccan

"You save someone's life, no problem whether it's Catholic or otherwise, it doesn't matter. It's a life, they are all people."	Muslim, Moroccan
"If you are able to help someone stay alive by giving a part of yourself than you should do that! God will reward you for this act."	Muslim, Moroccan
"The religion supports it. If you can save someone, why not?"	Muslim, Moroccan
"In Buddhism it's literally stated that you should save a life when you get the chance."	Buddhism, Surinamese
"You should take and give anything that is good for a human life."	Christian, Antillean

This table displays patients' attitudes with regard to living kidney donation from a religious perspective.

Possible religious objections: Possible objections for living organ donation and transplantation were raised and discussed by the patients. One main issue was the belief that the body should enter the grave whole. In particular Turkish and Moroccan patients referred to this issue (see Table 3). These patients were aware of this issue but did not view it personally as a barrier to living donation or acceptance of a kidney from a living donor.

Table 3

Possible religious objections – Integrity of the body

"It's in the Qur'an: It's the soul which goes to god not the body". "People think that you should be complete when you die. That's not in the Qur'an, in fact, it's the soul that goes to heaven/ascends and not the body"	Muslim, Turkish
"Bodily integrity is not relevant. Nonsense. The body, is like a machine that contains different parts. It has to function in it's entirety. If a part doesn't work anymore then you should repair or replace it."	Muslim, Moroccan

This table displays patients' attitudes with regard to living kidney donation from a religious perspective.

Additionally, a Christian Antillean patient believed that living organ donation can only take place within families based on religious beliefs: *"I thought that because of religion it can only be someone from your own family, but isn't allowed from someone else, that's what I thought."*

Patients' view on the attitude of the community

We also investigated the perceived attitude of the patients' communities on the issue of living donor transplantation. Our patients mentioned four different issues on this topic. First, the majority of our patients were quite uncertain about what their community's opinion on living donation might be. A Muslim Moroccan patient: *"Everyone in the community thinks differently about it. They all have different ideas."* Approximately half of the Turkish, Moroccan and Surinamese patients stated that they actually would not know what their community's point of view on living donation is. A minority reported that others in the community would adopt a positive attitude toward living donation from a religious perspective. A Muslim Turkish patient: *"Even the dinyanaat (the director of religious affairs in Turkey) was positive about living donation and even encouraged it."* None of our patients reported the belief that their community would be against living kidney donation for religious reasons. Our Cape Verdean patients could not tell us anything about their community's attitude. We did not record what the community of our European patients would think of living donation from a religious point of view.

Secondly, we observed that there are varying interpretations across cultures or countries. A Muslim Turkish patient: *"The interpretation of Islam is not always the same among Muslims, also among Moroccans and Turks"; "Some Turkish people are allowed to give. There are different areas. In the West they are more likely to give".*

Thirdly, patients refered to the lack of awareness within their community regarding living kidney donation. A Turkish Muslim: *"It's a big problem in our culture, there is a lot of ignorance about it";* Another Turkish Muslim: *"There's no influence of religion. It's a lack of awareness. The Mosque isn't negative about it, it's the people that are. Because they are not experts on this issue. But not only in this area. People talk about lots of topics but what they say usually isn't right".*

Finally, there are varying (mis)interpretations within the community regarding the viewpoint of religion with respect to organ donation. A Turkish patient reported that, for example, people from the Muslim community believe that their religion would disapprove of exchanging blood with a non-blood relative (this implies that they think blood exchange occurs when an organ is transplanted). A Turkish Muslim: *"People think for example that if you receive a kidney from someone else you also take on their blood and become part of their family."* However, this scenario is undesirable only in the case that the donor is either a non-Muslim or a non-Believer. Another Turkish patient who is also an Imam stated that a minority of the Muslim community (approximately 20%) believes in the preservation of the body after death. He explicitly stated and preaches in the mosque that this is a misunderstanding: *"Some people think that religion (Islam) forbids it. They think that you have to be complete when you die. This isn't in the Qur'an, in fact, it's the soul that ascends and not the body."*

Although there is uncertainty about what the community might think about the issue of organ transplantation and living donation, the educational/guiding role of the Imam was clear: A Turkish Muslim: *"The Imam has clearly said you can be a donor. If the Imam says that it can, then it's ok."*; A Surinamese Muslim: *"I think that in the mosque the Imam knows the most. But I don't know what their opinion* is *on this."*

Discussion

We aimed to investigate the role that religion plays in the observed inequalities in access to transplantation with the kidney from a living donor among our non-European kidney patients. Religion itself was not found to be a barrier to LDKT from the perspective of our patients. According to our patients Islam, Christianity and Buddhism do not prohibit the giving and receiving of living or deceased donor organs. It is rather on the contrary: the respondents indicated that their religion would encourage living donation, and we found that patients from various cultural and religious backgrounds share common reasons for why their religion supports organ donation. Saving a person's life and helping others in need were the shared religious arguments for promoting donation across the three religions. This finding suggests that the inequities seen in living donor kidney transplantation between Europeans and non-Europeans are not rooted in religious beliefs.

We have also identified some barriers to living organ donation from the perspective of the community from a religious point of view. We see that, for example, some of the Muslim patients would not accept blood and/or organs of a non-Muslim. They believe that if they receive non-Muslim bodily substances that they will become (partially) non-Muslim themselves. Bruzzone (2008) has also found that some Islamic scholars propose directed organ donation only to people with the same religion. AlKhawari et al. 2005 refer to the reasoning behind this directed donation since non-Muslim donors may have engaged in acts that are forbidden for Muslims, such as eating pork, drinking alcohol or smoking. However this line of reasoning would also prohibit the willingness to receive a deceased donor kidney since the recipient can never know from whom the kidney originated and what their colour, creed or behaviour was. Whereas, in living donation the source of the organ is known and generally from a loved one (family member or friend). This issue should not be considered as a barrier to living donation since the majority of the donors in ethnic minorities are usually of the same faith as the recipients (2). Because of this we assume that the majority of living donations within families is not faced with the issue of dealing with the donor's religion. This may also partially account for the fact that in Arab countries living donation is the most widely practiced type of donation (15). Based on present result we do not know whether *giving* blood or organs to a non-Muslim or a non-Believer would also be withheld based on religious grounds.

In the present study our Muslim patients shed more light on the issue regarding the bodily integrity of a Muslim person. The conception of bodily integrity is widely accepted within and outside medicine, discussed and contested in philosophy, and part of international law, that aims to protect individuals against undue interference with the body. Integrity of the body is not perceived as a reason to prohibit living donation among patients but is recognised as a possible barrier within the community. According to our patients there is a minority of people who do believe in the perseveration of the body by death. This can be seen as a belief that takes the accepted idea of bodily integrity one step further. The uncertainty regarding the nature of these beliefs and the corresponding misunderstandings are also recognized elsewhere (16) and need to be addressed by the spiritual leaders.

Varying interpretations of Holy Scriptures are common and generate confusion. Widespread lack of awareness and uncertainty regarding the viewpoint of religion regarding living donation may be a consequence of non-communication on this issue at a community level. Both the findings in our study and the study of Alkhawari (2005) refer to the Imam as an authoritative figure in the community who advises on such issues. Our patients will predominantly practice what their faith leader preaches. However, not all patients seem to know what their faith leader thinks about this topic. Positive messages had been disseminated by major faith leaders (e.g. the Pope Benedict XVI) (7, 17, 18). In the Islam, for example, the earliest discussions on transplantation of solid organs date back to 1982 following a meeting in Jeddah when the Saudi Grand Ulema (Islamic scolar) gave a *fatwa* (religious edict) on permitting both living and deceased donation according to the Shari'a (Islamic law) (19, 20). Permissity was granted on reasons such as the duty to help/save a life when possible, and the sanctity of human life. Nowadays, the Islamic Fiqh Academy (IFA), Muslim World League (MWL) headquartered in Mecca embodies the strict interpretation of the fiqh (Islamic jurisprudence) by the rules of the Shari'a. They have ruled that living kidney donation is permissible in the light of Shari'a as long as there is a) no significant harm for the donor and b) the donation is voluntarily and without any from of coericion (21, 22). Despite these clear rulings there is often, at the grass-roots level, a lack of consensus. One could consider reaching out to faith leaders to put this topic on their agenda when preaching to their community. One study has demonstrated a need for such an approach as many spiritual leaders know little about the organ donation program (5). This approach is in line with recent findings indicating that the faith leaders too are in favour of organ donation and some even actively promote this practice (18).

Although patients' beliefs regarding religion do not appear to form a barrier for living donation, our findings indicate that raising awareness in the community regarding LDKT from a religious perspective could be very useful. A possible target for intervention would be to educate the family and close network of the patient, since living donation is not a solely activity. This social approach would also be in line with tackling a social factor that we have discussed elsewhere, which is identified as 'social influence' (11). Using this approach, health care professionals could start with assisting their patients and their families in dealing with misunderstandings and communication issues. This approach would be consistent with Randhawa's grass-root approach. As health care professionals we can address the multifaceted issues in living organ donation by taking on this out-reaching approach at a local level (23).

To conclude, one should absolutely not forget to engage in dialogue and collaborate with the religious faith leaders also at a local level. This is essential given their authoritative and educational role in the community and given that these spiritual leaders may also be unaware of rulings on deceased and living donation. For purposes of a systemic approach we would recommend to additionally educating physicians on the aforementioned potential religious barriers. There remains to be a need of more intensified research in this area by including more religious (sub)groups and by more systematically discussing (living) organ donation with respect to religion in order to understand the attitude of ethnic minorities more clearly. Particularly, with respect to general universal human rights (i.e. acknowledging and cherishing the value of life) the Islam, Christianity and Buddhism are in favour of giving and taking an organ.

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Chapter 5

Modifiable factors in access to living donor kidney transplantation among diverse populations

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Abstract

Background: We have observed a significant inequality in the number of living donor kidney transplants (LDKT) performed between patients of non-Western European origin and those of Western European origin. The aim of this study was to investigate modifiable factors that could be used as potential targets for an intervention in an attempt to reduce this inequality.

Methods: A questionnaire on knowledge, risk perception, communication, subjective norm, and willingness to accept LDKT was completed by 160 end-stage renal patients who were referred to the pre-transplantation outpatient clinic (participation rate 92%). The questionnaire was available in nine languages. Multivariate analyses of variance were conducted to explore differences between patients with and without a living donor.

Results: There were significantly fewer patients of non-Western descent (11/82) that brought a living donor to the outpatient clinic than patients of Western descent (38/78). After correcting for the unmodifiable socio-demographic factors non-Western descent, low knowledge, little communication about their kidney disease and low willingness to communicate with individuals from the social network about LDKT were significantly associated with the absence of a living donor.

Conclusions: Knowledge and communication are identified as modifiable factors that are associated with the likelihood of identifying a potential living donor for LDKT. This observation makes knowledge and communication targets for interventions to reduce inequality in access to LDKT.

Keywords:

Living Kidney Donation; Ethnicity; Family Communication; Patient support program; Counseling

Introduction

Living donor kidney transplantation (LDKT) is associated with significant patient and graft survival benefits when compared to deceased donor kidney transplantation (DDKT) or dialysis. As a result of this and the lengthy waiting list for DDKT, LDKT rates have been steadily increasing and now exceed those of DDKT in the Netherlands (1). Although 44% of the patients on the waitlist for DDKT in our centre are from non-Western European origin, this group only constitutes 15% of the LDKT donors (2). This means that non-Western patients are less likely to benefit from the advantages of living donation. Recent studies reported on medical, socio-economic and ethnic factors which were each related significantly and independently to the chance of receiving a LDKT (3, 4). The little research available shows that shortcomings in knowledge (5), attitudes towards disease and treatment in general (6), communication about LDKT (7), and social support (8) may influence access to LDKT. In this paper we explore these latter 'modifiable' factors that are associated with the inequality in access to LDKT in an attempt to find potential targets for interventions.

In this present study we aimed to build a parsimonious, hierarchical model in which first the socio-demographic factors are added and secondly the cognitive and psychosocial factors which were retrieved from the Attitude-Social influence-Efficacy model (ASE-Model) (9). The ASE-Model is based on the Theory of Planned Behaviour (10) and is supplemented by elements from the Social Cognitive Theory (SCT) (11). The ASE-Model represents a theoretical framework to explain intention and behaviour by attitude, social influence, self-efficacy, knowledge, skills (communication), and barriers and resources (risk perception). While controlling for unmodifiable socio-demographic factors, the ASE-Model helps us to identify modifiable cognitive and psychosocial factors that are associated with the event that certain patients have identified a potential living donor and others do not.

Results

Univariate analyses

The following results concern the unmodifiable socio-demographic factors. There were significantly fewer non-Western (11/82) patients with a living kidney donor compared to the Western (38/78) patients ($p<0.001$). With respect to registration as an organ donor after death, significantly fewer non-Western patients were registered compared to Western patients ($p<0.001$). Also, patients without a living donor were undergoing haemodialysis more often than peritoneal dialysis compared to patients with a living donor ($p=0.002$). Patients without a living donor (*m*=29.4) have spent on average more months on dialysis compared to patients with a living donor (*m*=11.6) (*p*<0.001). Furthermore, there were also differences in working status: patients with a living donor were more likely to be employed than patients without a living donor (*p*<0.001). There were no differences between the four groups on age (*p*=0.06), gender (*p*=0.905), educational level (*p*=0.338), blood type (*p*=0.816), PRA maximum (*p*=0.164), prior deceased donor kidney transplantations (*p*=0.797) and history of LDKT (*p*=0.108). Table 1 shows the descriptive analyses for the socio-demographic variables.

The following results concern the modifiable cognitive and psychosocial factors. Patients with a living donor scored higher on the frequency of communication about their kidney disease (*p*=0.005) and their self-efficacy with regard to communication (*p*=0.022) compared to patients without a living donor. Western patients with a living donor were significantly more willing to accept a LDKT (*p*=0.039) than non-Western patients with a donor. Finally, western patients showed higher scores on knowledge (*p*<0.001), willingness to communicate with others about RRT's (*p*=0.038) and the frequency of discussing RRT's (*p*=0.028) than non-Western patients.

Table 1. Socio-demographic characteristics

	Western		Non-Western	
	(N=78)		(N=82)	
Characteristics	LDKT + (N = 38)	LDKT - (N = 40)	LKDT + (N = 11)	LDKT - (N = 71)
Gender (male / female)	22/16	22/18	5/6	40/31
Mean age in yr (SD)	55.8 (12.4)	59.2 (11.0)	48.7 (13.0)	53.9 (11.9)
Educational level (1-3, %)*	1=44.7	1=67.5	1=63.6	1=53.5
	2=44.7	2=20.0	2=27.3	2=23.9
	3=10.5	3=7.5	3=9.1	3=11.3
	Missing: 0.0	Missing: 5.0	Missing: 0.0	Missing: 11.3
Working (full- or part-time %)	47.4	27.5	27.3	9.9
Mean number of children	2	2	3	3
No Dialysis (%)	15 (39.5)	3 (7.5)	4 (36.3)	13 (18.3)
PD (%)	10 (26.3)	11 (27.5)	3 (27.3)	13 (18.3)
HD (%)	13 (34.2)	26 (65.0)	4 (36.4)	44 (62.0)
				Missing: 1 (1.4)
Mean mo on dialysis (SD)	12.2 (15.6)	32.6 (36.5)	9.3 (10.6)	27.6 (27.8)
A history of KTx (%)	4 (10.5)	4 (10.0)	2 (18.2)	6 (8.5)
History of LDKT (%)	2 (5.3)	0	0	2 (2.8)
PRA maximum >10% (%)	4 (10.5)	9 (22.5)	2 (18.2)	15 (21.1)
Registered for deceased organ donation (%)	17 (44.7)	17 (42.5)	1 (9.1)	6 (8.5)
Blood type (N)				
O (%)	19 (50.0)	19 (47.5)	5 (45.5)	39 (54.9)
A (%)	13 (34.2)	14 (35.0)	5 (45.5)	18 (25.4)
B (%)	5 (13.2)	6 (15.0)	-	11 (15.5)
AB (%)	1 (2.6)	1 (2.5)	1 (9.0)	3 (4.2)

Values in the table are presented as *n* with the percentage in parentheses or mean values with ±SD in parentheses. *The educational level was valued at three levels; 1 = Low; elementary school, 2 = Average; high school (+ some college) and 3 = High; college degree (+ some postgraduate/professional degree). KTx = kidney transplantation. LDKT=Living donor kidney transplantation. PRA=panel-reactive antibody.

Multivariate analyses

Firstly, in the first block on unmodifiable socio-demographic variables, analyses showed that non-Western descent (reference=non-Western: OR 7.50, $CI_{95\%}$ [2.67-20.83] is negatively associated with the likelihood of having a living donor. Religion was not significantly associated with having a living donor (*p*=0.985). Given the multicollinearity of religion with ethnicity we have modelled religion after removing ethnicity from the model. Again religion had no significant addition to the model (*p*=0.206).

Secondly, the modifiable cognitive and psychosocial factors were added to the model in the second block on top of the variable found in the first block. Results from this second block showed that knowledge (OR 2.01, $CI_{95\%}$ [1.14-3.57], *p*=0.017) is positively associated with the likelihood of having a living donor. Furthermore, the frequency of communication about kidney disease (OR 2.37, $CI_{95\%}$ [1.33-4.22], *p*=0.003) and patients' willingness to discuss RRT's with individuals from their social network (OR 2.16, $CI_{95\%}$ [1.32-3.56], *p*=0.002) are also positively associated with the likelihood of having a living donor. However, the communication about RRT's (OR 0.426, $CI_{95\%}$[0.23-0.80], *p*=0.008) shows a negative association with the likelihood of having a living donor.

Thirdly, when interaction terms between the unmodifiable socio-demographic and the modifiable cognitive and psychosocial factors were added to the model in a third block, none of the interactions remained significant in the final model (Table 2).

Table 2. Results of the multivariate binary logistic regression analysis of having a living donor

Variable	***P***	**Exp (*B*)**	**95% CI of Exp (*B*)**	
			Lower	**Upper**
Descent	**<0,001**	**7,496**	**2,698**	**20,828**
Knowledge	**0,017**	**2,013**	**1,135**	**3,571**
Willingness to communicate	**0,002**	**2,163**	**1,315**	**3,558**
Communication on kidney disease	**0,003**	**2,370**	**1,332**	**4,216**
Communication on RRT's	**0,008**	**0,426**	**0,227**	**0,797**

This table shows the characteristics of the most parsimonious model of independent factors associated with the likelihood of having a potential living donor using a multivariate binary logistic regression. RRT, renal replacement therapies; LDKT, living donor kidney transplantation; KTx, kidney transplantation.

The final model with the socio-demographic, cognitive and psychosocial factors showed good fitness properties. The significant factors in the model explained 38.9% of the variance and correctly predicted 69.2% of the cases with respect to having a living donor. The

Hosmer-Lemmeshow test confirms the goodness of the fitted model (X^2=8.85, df= 8, *p*=0.356). The ROC analysis showed excellent discrimination properties of the final model as a predictor of LDKT access (AUC: 0.859, $CI_{95\%}$ [0.770-0.903]) (Figure 1).

Figure 1

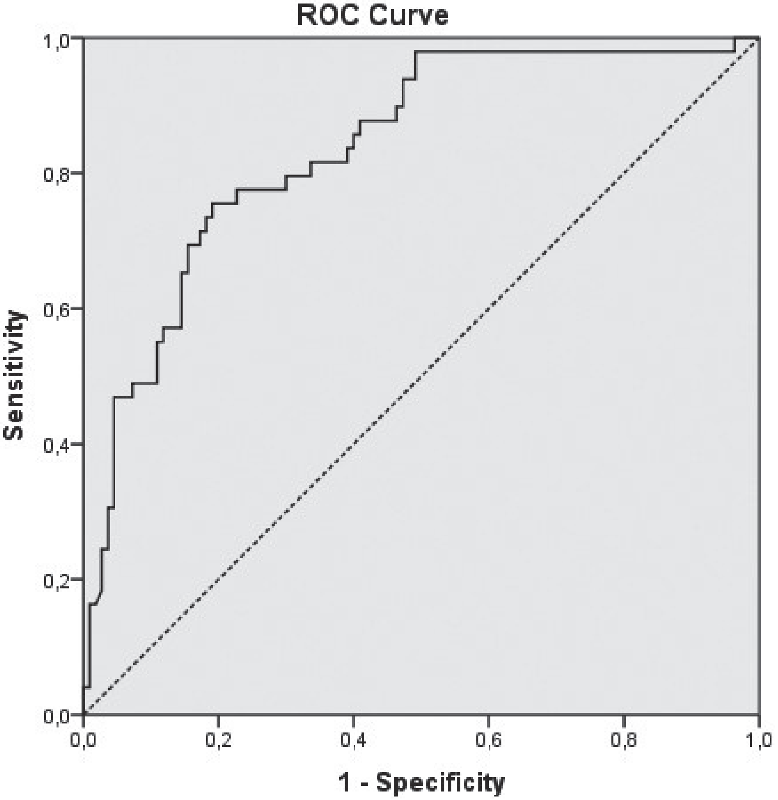

Figure 1: Receiver-operating characteristics (ROC) analysis showing the final model containing descent, knowledge, communication on one's kidney disease and willingness to communicate with individuals from the social network as independent factors associated with the likelihood of having a potential living donor for LDKT.

Discussion

This study set out to find modifiable cognitive and psychosocial factors that are associated with the likelihood of identifying a potential living donor in an attempt to find potential targets for interventions. The results showed that cognitive and psychosocial factors are significantly associated with the likelihood of identifying a living donor. Knowledge, the frequency of communication about kidney disease and willingness to communicate about

RRT's was positively associated with having a living donor. Remarkably, the frequency of patients' communication about RRT's is negatively associated with the likelihood of identifying a potential living donor.

The following potential limitations should be considered when interpreting our results. Although the magnitude of the difference between Western and non-Western patients was explored, the inherent underrepresentation of non-Western patients in the group with a living donor may have led to lower statistical power. Our presented results show associations between the factors and the outcome variable which is different from causations. Further prospective studies are warranted to test for causality. A comment should also be made with regard to the use of Likert-scales in a cross-cultural setting. Research has indicated that response patterns may be affected by culture (12). Finally, we are aware of the heterogeneity of the non-Western group also given the number of translations we have performed for our questionnaires as well as our written and DVD educational material. However, our dichotomous approach (Western versus non-Western) is line with a recent study which showed that it is rather being an ethnic minority that is unfavorable to the access of LDKT than having a particular ethnic background (3). In order to adequately explore the hypothesis of heterogeneity in minorities using the presented model more data should be collected on each of the ethnic groups. The potential discussion regarding the definition of ethnicity appeared not to be applicable to this study population following our sensitivity analysis. Hence, potential differences between a technical definition of ethnicity and a more cultural based definition showed no effect on the results of this study.

This study again reveals an inequality in the rates of LDKT even though we also found that non-Western patients have larger nuclear families. It seems that just having a large nuclear family is not necessarily beneficial in terms of LDKT. Together with the results on modifiable factors it appears that non-Western patients need to employ a more active role in terms of knowledge and communication to close the gap in LDKT rates with their Western counterparts. This need for a more active approach had indeed already been identified in the literature (13, 14). Another recent study has indicated that the social network can be very influential in the communication and decision-making surrounding LDKT (6). However, if that network lacks the appropriate knowledge and holds misconceptions regarding LDKT then social influence is likely to be negative. An alternative explanation might be related to the results of an earlier study that showed that there are still uncertainties and a lack of awareness about the position of religion regarding living organ donation within communities, confusion due to varying interpretations of Holy Scriptures and misconceptions regarding the process of donation (15). Thus we have added religion separately and in addition to ethnicity to the model and found that religious affiliation was not associated with bringing a potential donor to the pre-transplantation out-patient clinic. Another finding was that non-Western patients are less likely to register for deceased donation. This finding again stresses that non-Western patients' play a less active role in the Western health care system when compared to native residents (16). A way forward could be that health care professionals endorse a more out-reaching and patient-empowering approach for this group of patients in order to redress inequality in access to LDKT. The present study revealed targets for such a patient education and counseling intervention.

A unique finding in this study is that on top of the unmodifiable some modifiable factors associated with having a living donor have been identified. Firstly, knowledge was highlighted as a factor which was positively associated with patients' likelihood of identifying a potential donor. Thus, patient education to improve knowledge is crucial. Furthermore, the way in which patient education is delivered is also of importance. An earlier study showed that a more active/interactive transfer of knowledge facilitates patients' consideration and communication regarding LDKT (17). Secondly, patients' willingness to communicate with individuals from their social network about RRT's and the frequency of communication about kidney disease is positively associated with the likelihood of identifying a living donor. However, in our study we find that the frequency of communication about RRT's specifically (in contrast with discussion about kidney disease in general) is negatively associated with the likelihood of having a living donor. Apparently, patients should be willing to communicate about RRT's and initiate the communication by explaining their kidney disease. Whereas, direct communication about RTT options may have a detrimental effect. The reason for this is not yet clear. Indeed, patients find it difficult to directly discuss living donation with potential donors and patients' limited experience is often found to be discouraging (6, 18).

The findings point towards the need for a more interactive and out-reaching approach by health care professionals focusing on knowledge and communication. Several studies indicate that such an out-reaching approach can be successful in reducing inequality in LDKT (19, 20). There are also ongoing RCT's testing such interactive educational programmes (21, 22). This paper highlights modifiable targets for such interventions on top of the unmodifiable factors.

Materials and Methods

Participants: Patients who visited the pre-transplantation outpatient clinic of the Erasmus MC, between 1 March 2011 and 31 July 2012 were asked to participate in the study (n=174). None of the patients refused to participate by completing the questionnaire. However, 14 patients could not complete the questionnaire due to logistic issues. Thus 160 patients (92%) provided questionnaires for complete case-analyses.

Procedure: A questionnaire on knowledge, risk perception, self-efficacy, communication, subjective norm, and willingness to accept LDKT was completed by the participants. Patients completed the paper and pencil questionnaire in approximately 20 minutes in the presence of a researcher (either one of the two first authors) at the outpatient clinic. Considering the large variety in ethnicities in our municipality, patients could choose in which language they wished to complete the questionnaire from the following languages: Dutch, English, French, Spanish, Arabic, Turkish, Papiamento, Portuguese and Modern Hindi.

Measures: The factors that were measured in the questionnaires were retrieved from the ASE-Model. Knowledge was assessed with the validated Rotterdam Renal Replacement Knowledge-Test: R3K-T (23). The R3K-T contains 21 items which together cover knowledge on kidney disease and renal replacement therapies. The other variables of risk perception, self-efficacy, communication, subjective norm, and willingness were assessed using statements. The statements were rated on a Likert-scale using five to seven response categories (24). For example, '*How often have you recently talked with the people close to you about kidney transplantation from a living donor' (1 = never - 5 = very often).* A more detailed description of the development of the statements and more examples per variable are described elsewhere (22). The factors knowledge and risk perception are regarded to fall under the umbrella term 'cognitive' and the factors self-efficacy, communication, subjective norm, and willingness to accept LDKT to fall under 'psychosocial'. Socio-demographic data: age, gender, education, employment status, number of children and religion will be collected through medical records. Medical data: history of other RRT's, maximum panel-reactive antibody (PRA), current treatment, date of first dialysis, blood type and registration as an organ donor after death will be retrieved from the database of the pre-transplantation outpatient clinic.

Ethnicity: Descent was categorized in Western and non-Western. A patient was regarded 'non-Western' if either one of his or her parents were born in a non-Western European country. This definition is in line with the one which is used by the Central Agency for Statistics in The Netherlands (CBS)(25). In the population of the nuclear families of end-stage renal patients we found a high correlation (98.4%) between the CBS definition and the individuals' personal view of their ethnicity (Chi-square=769.7, $p< 0.001$). Individuals from the Caribbean and Indonesia showed a deviation of the CBS definition with regard to their ethnicity. These groups would be categorized as non-Western according to the CBS definition whereas some individuals within this group would view themselves as being Western (n=5). Thus far, it is assumable that this would validate the use of the CBS definition in this population. The Western group consists of only Dutch patients. The non-Western group is rather heterogeneous for example, Moroccan, Turkish, Surinamese, Caribbean, Cape Verdean, Indonesian, Chinese, and Vietnamese. These are the most prevalent groups. Less prevalent were patients from: Russia, Poland, India and Libya. The non-Western populations immigrated to the Netherlands after the Second World War. Many immigrants came to the Netherlands together with their families and friends. Indonesians arrived in the 1950's, Moroccans and Turkish in the 1960's, Surinamese, Caribbean and Africans in the 1970's. This results in the fact that second and moreover third generation non-Western patients are not sufficiently represented in this study. Thus generation as such will not be included in the analyses.

As for the outcome variable: During the first visit most recipients attend the pre-transplantation out-patient clinic without a donor. Our transplant physician informs the patients about living donation and gives them 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 in several foreign languages that are commonly spoken in the Rotterdam municipality. After 4-6weeks the patients revisit the pre-transplantation out-patient clinic to ask additional questions and to bring a prospective donor for assessment. Depending on the availability of a living donor who is ready for evaluation during this second visit recipients were either categorized into the group with or without a living donor for this study. Generally, in our practice the donors and recipients see the physician together.

Ethical approval was sought with regard to possible psychological burden of the questionnaire and given by the medical ethical committee of the Erasmus MC.

Data-analyses: The participants were initially divided in four groups based on descent (Western and non-Western) and the availability of a potential living donor (patients with and without a living donor) (see Table 1). The analyses were controlled for whether they were first visits or subsequent yearly scheduled visits. Pearson's chi-squared distribution analyses and univariate analyses of variance were conducted to explore differences between the four groups. All predictors significant at 20-25% level were selected for building the models. Subsequently, binomial multivariate logistic regression models were fitted to identify the most parsimonious model that could identify factors associated with the likelihood of having living donor. The full regression model was built in three blocks: (1) the socio-demographic variables; (2) the cognitive and psychosocial factors were added to the model; and (3) the two-way interactions between the variables were also added. After building the complete model through this block-approach, the backward elimination method was employed to retrieve the most parsimonious model. Collinearity diagnostistics were performed in such a way that factors with a Variance Inflation Factor > 10 were removed from the model (26). For the fitted models the respective t– and F–tests were also estimated, which returned corresponding *p*–values and R^2 (using the Nagelkerke correction). Additionally, to assess the goodness of fit of the prediction model Hosmer-Lemmeshow test (27) was employed. To indicate the accuracy and sensitivity properties of the model a receiver-operating characteristic curve (ROC) was plotted and the area under the curve (AUC) was calculated to quantify these properties. Results with a *p*–value of <0.05 were considered statistically significant.

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Chapter 6

A psychometric analysis of the Rotterdam Renal Replacement Knowledge-Test (R3K-T) using Item Response Theory

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Abstract

Background: Knowledge is a prerequisite for promoting well-informed decision making. Nevertheless, there is no validated and standardized test to assess the level of knowledge among renal patients regarding kidney disease and all treatment options. Therefore, the objective of this study was to investigate the psychometric properties of such a questionnaire for use in research and practice.

Methods: A 30-item list was validated in four groups: 1) 187 patients on dialysis, 2) 82 patients who were undergoing living donor kidney transplantation the following day, 3) the general population of Dutch residents (n=515) and 4) North American residents (n=550). The psychometric properties of the questionnaire were examined using Multidimensional Item Response Theory (MIRT). Norm-references were also calculated.

Results: Five items were found to distort ability estimates (DIF). MIRT analyses were subsequently carried out for the remaining 25 items. Almost all items showed good discrimination and difficulty parameters based on the fitted model. Two stable dimensions with 21 items were retrieved for which norm-references for the Dutch and North American, dialysis and transplantation groups were calculated.

Conclusions: This study resulted in a thorough questionnaire, the R3K-T, which enables reliable testing of patient's knowledge on kidney disease and treatment options in clinic and research.

Keywords: End stage renal disease, Health Education, Knowledge, Psychometric, Renal Transplantation.

Introduction

Knowledge can be seen as a prerequisite for promoting well-informed shared decision making (1, 2). Appropriate knowledge about risks and benefits of different treatment options is necessary to allow well-informed decision making (3). Research in pre-dialysis patients shows the benefits of knowledge and awareness on their decision-making, resulting in lower mortality risks, and punctual transplantation access (4, 5).Insufficiency of knowledge plays an even stronger role when patients are considering living kidney donor transplantation (LDKT), since this is more or less a free choice and involves a healthy person (6, 7). For defining the individual knowledge level an operationalization of 'knowledge' using a questionnaire is needed. However, a validated and standardized test of the level of knowledge among renal patients regarding kidney disease and all treatment options is not available. Existing questionnaires focus either solely on one treatment option or on kidney disease (8-11). A standardized test of the knowledge regarding kidney disease and treatment options has two clear practical applications. Firstly, to identify possible gaps in patients' knowledge in order to support informed decision making from a clinical point of view. Secondly, to have a validated instrument which is also sensitive to changes in knowledge. This can then serve the implementation and testing of educational efforts from a research point of view.

Therefore, in this study we aimed to develop and explore the psychometric properties of a questionnaire on knowledge of renal replacement therapies and kidney disease by applying a multidimensional analysis to validate its use in research and clinic. Additionally, the most optimal methodology for calculating norm-references was investigated.

Patients and Methods

Phase 1: Development of the Rotterdam Renal Replacement Knowledge Test (R3K-T): In order to generate an item pool, we searched the literature for available questionnaires measuring knowledge on renal replacement therapy. This resulted in 3 measures (9, 12, 13). We also consulted members of the Dutch Renal Patient Society and experts in the area of nephrology and transplantation (e.g. nephrologists, psychologist, transplant coordinators, social workers) for additional items that were not represented in the existing measures. This resulted in a pool of 61 items, after deleting duplicate items. To ensure face validity six patients were asked to comment on these items and give feedback on for example the formulation and relevance of the questions and appropriateness of the responses. Based on this information the items were adapted. Next, a pilot study was conducted among dialysis patients in The Netherlands (*n*=116) to investigate the content validity of these items that measured knowledge on kidney disease, dialysis and transplantation options. To further examine validity, we performed an exploratory factor analysis

(14). For most items the response categories were true/false/don't know. However, considering the nature of several questions (e.g. 4, 12, 22) some items have a multiple choice format with four different categories. In the supplementary material the questionnaire is included to review the different response options for all the items. Nevertheless, there is always only one correct answer. In order to avoid the possibility of patients responding without knowing the answer, the response option of "I don't know" was added to all items (scored as if it were an incorrect answer). Thirty items were retrieved from this analysis. We refer the reader to our technical report for a detailed description of the development of this 30 item version as well as the translated versions of the test (15).

Phase 2: Validation of the R3K-T:

Participants: The 30-item list is validated in the present paper in patients on dialysis (n=187, response rate = 31.3%) and patients who were undergoing a living donor kidney transplantation the next day (n=82, response rate = 53.9%) in The Netherlands. For labeling purposes we refer to former group as the 'Dialysis group' and the latter group as the 'Transplant group'. The dialysis patients in this study were recruited from 4 different dialysis centers which have approximately a total of six-hundred patients per year. Patients were asked to participate once they came to the hospital for a dialysis session or for a consultation with their nephrologist. Patients in the transplant group were recruited from the Erasmus Medical Center, Rotterdam, which carries out one third of the national living donor kidney transplantations per year. The tests were administered in seven different languages. In addition, the test was administered to two representative reference groups, 515 Dutch residents (response rate = 53.0%) and 550 North American residents (response rate = 78.0%) using a web based survey. These two reference groups were carefully selected by an independent research bureau to be representative for the general Dutch and the North American populations with quality controls based on age, gender, education, postal code, employment status, attitudes, and lifestyle. The research bureau uses an "open-door" flexible sourcing in which they include anyone who wants to share their honest opinions – even those who would never join a survey panel are recruited through social media, online communities and affiliated partners. The quality of the data is reassured by an external auditing agency (Center for information based decision-making & marketing research). The research bureau that performed the sample selection for this study were certified with regards to the required standards regarding the representativeness of the samples. Ethical approval was sought from the Medical Ethical Committee of the Erasmus MC, Rotterdam, but was deemed unnecessary for this kind of non-interventional research.

Analysis: Differential Item Functioning (DIF) was used to investigate the degree to which some items advantage or disadvantage certain participants groups with respect to the estimates of their knowledge ability using the ltm package in R (2.13.0, R Development Core Team 2011) (16). The rationale of DIF analyses is to identify items that distort the ability estimates for participants and thus jeopardizes correct overall test measurements (17). Items that are identified to distort test measurement are referred to as having DIF. t. If a particular item contains DIF then this is indicated by significant p-values for the DIF parameter. The goal of DIF analyses is to remove items with DIF from the test early on in the validation process.

After removal of items with DIF, the initial test validation process can be undertaken. Classical Test Theory (CTT) has been the mainstay of psychological test validation from the initial explosion of testing in the 1930s. However, CTT is now being rapidly replaced by Item Response Theory (IRT) as the mainstream basis for educational and psychological test development (18). A critical assumption of IRT is unidimensionality, which refers to whether patients' responses to an item is accounted for by their 'first' factor score (in terms of CTT) and not by other factors. Thus, unidimensionality was tested in two ways: 1) Modified Parallel Analyses (MPA) incorporated in the ltm package were employed to test for the probability of unidimensionality (α=0.05) (16, 19) and 2) the rule of thumb that the ratio of the first to the second 'eigenvalue' should be above 3 (20).Accordingly, Rasch, 2PL and 3PL IRT models were fitted using the ltm R package (16). The assumption of unidimensionality has been relaxed with the development of Multidimensional Item response Theory (MIRT) approach. This was seen as a necessary extension of IRT as most psychological constructs are multidimensional in nature(21). Therefore, we sought to examine the psychometric properties of the R3K-T using Multidimensional IRT (MIRT) (22). MIRT analyses were carried out using the mirt-package for dichotomous data in the R software package (23). The MIRT analyses return alpha and β-parameters for each item per dimension. The alpha parameter indicates the discriminative power of that item. Items with higher scores on this alpha parameter are better able to discriminate between knowledgeable and less knowledgeable patients. The beta parameters present the difficulty for the imminent dimensions. In MIRT the interpretation of this parameter is that higher absolute scores, indicate easier items: scores towards zero indicate difficult items. Squared β-parameters indicate the degree in which a certain item explains the variance within a certain dimension (24). The statistical cut-off for the β-parameters is 0.32, since items with this factor loading explain the variance in a certain factor for 10% (0.32^2=0.10), which is considered to be poor.

We sought to determine the optimal number of dimension for the test using MIRT analyses. Comparisons between different models with varying numbers of dimensions was performed by 1) applying a deviance test (Chi-squared test) and 2) comparing the differences in Akaike's Information Criterion (AIC) and the Bayesian Information Criterion (BIC). Both AIC and BIC use penalty terms for the number of estimated parameters in the different models in order to prevent the model from overfitting. Overfitting is a statistical problem which occurs when the fitted model describes noise instead of a true structure. The BIC is from a statistical point of view preferable since it is more able to prevent the model from overfitting than the AIC (25). Lower AIC and BIC values indicate a better fitting model. For the selection of the appropriate number of dimensions statistical solutions and content driven arguments need to be weighted.

Finally, in order to make the R3K-T ready for practical use, test scores were calculated using the CTT approach and compared to test scores generated through IRT analyses. In CTT the test scores are simply a sum of the number of correctly answered items (each correctly answered item is assigned one point). Thus we do not take into account that one respondent might have only correctly answered easy items and that another respondent only the difficult ones. On the contrary IRT scores account for the level of difficulty per item. These scores are presented as the probability that a respondent answers a particular item correctly given the difficulty of that item and the percentage correctly answered items over the total test. Next, the scores generated in terms of CTT and those that were generated via the IRT analysis were compared using a Pearson correlation test. If CTT scores are a close approximation of the IRT derived test scores then CTT scores may be favored for practical proposes as they are easier to calculate. Norm-references, cutoffs, and reliable change index (RCI) scores were calculated for the total scale and any produced subscales (26). Cohen's *d* effect sizes are used to estimate the magnitude of the RCIs (27). Additionally, a score sheet based on percentiles was provided for the total test scores to ease the clinical interpretation of the test scores.

Results

Participant characteristics: Table 1 shows socio-demographic characteristics of the participants. There were significantly more males in the transplantation group (p= 0.02) compared to the other groups. The two patient groups also showed a significantly higher proportion of participants with a low educational level (p< 0.001). With respect to registration as an organ donor after death, significantly more participants from the Dutch reference group reported to be registered compared to the other three groups (p<0.001). For the patient groups no differences were found with respect to the distribution of their original disease and duration of dialysis.

Table 1. Participant characteristics (N=1335)

Characteristics	US (N = 550)	Dutch (N = 515)	Dialysis (N = 187)	Transplantation (N = 82)
Gender (male %)	46.5	47.8	46.5	67.9
Mean age in yr (SD)	44.8 (16.4)	47.9 (15.5)	54.1 (13.3)	53.58(13.2)
Educational level (1-3 %)*	1=3.8 2=57.3 3=38.9 Missing: 0.0	1=1.4 2=67.0 3=31.3 Missing: 0.3	1=20.9 2=42.6 3=12.2 Missing: 24.4	1=15.9 2=57.3 3=20.7 Missing: 4.9
Mean Duration test in min (SD)	6.9 (3.3)	7.73 (4.0)	NA	NA
Registered for organ donation after death %	39.1	58.8	30.1	31.7
Mean mo on dialysis (SD)	NA	NA	20.4 (22.6)	13.0 (19.3)
Original disease (%)	NA	NA		
Glomerular nephropathy			13.4	12.0
Congenital hereditary			15.9	13.3
Hypertension			15.9	13.3
Diabetes mellitus			17.1	19.3
Systemic diseases			4.9	2.4
All other			32.9	39.8

Values in the table are presented as *n* with the percentage in parentheses or mean values with ±SD in parentheses. *The educational level was valued at three levels; 1 = Low; elementary school, 2 = Average; high school and 3 = High; college degree (+ some postgraduate/professional degree). NA=not available.

Differential Item Functioning (DIF): Five items were identified as candidates to be deleted from the list and subsequent analysis due to distorted ability estimates, as indicated by a significant DIF. For example, patients on dialysis would get relatively lower ability estimates on items 6 “How many times a week does a haemodialysis patient generally undergo dialysis?” when compared to the reference groups (p=0.002). This distortion also holds for item 1 (p<0.001), 16 (p<0.001), 23 (p=0.002), and 28 (p=0.043). Therefore, these five items were excluded from further analyses. Items 22 (*p*=0.010) and 27 (*p*=0.026) also showed statistically significant DIF parameters, however, the direction of the ability estimates is consistent with the expected knowledge level of the respective groups: these items favor the knowledgeable groups more than the reference groups. For item 22 the proportion of the North American, Dutch, Dialysis and Transplant participants with a correct answer was 0.57, 0.70, 0.70, and 0.87 respectively: for item 27 the respective proportions were 0.30, 0.17, 0.60, and 0.80. The consistency in the estimation is reflected in the increasing nature of the proportions as the expected knowledge level of the different groups increases.

Multidimensional IRT (MIRT): Before fitting an appropriate IRT model the critical assumption of unidimensionality was assessed. The test for unidimensionality using MPA on all participants together was significant (*p*=0.009). This indicates multiple dimensions. The ratio of the first to the second eigenvalue was 7.342/2.191=3.35. Given these findings in support of multidimensionality, MIRT was performed on the remaining 25 items. A single dimensional model, postulating general knowledge was tested against a two-, three-, and four-dimensional model. Table 2 shows that the difference between the models up to model 3 is significant at α=0.05 level.

Table 2. Comparing MIRT models

Model	Log-likelihood	AIC	BIC	Comparing models
1	-15072.57	30229.14	30447.33	
2	-14679.19	29484.39	29811.68	mod1 versus mod2) (χ^2=786.75, df=20, p<0.001)
3	-14610.98	29389.96	29826.35	(mod2versus mod3) (χ^2=136.43, df=19, p<0.001)
4	-14648.25	29506.50	30052.00	(mod3 versus mod4) (χ^2=-74.54, df=18, p=1.000)

This table shows the log-likelihood, AIC and BIC parameters for the for the fitted models with the mirt() function. The final column shows the comparisons between the nested models using a deviance test (Chi-squared statistic, degrees of freedom, *p*-value). The models reflect the number of dimensions tested (‘mod1’ contains one dimension, ‘mod2’ contains two dimensions, etc).

The decreases in the log-likelihood and the AIC also show that the additionally estimated parameters for the third dimension could provide further significant information. Table 3 displays the parameters for the items in the third factor. The best factor loading in that third factor explains 24% (R^2=0.491^2=0.241) of the variance in that factor: this explained variance is considered to be fair. From a conceptual point of view, we judge that this third factor contains items which cover varying subject areas (insurance (5), kidney disease (8), treatment option (17), and immunology (21)). Also the BIC, which is for statistical reasons preferred over the AIC, increased when moving to three-dimensional model. In other words, the two-dimensional model has a better fit and a more coherent content compared to the three-dimensional model. Hence, we rejected the three-dimensional solution and items 3, 8, 23 and 21 were excluded from further analyses. However, item 5 is viewed by the authors as clinically quite informative. Considering the conceptual nature of this item it fits the second factor better than the first and it still explains the variance in the second factor fairly (15%) (R^2=0.393^2=0.154). Finally, table 4 presents the factor loadings that were extracted from the two-dimensional solution, producing an easily interpretable and cohesive structures for the 21 items.

Table 3. Third factor items following the factor parameterization in MIRT

Items	Short item description	α [SE]	β_1 [SE]	β_2 [SE]	β_3 [SE]
05	Hospital costs of a LDKT are paid for by the health insurance of the recipient.	0.294 [0.092]	0.183 [0.111]	-0.303 [0.087]	**0.410** **[0.063]**
08	Patients with renal disease should not eat too much salty food.	0.321 [0.081]	0.136 [0.111]	-0.248 [0.097]	**0.491** **[0.126]**
23	For the treatment of end-stage renal disease kidney transplantation is preferred over dialysis	0.409 [0.089]	0.370 [0.074]	-0.367 [0.098]	**0.371** **[0.094]**
21	A full match between the tissue of the donor and the patient provides the best survival.	0.336 [0.163]	0.142 [0.122]	-0.366 [0.084]	**0.426** **[0.082]**

Items are paraphrased for brevity. This table displays slopes transformed into varimax rotated factor loadings metric of the deleted items from the third factor: item discrimination parameter (**α [SE]**) and item difficulty parameters for the three respective dimensions (**$\beta 1$ [SE], $\beta 2$ [SE], *and* $\beta 3$ [SE]).**

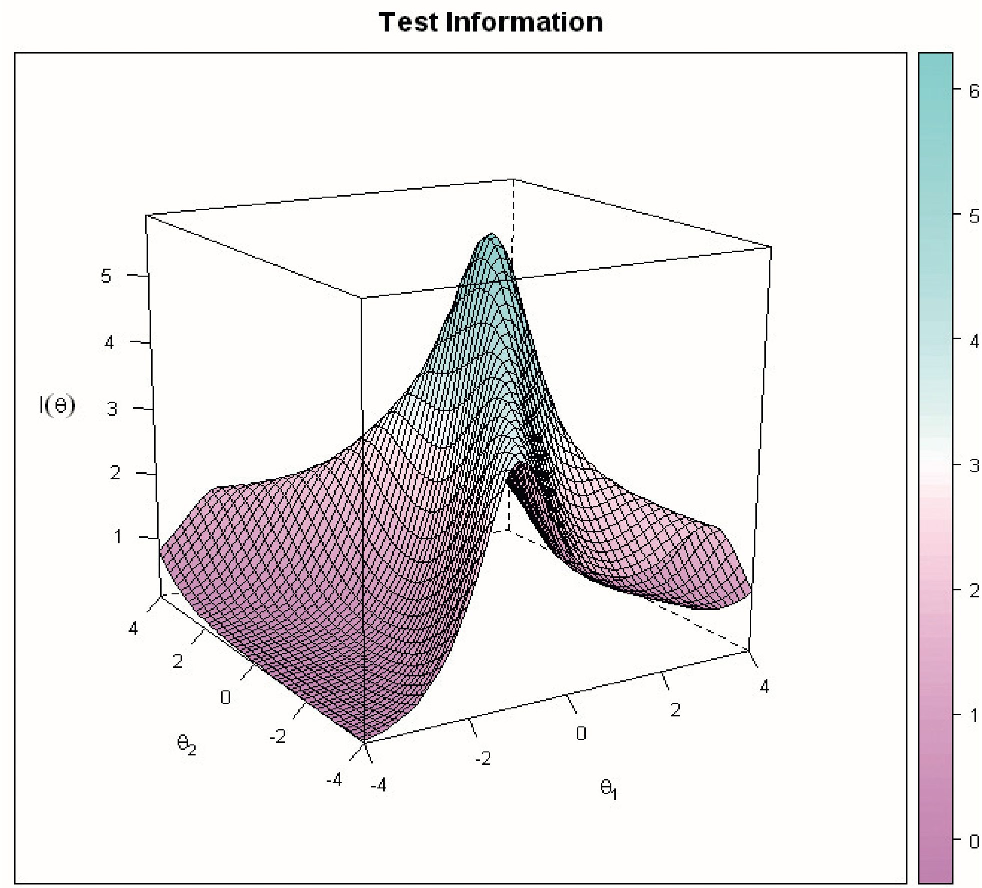
After the aforementioned analyses a two-dimensional R3K-test was constructed based on 21 items. Table 4 presents the two-dimensional solution with the factor labels. The factor labels "Dialysis & Transplantation" (DT) and "Living Donation" (LD) reflect the content of the respective factors and were agreed upon through a consensus meeting with the authors. A didactic presentation of these two factors is presented in figure 1. The first factor (θ_1) retrieves the most test information at moderate knowledge levels, whereas the second factor (θ_2) contains items that retrieve test information across almost the whole range of knowledge levels.

Table 4. Item characteristics on the two subscales of the 21-item R3K-T

Items	Short item description	a [SE]	β_1 [SE]	β_2 [SE]
	Dialysis & Transplantation			
04	Peritoneal dialysis: Which part of the body makes this possible?	0.788 [0.137]	**0.862 [0.195]**	-0.211 [0.129]
12	An advantage of peritoneal dialysis is…	0.758 [0.174]	**0.848 [0.180]**	-0.197 [0.125]
18	Peritoneal dialysis: What happens with the fluid after it is brought into the abdominal cavity through a catheter?	0.646 [0.125]	**0.803 [0.126]**	-0.015 [0.113]
24	Is peritonitis one of the biggest problems with patients with peritoneal dialysis?	0.623 [0.087]	**0.748 [0.126]**	-0.251 [0.087]
26	Certain vitamins are lost during dialysis. If you are on dialysis you are therefore prescribed extra vitamins.	0.504 [0.074]	**0.687 [0.106]**	-0.180 [0.084]
20	How many hours a day is a haemodialysis patient connected to the machine?	0.559 [0.074]	**0.650 [0.112]**	-0.370 [0.075]
10	Renal replacement therapy is necessary if kidney function is only 50%.	0.531 [0.102]	**0.643 [0.125]**	-0.344 [0.082]
14	A permanent access to the bloodstream is needed for haemodialysis.	0.424 [0.065]	**0.583 [0.089]**	-0.288 [0.068]
27	Kidneys from living donors have longer graft survival than from deceased donors.	0.381 [0.078]	**0.535 [0.094]**	-0.308 [0.071]
17	ESRD: Kidney transplantation is generally preferred to dialysis.	0.497 [0.069]	**0.514 [0.102]**	-0.483 [0.069]
22	Immunosuppressive drugs are administered to transplant patients for	0.325 [0.068]	**0.303 [0.080]**	-0.483 [0.067]
	Living Donation			
15	Surgical complications after donation are common in living kidney donors.	0.755 [0.086]	0.210 [0.147]	**-0.843 [0.114]**
11	Donating a kidney increases the risk of developing a kidney disease.	0.640 [0.083]	0.172 [0.114]	**-0.781 [0.098]**
13	Most living kidney donors remain in the hospital for 2 weeks after surgery.	0.544 [0.088]	0.334 [0.113]	**-0.658 [0.081]**
07	Very few living kidney donors have long-term health problems after donation.	0.399 [0.072]	0.143 [0.088]	**-0.615 [0.079]**
25	Kidney donation may affect a woman's chances of getting pregnant.	0.428 [0.076]	0.274 [0.093]	**-0.594 [0.093]**
19	Most living kidney donors can participate in sports and work within 4-6 weeks after donation.	0.446 [0.067]	0.346 [0.092]	**-0.571 [0.070]**
30	When the kidney of a living donor does not match the recipient, living donation is not an option with this donor.	0.383 [0.075]	0.386 [0.091]	**-0.484 [0.069]**
09	A living kidney donor has to be younger than 50 years old.	0.405 [0.068]	0.428 [0.092]	**-0.471 [0.067]**
02	Only direct family members (brothers, sisters, parents or children) can donate a living kidney.	0.201 [0.093]	0.047 [0.082]	**-0.446 [0.083]**
05	Hospital costs of a LDKT are paid for by the recipient's health insurance.	0.230 [0.071]	0.274 [0.079]	**-0.393 [0.067]**

Items are paraphrased for brevity. This table displays slopes transformed into varimax rotated factor loadings metric: item discrimination parameter (***α [SE]***) and item difficulty parameters for the two respective dimensions (*β1 [SE] and β2 [SE]*).

Figure 1



Legend to Figure 1. This figure presents the two-factors test information plot. On the x-axis the ability levels are shown and on the y-axis the discriminative power of the tests. The 21 items are represented under the surface of the ‘cloth’. The peak in the middle of the figure shows that both factors have the best discriminative power for patients with an average ability level (0). As one moves towards the end points of the ability scale (-4 and 4) the figure shows that the discriminative power decreases.

Norm-referenced test scores and RCIs: The CTT total sum score method was compared to the IRT ability estimates. The correlation between these two approaches on the total individual scores was very high (r=0.986, p=0.001). Table 5 presents the normative data for interpreting the test scores based on CTT scores for the total and subscale scores. There were no significant differences in the total group scores between the Dutch and North American general population groups (p=0.955). The more knowledgeable group (dialysis patients) showed significantly higher test scores compared to their reference group (Dutch) (p<0.001). The “most” knowledgeable group in this study (transplant group) showed superior test scores compared to the dialysis patients (p=0.016). The optimal cutoff scores between the Dutch, dialysis and transplant group (respectively: 10.51 and 14.22) represent significant shifts to a better informed group.

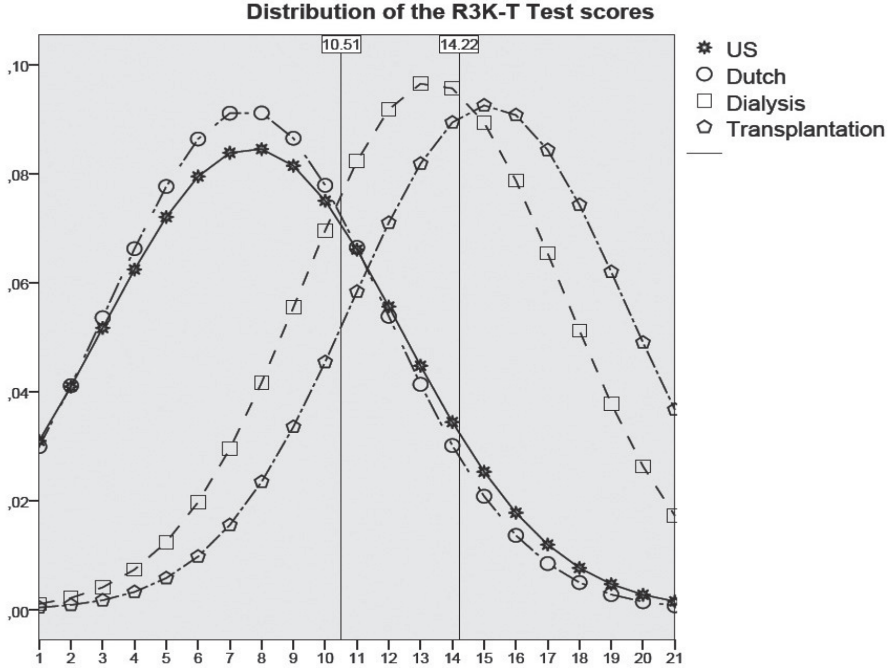
Table 5. Norm-reference scores and Reliable Change Index (RCI)

Norm-references R3K-T	US (N = 550)	Dutch (N = 515)	Dialysis (N = 187)	Transplantation (N = 82)
R3K-T total score (SD)	7.68 (4.71)	7.51 (4.35)	13.35 (4.12)	15.14 (4.31)
RCI (Cohen's *d*)			4.30 (1.36)	5.42 (0.43)
Cutoff (*p*-value)			10.51 (<0.001)	14.22 (0.002)
Subscale DT (SD)	3.57 (2.66)	3.32 (2.32)	7.91 (2.29)	8.35 (2.54)
RCI (Cohen's *d*)			2.64 (-1.98)	3.59 (0.18)
Cutoff (*p*-value)			5.63 (<0.001)	8.12 (0.023)
Subscale LD (SD)	4.11 (2.65)	4.19 (2.58)	5.43 (2.49)	6.89 (2.48)
RCI (Cohen's *d*)			2.92 (-0.48)	3.77 (0.58)
Cutoff (*p*-value)			4.82 (0.003)	6.16 (<0.001)

This table presents mean group scores (standard deviation), cutoff scores (significance level, α=0.05), and reliable change index scores (Cohen's *d* effect size) for the total test scores and the subscale scores. The cutoff scores present the cutoff value between that group and the preceding. The reliable change index scores present the minimum improvement a person in that group should make for a reliable shift to the next group. The subscale DT = Dialysis & Transplantation and subscale LD = Living Donation.

Figure 2 graphically displays the distribution of the test scores for the different groups and the two significant cutoff scores. The RCIs show that the clinical shifts between the Dutch-dialysis and dialysis-transplant groups have large and medium effect sizes for the total scale and the two subscales (Table 5). Finally, table 6 provides the percentiles for the four study groups. These percentiles indicate the total test score below which a certain percent of the participants fall. For example, the 40th percentile is the score below which 40% of the participants may be found.

Figure 2



Legend to Figure 2. This figure shows the parametric distribution of the test scores with the accompanying cutoff vales between the Dutch versus dialysis and dialysis versus transplantation groups. The cut-off values are represented as interpolation lines in this figure. The x-axis are the test scores displayed (min=0, max=21) and on the y-axis the respective proportion of participants with that score.

Table 6. Score sheet of the 21-item R3K-T based on percentiles

Percentiles %	**10**	**20**	**30**	**40**	**50**	**60**	**70**	**80**	**90**
US	0-1	2-3	4	5-6	7-8	9	10-11	12	13-21
Dutch	0-2	3	4-5	6	7	8-9	10	11	12-21
Dialysis	0-8	9-10	11-12	13	14	15	16	17	18-21
Transplantation	0-8	9-11	12-14	15	16	17	18	19	20-21

This table presents the score sheet for the knowledge test for each group separately. The percentiles indicate the total test score below which a certain percent of the participants fall. For example, the 40th percentile is the score below which 40% of the participants may be found. The test scores vary from 0 to 21.

Discussion

This study aimed to develop and validate an instrument with which knowledge of kidney disease and the related treatment options can be reliably measured. Since knowledge measurement is indirect, a patient's ability must be inferred from test scores. In this validation study we used a multilevel approach to infer these test scores. Most items showed good discrimination parameters based on the model that was fitted, which indicate that patients with various knowledge levels can be discriminated adequately.

The result of this study is a knowledge test with two solid dimensions. The deviance test and the AIC indicated that there was potentially a third dimension, while the BIC points towards a two-dimensional solution. When we looked for content driven argumentation for a potential three-dimensional solution we found conclude that the third dimension is incoherent and was thus not of additional value for the practical use of the test. Hence, we conclude that a two-dimensional test is the best solution in this case. All the items in the two scales show fair to excellent item properties. Only item 22 about immunosuppressive drugs had psychometric shortcomings. However, this item was regarded as conceptually unique and informative. One practical solution for improving the test performance of item 22 may be the reduction of the number of response categories: dichotomizing the response categories into a true/false format (28).

For the practical use of the test in the clinic and research the most optimal scoring method was determined. Determining test scores for the 21 items using both CTT and IRT, showed very high correlation. In light of this, the CTT method is preferable since these calculations are easily performed by hand: each correct response receives a score of 1 and an incorrect response a score of 0. From a clinical point of view, if patients are to make a well-informed decision regarding renal replacement therapy, they should score highly on both subscales as this indicates sufficient knowledge of all their treatment options. Therefore, total scores are preferred. Subscale scores become relevant when one identifies a certain group for which it has clear clinical implications to contain knowledge on a specific scale. For instance, for potential donors it may be relevant to have sufficient knowledge on the ‘Living Donation’ subscale relative to the ‘Dialysis & Transplantation’ subscale. Further validation of the R3K-T in more specific groups, such as living kidney donors, for which subscale scores may contain clinically relevant information would increase practical rigor of this test. Furthermore, since most people are more familiar with percentiles rather than reliable change index scores, a score sheet based on percentiles is also presented to ease the practical use of the test.

Several limitation of this study may be considered: Firstly, a validation of this test in the population of pre-dialysis patients is unfortunately lacking in this study. This subpopulation is very interesting since they are yet to the make a (well-informed) decision regarding the different renal replacement therapies. Secondly, given the sample size of the two clinical groups in this paper representativeness of these populations can be questioned. However, given the relatively low number of items with DIF and the relative ease at which the analyses returned a valid and cohesive two-dimensional structure, the sample size and the distinctiveness of the different subgroups did not indicate any flaws regarding the samples for now. Nonetheless, future validation studies using the flexibility of IRT analyses to easily incorporate additional and larger samples are warranted. This is particularly needed for the pre-dialysis group but also for the dialysis group given the relatively low response rate. Thirdly, patients interested in receiving a LDKT who were ruled out and patients who are on the waitlist for a deceased donor kidney transplantation but who are not willing to get a LDKT may be clinically distinctive from the general dialysis population. These potential subgroups were not treated as a separate group in this study and categorized according to their current treatment (dialysis). The design for the current study was set out to make an initial distinction between the most apparent groups, namely the general population, dialysis patients and transplant patients. Nevertheless, we appreciate that from a clinical point of view more subpopulations may exists for which statistical validation is needed. However, with current data no sufficient variation is present to make such a distinction statistically. Fourthly, the items on financial matters were rather weak in their test performance when administered across borders. These financial items were valid in the Dutch test case (15). However, in this initial cross-cultural validation using data from North American residents the items on financial issues dropped dramatically in their test performance. This is likely to be due to different legislations when it comes to reimbursement of health related costs by public funds or insurance companies. Yet, item 5 *"Hospital costs of a LDKT are paid for by the health insurance of the recipient"* remained in the questionnaire. It is psychometrically not a very strong item but it could be regarded as a starting point from which one or two extra items on financial issues could be added in line with the local legislation. This point on the financial items could be seen as a limitation. However, given the ever changing nature of insurance legislation and policy on financial compensation, it will be difficult to make standardized items that can be used irrespective of time or setting.

In conclusion, this is a psychometrically solid, brief, and comprehensive self-report test on knowledge of renal replacement therapies that can be implemented in research and the clinic. Further validation of the R3K-T is warranted in larger local subgroups, pre-dialysis patients and in general populations other than those of the US and the Netherlands. The various translations of the R3K-T could facilitate these international validation studies.

Supplementary material

Enclosed is the English version of the final 21-item questionnaire.

Supplementary material

Rotterdam Renal Replacement Knowledge-Test (R3K-T)

This questionnaire is about kidney diseases and the different kinds of renal replacement therapies. With these questions we would like to get an impression of the degree to which you are familiar with kidney disease and the treatments.

It will take no more than 10 minutes to fill in this questionnaire. To get a good impression of what you know, we would like to ask you ***not to guess***. If you are not sure of the answer, please choose “I don’t know”.

It is very important that you do not look up the answers, but fill in what you really know. In this way we know which knowledge is missing and what information we can provide you with.

Sample question:

People usually have 2 kidneys.

(a) True
(b) False
(c) I don’t know

You can now choose between either “True” or “False” regarding this statement. If you do not know whether it is true or false you can choose for the “I don’t know” option. In this case the correct answer is (a).

1. Deleted	Kidney disease is something you get when you are older. Young people do not get this disease.
	a) True **b) False** c) I don’t know
2.	Only direct family members (brothers, sisters, parents or children) can donate a living kidney.
	(a) True **(b) False** (c) I don’t know.
3. Deleted	A patient with kidney disease can develop high blood pressure, swollen ankles and rapid weight gain when the body is burdened with too much:
	(a) Protein (b) Waste **(c) Water** (d) I don’t know

4.	Peritoneal dialysis is a form of dialysis for treating patients with end-stage renal disease. Which part of the body makes this treatment possible?
	(a) The peritoneum (b) The bladder (c) The renal pelvis (d) I don't know
5.	All the hospital costs of a living kidney donation are paid for by the recipient's health insurance and not by the donor's insurance.
	(a) True (b) False (c) I don't know
6. Deleted	How many times a week does a hemodialysis patient generally undergo dialysis?
	(a) 2-3 (b) 5-6 (c) I don't know
7.	Very few living kidney donors have long-term health problems after donation.
	(a) True (b) False (c) I don't know
8. Deleted	Patients with renal disease should not eat too much salty food.
	(a) True (b) False (c) I don't know
9.	A living kidney donor has to be younger than 50 years old.
	(a) True **(b) False** (c) I don't know
10.	Renal replacement therapy is necessary if kidney function is only 50%.
	(a) True **(b) False** (c) I don't know
11.	Donating a kidney increases the risk of developing a kidney disease.
	(a) True **(b) False** (c) I don't know

12.	Peritoneal dialysis is a form of renal replacement therapy that can be used as an alternative for hemodialysis. An advantage of peritoneal dialysis is:
	(a) That you have more freedom of movement in between the in and out flow of the dialysis fluid. (b) It only needs to be done once a week. (c) It doesn’t have to be preceded by surgery. (d) I don’t know.
13.	Most living kidney donors remain in the hospital for 2 weeks after surgery.
	(a) True **(b) False** (c) I don’t know
14.	To be connected to the hemodialysis machine, there must be permanent access to the bloodstream.
	(a) True (b) False (c) I don’t know
15.	Surgical complications after donation are common in living kidney donors.
	(a) True **(b) False** (c) I don’t know
16. Deleted	When someone has a kidney disease, the kidneys have to be removed before dialysis can start.
	(a) True **(b) False** (c) I don’t know
17.	Kidney transplantation is generally preferred to dialysis for the treatment of end-stage renal disease.
	(a) True (b) False (c) I don’t know
18.	During peritoneal dialysis, fluid is brought into the abdominal cavity through a catheter. What happens with the fluid after that?
	(a) The fluid stays in the abdominal cavity, after a couple of hours it is removed. (b) The fluid stays in de abdominal cavity, until it is completely absorbed by the body. (c) The fluid flows into an artificial kidney through another catheter. (d) The fluid flows into an artificial kidney though the same catheter.

19.	Most living kidney donors can participate in sports and work within 4-6 weeks after donation.
	(a) True (b) False (c) I don’t know
20.	How many hours a day is a hemodialysis patient connected to the machine?
	(a) 3-8 (b) 12-16 (c) Continuous (d) I don’t know
21. Deleted	A full match between the tissue of the donor and the patient provides the best survival.
	(a) True (b) False (c) I don’t know
22.	Immunosuppressive drugs are administered to transplant patients for:
	(a) Prevention and treatment of rejection of the kidney. (b) Treatment of blood clotting in the new kidney. (c) Protection against infections caused by a virus or bacteria. (d) I don’t know.
23. Deleted	Which treatment gives the best quality of life?
	(a) Hemodialysis **(b) Transplantation** (c) Peritoneal dialysis (d) I don’t know
24.	Peritonitis is an infection of the peritoneum. This is one of the biggest problems with patients with peritoneal disease.
	(a) True (b) False (c) I don’t know
25.	Kidney donation may affect a woman’s chance of getting pregnant.
	(a) True **(b) False** (c) I don’t know

26.	Certain vitamins are lost during dialysis. If you are on dialysis you are therefore prescribed extra vitamins.
	(a) True (b) False (c) I don't know
27.	Kidneys from living donors have a longer graft survival rate than kidneys from deceased donors.
	(a) True (b) False (c) I don't know
28. Deleted	A person can not miss a kidney because they are vital organs and both are necessary for a healthy life.
	(a) True **(b) False** (c) I don't know
29. Deleted	Most insurance companies pay travel expenses and costs paid for by the employer for a living kidney donor.
	(a) True (b) False (c) I don't know
30.	When the kidney of a living donor does not match the recipient, living donation is no longer an option with this donor.
	(a) True **(b) False** (c) I don't know

The **bold** response options are the correct answers.

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Chapter 7

Multisystemic engagement & nephrology based educational intervention: a randomized controlled trial protocol on the kidney team at home-study

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Abstract

Background: Living donor kidney transplantation (LDKT) is the most successful form of renal replacement therapy in terms of wait time and survival rates. However, we observed a significant inequality in the number of LDKT performed between the Dutch and the non-Dutch patients. The objective of this study is to adapt, implement and test an educational home-based intervention to contribute to the reduction of this inequality. Our aim is to establish this through guided communication together with the social network of the patients in an attempt that well-informed decisions regarding renal replacement therapy can be made: *Multisystemic Engagement & Nephrology*. This manuscript is a detailed description of the Kidney Team At Home-study protocol.

Methods and design: All patients (>18 yrs) that are referred to the pre-transplantation outpatient clinic are eligible to participate in the study. Patients will be randomly assigned to either an experimental or a control group. The control group will continue to receive standard care. The experimental group will receive standard care plus a home-based educational intervention. The intervention consists of two sessions at the patient's home, an initial session with the patient and a second session for which individuals from their social network are invited to take part. Based on the literature and behavioural change theories we hypothesize that reducing hurdles in knowledge, risk perception, subjective norm, self-efficacy, and communication contribute to well-informed decision making and reducing inequality in accessing LDKT programs. A change in these factors is consequently our primary outcome-measure. Based on power calculations, we aim to include 160 patients over a period of two years.

Discussion: If we are able to show that this home-based group educational intervention contributes to 1) achieving well-informed decision regarding treatment and 2) reducing the inequality in LDKT, the quality of life of patients will be improved while healthcare costs are reduced. As the intervention is investigated in a random heterogeneous patient group in daily practice, the transfer to clinical practice in other kidney transplant centers should be relatively easy.

Trial registration: Netherlands Trial Register, NTR2730.

Keywords

Family Therapy, Cultural Diversity, Kidney transplantation/psychology, Living Donors/psychology, Patient education, Accessibility of health services

Background

Patients with end-stage renal disease have various options for renal replacement therapy (RRT): hemodialysis, peritoneal dialysis, deceased donor kidney transplantation (DDKT) and living donor kidney transplantation (LDKT). Although dialysis is a life-saving treatment, the patient is faced with a substantial loss of quality of life and a significantly increased risk of morbidity and mortality [1]. At least one quarter of the patients die on the wait list for DDKT [2]. The calculation of the time spent on the wait list for a DDKT starts on the first day of dialysis and is on average three to five years in the Netherlands [3]. Research shows that LDKT is associated with significant patient and graft survival benefits when compared to DDKT [4]. One of the benefits of early LDKT is avoiding or minimizing time on dialysis. However, one of the main concerns among patients is the health of the living donor. Studies have shown that among healthy screened individuals, the health risks for the donor are limited [5]. The donor is usually admitted for 3–4 days for the nephrectomy, can resume preoperative social and professional activities within four to six weeks and in general the perceived quality of life remains the same [5,6]. LDKT rates have steadily been increasing and now exceed those of DDKT in the Netherlands [3]. However, there appears to be an inequality in access to the LDKT program between Dutch and the non-Dutch patients. In our center 44% of patients on the wait list for DDKT are from non-Dutch descent [7]. However, non-Dutch patients represent only 18% of the patients transplanted via the LDKT program (period: 2000–2010). Therefore, fewer non-Dutch than Dutch benefit from the advantages of LDKT. This inequality is also present in other western countries [8-10]. This health care inequity needs to be addressed [11,12]. This discrepancy is partly attributable to medical, socio-economic and ethnic factors, which exert an independent significant influence on the chance of receiving a LDKT [7]. Due to an accumulation of unfavorable factors in the non-European population, their chances for a LDKT dropped to only 10% compared to the reference population (69%) [13]. Of the socio-economic hurdles, health insurance is less relevant in the Netherlands due to a health insurance system which is accessible for all Dutch citizens. Other possibly contributing factors to this inequality are potentially modifiable psychosocial (e.g. patient education, cognitions and emotions) and culture-specific factors (social influences, communication attitudes) [14,15]. The Kidney Team At Home-study focuses on addressing those potentially modifiable factors in a home-based educational intervention.

In response to this situation, we developed an educational program based on some of the principles of Multi System Therapy (MST) [16]. MST is an evidence-based therapy, which has been developed for derailed adolescents and families. Such serious pathology is unlikely to be found in the current study population. This means that the intervention applied here will be much less intense than MST in a pure form. The current intervention is an adaptation of the intervention developed by Rodrigue, which was also MST-based and proven to be effective in reducing inequality in patients with end-stage renal disease [17]. The intervention was adapted to the Dutch situation with regard to the culture specific factors and the content of the education appropriate to the Netherlands. We designed our intervention with respect to the MST framework in such a way that we strive for engagement of the patient's family and social network in the disease process: *Multisystemic Engagement & Nephrology*.

We developed an intervention protocol based on empirical data on psychosocial hurdles to LDKT and influential theories from health psychology that focus on decision-making process and behavioral change. A close fit was found between data-driven hurdles and the following theory: Attitude-Social influence-Efficacy model (ASE-Model) [18]. The ASE-Model is based on the theory of Theory of Planned Behavior (TPB) of Fishbein and Ajzen [19] and is supplemented by elements from the Social Cognitive Theory (SCT) of Bandura [20]. ASE has a wide scientific acceptance and represents a theoretical framework for explaining behavior by connecting attitude, social influence, self-efficacy, knowledge, skills (communication), and barriers and resources (risk perception) to intention and behavior. Firstly, the factor regarding '*attitude*' in this theory is based on 1) the belief that people think that a certain behavior will have positive or negative consequences and 2) their evaluation of the according consequences. In other words, attitude is a function of how we integrate the information that we have on a subject. Secondly, *social influence* is defined as the approval or disapproval of the pursued behavior by others within the patient's social network. Thirdly, *self-efficacy* looks at the extent to which individuals believe in their own abilities in relation to a particular behavior. These factors influence a person's *intention* to carry out certain behavior. Empirical data in this area has shown that factors such as *knowledge, risk perception, attitude, communication, social influence, self-efficacy and intention* reveal good predictive values in the light of living organ donation [21-26].

Objectives

The objective of the Kidney Team At Home-study is to contribute to the reduction of ethnic inequalities in LDKT health care access. We translated this objective in two concrete research questions. The primary research question is to investigate whether this home-based educational intervention results in improved knowledge and communication as compared to the standard educational care. The intervention should in this matter help the patients and their social network to reach a *well-informed decision* with regard to the most suitable treatment option. This is deliberately set as a primary research question, as a well-informed decision does not necessarily have to lead to LDKT. The secondary research question is to investigate whether this intervention leads to reduced ethnic inequality in the pursuit of LDKT. This is operationalized by looking into distribution of LDKT activities between the experimental and control group. This study protocol provides a detailed description of the Kidney Team At Home-study and the design of the randomized controlled trial (RCT) in line with the CONSORT (consolidated standards of reporting trails) checklist [27,28].

Methods and design

Study population

Patients

Eligible candidates are end-stage renal patients who have been referred to the pre-transplant clinic and are currently listed on the wait list for a DDKT and who do not have a potential living donor yet. This includes patients (>18 yrs) newly referred for transplant preparation as well as patients who are already listed. Patients who are mentally incapable (e.g. mental deterioration, schizophrenic) or those with a compromised medical condition who are unable to withstand the intervention will not be included.

Invitees

Individuals in the social network of the patients are also invited to take part in this study. This practice is in line with the multisystemic approach of MST. For the invitees there are no limits set to ethnicity or the relationship with the patient. The number (≥1) of invitees (>18 yrs) participating will depend on the number that responds to the invitation of the patient.

Design & procedure

In this prospective RCT all patients will be invited to participate by the educators after the consultation with the transplant nephrologists. During the face-to-face informational consultation the patient will receive written and verbal information on the aims and procedures of the study. Spouses, relatives or friends accompanying the patient to the hospital may be present during this consultation. Our target is to include 80 patients of Dutch origin and 80 patients of non-Dutch origin in the study over a period of two years in order to compare effectiveness of the intervention among these two groups. With respect to the inequality in LDKT, patients of non-Dutch origin will inherently be overrepresented in the study. After informed consent is obtained, patients will be randomized to either the control or the experimental group. The control group will receive standard care. The experimental group will receive standard care plus a home-based educational intervention. In the face of the equity principle, we will provide all the study materials (e.g. brochures, questionnaires) in the six most common foreign languages in the Rotterdam municipality namely, English, Arabic, Turkish, Papiamento, Portuguese and Modern Hindi [29].

Control condition

Patients assigned to the control group will receive standard care only. In the standard care all patients visiting our pre-transplantation outpatient clinic receive a consultation with a transplant nephrologist, a transplant coordinator, and a social worker. Additional to this verbal information, the patients receive a variety of written educational material and a DVD regarding various living donation and transplantation programs. All materials are translated in the six afore mentioned foreign languages. They can study this material in the coming four weeks before their second visit to the outpatient clinic during which they have the opportunity to ask additional questions. Additionally, our patients are invited to attend 4–6 times a year informational meetings held in the various regional hospitals. The baseline and post-measurements will be either handed out by the educators during the hospital visit or sent via mail. If necessary the educators may help in completing the questionnaire. The questionnaires are also available in six languages.

Experimental condition

The intervention consists of two sessions at the patient’s home. Session One: Firstly, at the beginning of the session the patient completes the baseline measurement. Secondly, the family network of the patients will be depicted on a genogram the educator in order to get familiar with the family structure and to recognize the values of that social system. The observation of the educators during the sessions represents an important source of information about how the present individuals relate to each other. In fact, the educators never rely solely on the individual’s verbal self-description to investigate social relations. Only by observing how the individuals behave with each other can the educators support or reject hypotheses based on self-reports. During this first session the educators watch for non-verbal clues that confirm or contradict what the social system is telling them. As the educators form tentative hypotheses about psychosocial hurdles, they do not offer advice or share their observations to avoid defensiveness. They rather focus on engagement by showing helpful interest while listening to the needs of the individuals and reinforcing the strengths of the respective social system. At the end of the first session the educators will make an inventory of individuals that the patient will invite for the second session. The educators may help in inviting identified individuals. The invitation will be conducted verbally accompanied by a brochure containing the 1) study purpose, 2) education content, and 3) contact information of the educators.

Session Two: The educators organize this session in such a way that they will do ‘what ever it takes’, in line with one of the basic principles of MST, to make this event as patient-tailored as possible. This means that the intervention will usually take place in the evenings and weekends since most friends and family members are working during office hours. The primary goal of this intervention is educational, therefore, it is not necessary that all the invitees are potential donors. The baseline-outcome measurement for the invitees will take place at the start of the second session. In exceptional cases multiple sessions are required in order to reach the goals set for those sessions. Table 1 shows the topics that will be discussed during the second session.

Table 1. The educational topics discussed in the second session

1	Introduction	The purpose of the Kidney Team At Home-study
2	Kidney disease	An introduction to kidneys and kidney diseases
3	Dialysis	The various forms of dialysis
4		Morbidity and mortality associated with dialysis
5		The psychosocial consequences of a kidney disease and dialysis
6		The advantages and disadvantages of dialysis compared to kidney transplantation
7	Transplantation	The medical evaluation in preparation for donor nephrectomy and kidney transplantation
8		The various programs of donation and transplantation (DDKT and LDKT)
9		The number of DDKT and LDKT performed nationally and locally
10		The differences in ethnicity regarding access to LDKT
11		The differences in graft survival between DDKT and LDKT
12	LDKT	Additional advantages and disadvantages of LDKT
13		The risks and psychosocial aspects associated with donor nephrectomy
14		The personal, emotional and financial aspects of LDKT for the recipient
15	Discussions	Whether present individuals have considered to donate their kidney

During both sessions at the patients' home we will use the therapeutic framework of MST in order to stimulate open communication between the patient and the family members and to use and profit of the strengths and possibilities of the natural network of the patient. The objective of MST is to achieve a lasting consensus on the patient's goals and how these goals can be reached with engagement and/or support of his/her social ecology. Such long-term consensus cannot be achieved if the interpersonal relations, personal autonomy and feelings of those involved are not sufficiently considered. Therefore, creating a 'safe' environment during the intervention is regarded as an important aspect of a successfully implemented intervention. The licensed psychologist who will be implementing this protocol is certified in practical systemic therapy. Both the psychologist and the transplant coordinator (educators) will be supervised by an official MST supervisor throughout the study period.

In order to minimize hurdles for participation interpreters are used when Dutch is not the primary language of those present. The interpreter will also help patients and invitees with questionnaires or understanding the informed consent if that may ease the transfer of information. At the end of the second session the patient and the invitees will receive the post-measurement. This questionnaire can be completed immediately or returned via the mail within a week. In Figure 1 one can find the graphical depiction of the RCT.

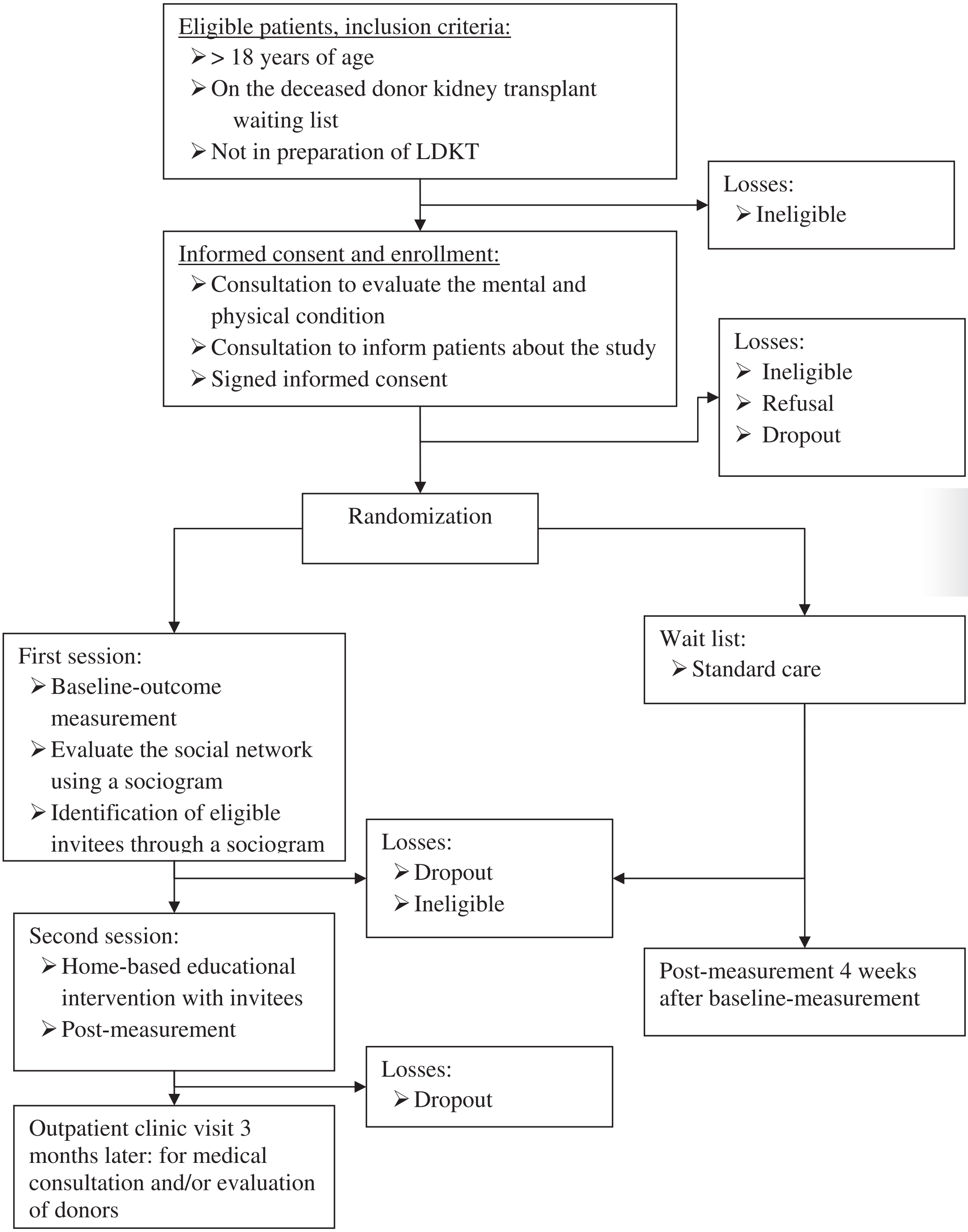

Figure 1.
Design of the randomized controlled trial

Knowledge

Because there was no suitable instrument to measure knowledge on kidney diseases and all the possible RRT's, we developed the Rotterdam Renal Knowledge-Test (RRK-T) based on Devin et al (1990), Stothers et al (2005) and Rodrigue et al (2007). The RRK-T consists on 21 true / false or multiple choice questions on kidney disease, dialysis and transplantation with a living or deceased donor [29]. For example, *'Renal replacement therapy is necessary when the kidneys function for only 50%'.* A clinically significant change will be indicated by 5 points of difference compared to the baseline measurement and is additional to passing the clinical cut-off point of 11 points (each correctly answered questionnaire is awarded 1 point).

Attitude

This is operationalized as the attitude that one has towards the discussion of RRT's (for patients and invitees) and the acceptance (patients) or the donation (invitees) of a kidney (TPB) [25,26,30,31]. For example, *'From my point of view discussing renal replacement therapy with my family and friends is pleasant / unpleasant' and 'I think that accepting a kidney from a living donor is good / bad.'* These were rated on a scale from 1–7.

Risk perception

The questionnaire structure is similar to other studies in which the PMT is used [32,33]. Negative and positive aspects of living kidney donation were rated on a 5-point scale (1 = not at all - 5 = a lot). For example, *'I think discussing living kidney donation is emotionally burdensome'* and *'I am afraid that in the future I could get a kidney disease from kidney donation.'*

Communication

Patients and invitees are asked if and how often they talk about kidney diseases and RRT with their family and friends. The development and selection of these questions was based on the validated 'Family Functioning Questionnaire' [34]. This questionnaire is designed to pinpoint the way families communicate and make choices regarding psycho-educational interventions. For example, '*How often have you recently talked with the people close to you about kidney transplantation from a living donor' (1 = never - 5 = very often).*

Self-efficacy

We will measure the patients' and invitees self-efficacy to communicate about LDKT. Participants could answer on a 5-point scale ranging from 'I am able to …' to 'I am not able to …' [25,35]. For example, *'I am able to discuss renal replacement therapies with my family and friends.'*

Subjective norm

Questions will be asked to determine if and how much patients and invitees value the thoughts of the other party regarding LDKT [35]. For example, *'I value the opinion of people who are important to me' (1 = not at all- 5 = very much).*

Intention

This factor measures the extent to which patients and invitees plan to / are willing to discuss RRT's or if they would give or accept a kidney [25,26]. For example: *'How much do you want to donate a kidney to the patient' (1 = not at all - 5 = very much).*

Secondary outcome measures

Secondary outcomes are operationalized in terms of behavior that may lead to LDKT or LDKT itself. This is divided into three categories: the number of applications for LDKT evaluation, the number of actual evaluations for LDKT, and the number of LDKT's. These outcomes will be monitored using the patient's medical records during the year following the intervention date. Furthermore, we will also monitor the timeframe between the intervention and the moment that the event arises (time-to-event).

Other outcome variables

Several other factors (e.g. confounders, effect modifiers) that may have an effect on the outcome of the intervention are defined as follows: Satisfaction with the intervention and / the process leading to the well-informed decision for both the patient and the invitees, the number of invitees, the relationship of the invitee to the patient, the duration of the meeting, the use of an interpreter, the number of visits necessary for the intervention, the treatment adherence of the professionals and the satisfaction of the professionals. These outcomes are recorded by the educators on a questionnaire for each intervention.

Product evaluation

Patients and invitees will be asked four questions on their opinion of the intervention provided by the educators: satisfaction regarding the educational intervention (e.g. usefulness, clarity). For example, *'How satisfied are you with the clarity of the received information '(1 = very dissatisfied - 5 = very satisfied).*

Process evaluation

Patients and invitees will be asked eight questions on their opinion and satisfaction regarding the way in which the intervention is delivered. (e.g. logistics, cooperation, understanding, professionalism). The questions asked are based upon the concepts and the structure of the Revised Treatment Adherence Measure (TAM; [36,37]. The main underlying question of the TAM is: 'Did the health care providers do what they were ought to do in congruency with their protocol?' For example, *'The researchers encouraged communication between me and my family/friends' (1 = not at all - 5 = to a large degree).*

Educator process evaluation

This questionnaire (12 items) will be completed by the co-educator to determine whether the intervention was able to reach the right audience (reach) and whether it was implemented as intended (fidelity) [38]. For example, *'How satisfied are you with the communicative aspects of the home visit?' (1 = very dissatisfied - 10 = very satisfied).* Followed by, *'What went well and what could have been improved?' (open questions).*

Background variables

Socio-demographic data: date of birth, gender, education, employment status, marital status, number of children, ethnicity and religion will be collected through medical records. Medical data: medical diagnosis, history of other RRT's, current treatment, date of first dialysis and blood type.

Sample size calculation

An *alpha* of .05 and a *power* of .80 was used in the following calculations, as proposed to be appropriate for behavioral research [39]. To determine an adequate sample size for detecting the effect we did a power analysis based on the proportion of LDKT’s performed in the control versus the experimental group in previous research [17]. We used this parameter since this is the only one on which there has been reported in the literature with regard to the current study parameters. Moreover the other parameters would reveal inconsistent sample estimates. For example, the knowledge parameter would show a large effect size which would result in a very low sample size whereas, self-efficacy would require a lager sample size. The required sample sizes to achieve a nominal power of $1-\gamma = 0.8$ on a two-sided test with a $\alpha = 0.05$ using a Fisher distribution revealed that at least 78 patients are required per study group to enable statistical judgments that are accurate and reliable. Calculations were performed in SAS; Power and Sample Size version 3.1.

Statistical analysis

Following the updated CONSORT statement [40], for this study the intention-to-treat population is defined as all randomized patients who are known to have received at least one home visit and who provide data for at least one post-baseline measurement for one or more of the key efficacy variables: no patient will be excluded for protocol violations which occurred during subsequent follow-up (modified intention-to-treat) [41]. Additional effort will be exerted by the educators to ask the drop-out patients to complete the post-measurement for the primary outcome.

For comparing the patients’ baseline-variables between the two research conditions the two tailed t-test for independent samples for the continuous variables, the two-tailed Mann–Whitney U-tests for the ordinal variables and the Chi-square tests for the categorical variables will be used. The effectiveness of our home-based educational intervention for the primary outcome variables will be analyzed with mixed modeling, i.e. multilevel regression modeling. The additional value of this multilevel testing lies in the flexibility to model individual growth trajectories and to handle missing data. The latter will only hold if structure of the missing data is Missing Completely At Random (MCAR) or Missing At Random (MAR), but not if the data turns out to be Missing Not At Random (MNAR). This technique is appropriate since missing data and drop-outs are inevitable in longitudinal research. Moreover, missing data affects study power simply by the reduced availability of data points [42]. We will strive to firstly minimize missing data, and to subsequently take this into account during analysis. The methodology of mixed modeling for repeated measures allows us the use of flexible error variance-covariance structure. Additionally, the predictive value of the baseline-parameters (main-outcome variables) on effectiveness can be estimated.

Finally, semiparametric regression analysis will be employed using Cox Proportional Hazard Model to examine the significance of the contingency between the hazard for an event of the experimental and control group on the secondary outcome variables. This model enriches the analysis by incorporating covariates in the regression equation (e.g. age, gender, ethnicity, dialysis time). Time-to-event graphs will be depicted for the experimental and control group separately. Patients with a LDKT will be regarded as having the 'event' whereas patients who continue dialysis during the follow-up period will be censored. DDKT is modeled as a competing event and therefore patients who take-up this treatment will also be censored.

Ethical considerations

The Medical Ethical Committee of Erasmus Medical Center, Rotterdam, The Netherlands, has approved this study, registered under MEC-2011-004 / NL34535.078.10. Firstly, the ethical feasibility of an intervention as we propose in this protocol had been evaluated. In that research it had been argued that an active intervention in peoples' live is justified [43]. The proposed education and therapeutic counseling in this protocol needs to be relative to the social context and the personal condition of the subsequent patients in order to ensure ethical justification. Secondly, in our center we have recently published an article on the ethical considerations of such a home-based educational intervention for kidney patients and their social network [44]. The authors concluded that a home-based approach is ethically justified when certain essential conditions had been satisfied. We consider the following as the most important: 1) participation must be completely voluntary at any point during the intervention, 2) the intervention must not be persuasive (i.e. advocating for a certain treatment option), and 3) the goal and the procedure of the intervention must be clear to all participants.

Discussion

LDKT has become a successful commonplace treatment option. The donor is often a family member but can also be a friend or an acquaintance in the Netherlands [45]. This has led to a broadened range of potential living donors. The graft survival rates of LDKT are better than those of the deceased donor transplantation [46]. Although research and clinical experience have shown LDKT to be a better alternative for patients with end-stage renal disease, the uptake of LDKT remains stagnant in culturally diverse populations. This inequity needs to be addressed [12,14,47]. Consequently, our aim was to address this inequality within a therapeutic framework that has already been scientifically established. We integrated the principles of MST within health behavioral change theories to create this home-based educational intervention. Combining these principles with the results of previous research on psychosocial and culture specific potentially modifiable hurdles [14,15] has resulted in the Kidney Team At Home study. The primary research question of this study is to investigate whether a home-based educational intervention is effective for end-stage renal patients in reducing hurdles to LDKT. The secondary research question is to investigate whether the intervention increases the rates of LDKT among ethnically diverse populations. We will try to establish this through guided communication, which if effective, can support and encourage well-informed decision making. Discussing a difficult to broach topic such as living donation, which hitherto could not be adequately discussed [48], may be an emotional burden to the patients and their social network. Within the MST framework it is the explicitly framing of this very burden that is crucial to the intervention. With this multisystemic approach one seeks to resolve existing tensions in collaboration with the participants and try to pave the way for the emergence of a stable and suitable consensus on the issue at hand. This consensus will embrace a well-informed decision, which can be the pursuit of LDKT but may also be (continuation of) dialysis. The discussion of living donation is for health care professionals not one of the toughest conversations one can imagine. Indeed, the discussion should be seen as a complicated but nevertheless as a mild social dilemma for the educators. Since MST is an evidence-based therapy, we believe that MST is able to provide us with tools that allow us to safely frame the transfer of information and the discussion of LDKT in the family network of the patient.

Other ongoing studies

In our center we are currently also investigating a multicenter home-based intervention in a cross-over design [44]. However, the target population is different for that study compared to the KTAH-study. The target population are pre-emptive patients, who are Dutch speaking, and without a history of other renal replacement therapies. Additionally, in contrast to the KTAH-study, this pre-emptive study focuses on primary knowledge provision without implementing a psychotherapeutically intervention. Another culturally sensitive study protocol has been recently published [49]. However, also that study focuses on pre-emptive patients.

Practical considerations

Kidney patients in the experimental group are hosts for the sessions at their home. In most cases the patient and his/her family appreciate this informal setting and the fact that they do not have to make extra visits the hospital to participate in this study. However, if the patient does not wish to have the session at their home it may be held at a different location (e.g. community center, church). An additional flexibility in this protocol is that we will provide them with interpreters who were trained on the matter at hand for those to whom the Dutch language may be a barrier. Finally, if the per protocol number of visits appears not to be sufficient enough to reach the pre-specified goal by the educators, multiple sessions may be held in agreement with the participants. All these flexibilities are justified under the ‘what ever it takes’ principle of MST and is being done to make the intervention easily accessible for the patients and the individuals from their social network.

Conclusion

If we show that this method is effective in reducing hurdles for LDKT the hypotheses will hold that patients will reach more stable and well-informed decision regarding renal replacement treatment options together with their social network. This supplementary home-based educational intervention may contribute to reducing inequalities in access to LDKT by addressing specific psychosocial and cultural hurdles at a grass-roots level.

Competing interest

The authors declare that they have no competing interest.

Authors' contributions

JJVB, WW, EKM and WCZ developed the original idea of the study, submitted a grand application to the Dutch Kidney Foundation, and all supervised the implementation of the project. SYI and AEL wrote the study protocol, the ad verbatim *Multisystemic Engagement & Nephrology* manual and are the educators who are implementing the study in the outpatient pre-transplant clinic of the Erasmus Medical Center, Rotterdam, The Netherlands. CB, contributed to the development of the protocol, our therapeutic multisystemic framework and will continue to supervise the implementation throughout. All authors read and corrected the draft versions. All authors approved the final version of this protocol.

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Chapter 8

A Randomized Controlled Trial of a Home-based Family Educational Intervention: The Kidney Team at Home Study

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Abstract

Our aim was to develop and test an educational program to support well-informed decision making among patients and their social network regarding Living Donor Kidney Transplantation (LDKT). 163 patients who were unable to find a living donor were randomized to standard care or standard care plus home-based education. In the education condition patients and members of their social network participated in home-based educational meetings and discussed renal replacement therapy options. Patients and invitees completed pre-post self-report questionnaires measuring knowledge, risk perception, communication, self-efficacy, and subjective norm. LDKT activities were observed for 6 months post-intervention. Patients in the experimental group showed significantly more improvements in knowledge ($p<0.001$) and communication ($p=0.012$) compared to the control group. The invitees showed pre-post increases in knowledge ($p<0.001$), attitude towards discussing renal replacement therapies ($p=0.020$), attitude towards donating a kidney ($p=0.023$) and willingness to donate a kidney ($p=0.039$); and a decrease in risk perception ($p=0.003$). Finally, there were significantly more inquiries (29/39 versus 13/41, $p<0.001$), evaluations (25/39 versus 7/41, $p<0.001$) and actual LDKTs (17/39 versus 4/41, $p=0.003$) in the experimental group compared to the control group. Home-based family education supports well-informed decision-making and promotes access to LDKT.

Keywords: Living Kidney Donation; Ethnicity; Family Communication; Patient support program; Counseling

Introduction

The superior outcomes for Living Donor Kidney Transplantation (LDKT) compared to Deceased Donor Kidney Transplantation (DDKT) as a treatment for renal end-stage disease are now well-established (1). However, as found in other countries (2-3), there is inequality in access to LDKT among ethnic minorities in the Netherlands (4). Several studies have reported on factors contributing to access to LDKT. A number of unmodifiable factors such as medical, socio-economic and ethnic factors have shown to be independently related to the chance of receiving a LDKT (5-7). A number of modifiable factors, such as knowledge, attitudes, risk perception, communication and cultural sensitivity, are also independently related to the chance of receiving a LDKT (8-11). A recent paper explored which of the modifiable cognitive and psychosocial factors are associated with LDKT while controlling for unmodifiable socio-demographic factors (12). Knowledge on kidney disease and renal replacement therapies among patients and discussing LDKT with significant others were suggested to be potential targets for interventions to promote access to LDKT.

In North America differences in uptake of LDKT between ethnic groups have been reported (13). This health care inequality, for ethnic minorities and individuals who find it hard to discuss living donation, needs to be addressed (14). In response, a home-based intervention have been developed (15). The results showed superior effects for the home-based education compared to standard hospital-education in terms of higher knowledge, more communication with others regarding LDKT and fewer concerns towards LDKT (15). Additionally, there was a significant increase in the number of living donor inquiries, living donor evaluations and LDKTs performed in the home-based education group. The 'house-calls' approach was even more beneficial for black patients in the number of donor evaluations and LDKTs compared to white patients (16). This additional effort to increase LDKT rates is needed since a recent paper points towards a decline in living kidney donations in North America (17). In the current study, we adapted the home-based group education approach to the Dutch situation and investigated the efficacy of our program in a randomized controlled trial. Unique to the present study is the investigation of the impact of the intervention on members of the social network and the inclusion of only patients that were yet unable to find a living donor. The objective of the program was to support well-informed, shared decision-making regarding renal replacement therapy and to promote access to LDKT among both patients of Western and non-Western descent who remained on the deceased donor waiting list.

Materials and methods

Participants: Between March 2011 and March 2013 179 patients with end-stage renal disease who were unable to find a living donor were invited to participate in the ‘Kidney Team at Home’ study. Eligible candidates were either newly referred for transplant preparation or already listed for DDKT from both Western and non-Western descent. Eligible candidates were required to be ≥18 years and medically (e.g. no hospital admission) and mentally fit (e.g. no mental deterioration). Of the eligible patients 16 refused to participate. These patients reported that individuals from their social network would not appreciate the home-based intervention. The remaining 163 patients all signed an informed consent form. A total of 440 family members, friends and acquaintances were present during the home-based educational meetings, of which 246 participated in the study. These participants were also required to be ≥18 years, medically and mentally fit and to have signed an informed consent form. See also figure 1 (flowchart).

Procedure: In this randomized controlled trial (18) all patients were invited to participate by the home-educators after at least two consultations with one of the transplant nephrologists. During the face-to-face informational consultation with the home-educator the patients received written and verbal information on the aims and procedures of the study. In line with the equity principle, all the study materials (e.g. patient information forms, questionnaires) were available in the eight most common languages in the Rotterdam municipality, namely Dutch, English, Arabic, Turkish, Papiamento, Spanish, Portuguese and Modern Hindi. All patients were approached for participation after they received the standard educational care. After informed consent was obtained, patients were randomized to either the control or the experimental group (see details below). Urn randomization was carried out via an adaptive biased-coin algorithm by another researcher. When needed, independent interpreters were used for patients and/or members of the social network during the intervention. The home-educators (a medical psychologist and a transplant coordinator) were trained in the general aspects of kidney disease, renal replacement therapies, multisystem therapy and supervised by a multisystem therapy supervisor throughout the study period. Ethical approval was provided by the Medical Ethical Committee of the Erasmus Medical Center. The trial is registered in the Netherlands Trial Register: NTR2730.

The control group received standard care. In the standard care all newly registered patients visiting our pre-transplantation outpatient clinic receive consultations with a transplant nephrologist, a transplant coordinator and a social worker. After that all patients receive a yearly check-up with the nephrologist or a nurse practitioner. In addition to verbal information, patients receive a variety of written educational material and a DVD regarding the various living donation and transplantation programs (e.g. national exchange).

The experimental group received standard care plus a home-based educational intervention. The intervention consisted of two sessions at the patient's home. During the first visit (approximately 1 hour) the family network of the patients was depicted on a sociogram by the educators in order to familiarize themselves with the family structure and to recognize the values of that particular social system. At the end of the first session the educators helped the patient to make a list of individuals who they were going to invite for the second session. The goal of the second session (approximately 2.5 hours) was to provide information and support communication, therefore, it was not necessary that all the invitees were potential donors (see page 104). The educators also explored the possibilities of LDKT within the patients' social network. The process of the intervention was based on principles and communication techniques drawn from Multisystemic Therapy (MST) (19). The educators stimulated an open communication between the patient and the family members and used the strengths and possibilities of the natural network of the patient. The objective of MST is to achieve a lasting consensus on the patient's goals and how these goals can be reached with engagement and/or support of his/her social ecology. The second session was organized in such a way that the educators had to do 'whatever it takes', in line with one of the basic principles of MST, to achieve that lasting consensus on the various renal replacement therapies. Thus in some cases multiple sessions were offered/requested in order to assist patients and invitees to receive all the information and/or to support communication (18).

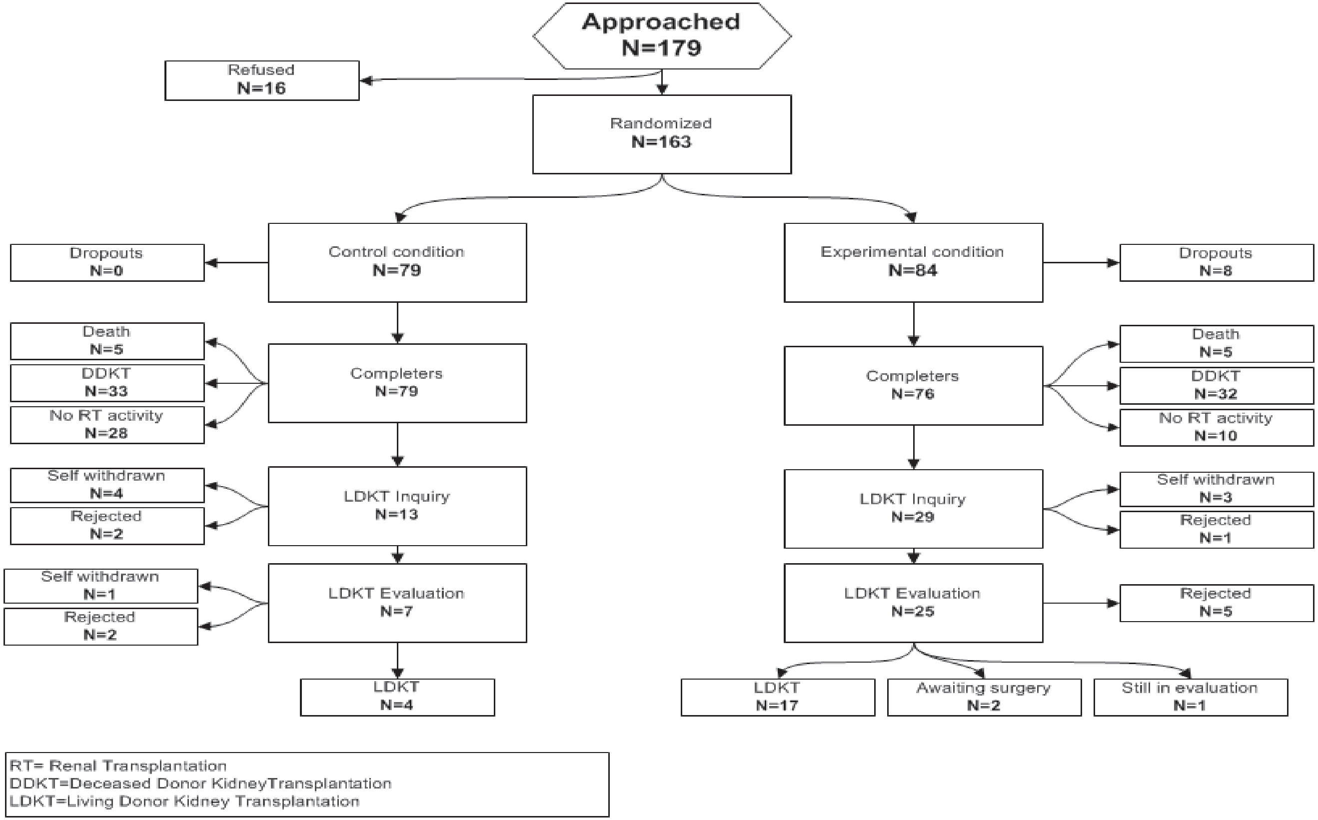
Measurements: All the study participants completed a pre and a post intervention (4 weeks period) self-report questionnaire. The first self-report was completed right after randomization and the second within 1-3 days after the intervention. The primary outcome measures were derived from the Attitude-Social influence-Efficacy model (20): knowledge, risk perception (fears and concerns), self-efficacy, attitude towards communication, communication on renal replacement therapies, subjective norm, and willingness to accept LDKT/donate. Knowledge was assessed with the reliable and validated Rotterdam Renal Replacement Knowledge-Test (R3K-T) (21). The other variables were assessed using statements. The statements were rated on a Likert-scale using five to seven response categories (22). A more detailed description of the development of the statements and examples of the questionnaire per variable can be found elsewhere (18). The secondary outcome measure was access to LDKT, operationalzed by measuring three times-to-event of LDKT activities separately (living donor inquiries, evaluations and actual LDKTs) between the experimental and control group up to nine months after the last patient was included. Patients were registered as having an inquiry if one or more potential donors expressed the desire/will to donate a kidney at the pre-transplant clinic. Similarly, patients were registered as having an evaluation if one or more potential donors underwent the medical screening for donation. This data was obtained from the medical records. Background characteristics were also retrieved from medical records (see Table 2). At the end of the educational session each patient and participating invitees received a 12-item evaluation form to appraise the content and the process of the intervention they received. Additionally, an administrative person that was not directly involved in the study performed an independent 15-item evaluation by telephone. Both evaluations were formulated as statements which could be rated on a 5-point Likert-scale (1=very unsatisfied to 5=very satisfied) regarding the professionalism, communication skills and availability of the educators and the extent to which the intervention goals were achieved. Only a score of 5 on each item is regarded as protocol adherent and all other scores are regarded as not adherent. The adherence scores range from 0-1 with a score of 1 representing adherence.

Sample size calculation: To determine an adequate sample size for detecting the effect we did a power analysis based on the primary outcomes found in previous research (15-16). The knowledge parameter shows a large effect size which would result in a very low sample size whereas, self-efficacy would require a lager sample size. Thus, to determine sample size we used the variable with the lowest effect size. The required sample sizes to achieve a nominal power of $1-\gamma = 0.8$ on a two-sided test with a $\alpha = 0.05$ using a Fisher distribution revealed that at least 78 patients are required per study group to enable statistical judgments that are accurate and reliable.

Data-analyses: All patients randomized were included in the analyses in accordance with the intention-to-treat principle. Pearson’s chi-squared distribution analyses and univariate analyses of variance were conducted to explore differences on the baseline characteristics of the participants between the two study conditions. The efficacy of our home-based educational intervention for the primary outcome variables was analyzed with mixed modeling, which was used for longitudinal analyses. Mixed modelling can efficiently handle data with missing and unbalanced time-points. It corrects for bias when absence of data is dependent on covariates that are included in the models (covariate dependent dropout), however, other causes of dropout not associated with the covariates remain potentially present (23). Our model consisted of two levels: the patients constituted one level and the repeated measures the other level. First, for each outcome variable a saturated model was postulated, with the primary outcomes as dependent variables. The saturated models included treatment group, time, all covariates (see table 2), all treatment-time and treatment-covariate interactions as fixed effects and analysed with the backward method. Using Wald tests, the saturated fixed part of the models was reduced by eliminating non-significant fixed effects, respecting that interaction effects must be nested under their main effects (24). The significance of the difference between the saturated models and the parsimonious final models was determined with the deviance statistic using ordinary maximum likelihood. The residuals of the model were checked to be normally distributed, a necessary assumption for a correctly fitted mixed model. Finally, effect sizes were calculated from dividing differences between time-point estimations and baseline by the estimated baseline standard deviation. Cohen’s definition was used for the interpretation of the effects sizes: an effect size of 0.20 is considered a small effect, 0.50 medium and 0.80 a large effect (25).

The secondary outcome (time to an inquiry, an evaluation and an actual LDKT) was analyzed with three Kaplan-Meier survival analyses to examine differences between experimental groups. Next, semi-parametric regression analyses were carried out using Cox Proportional Hazard Model to examine the hazard ratio comparing the experimental to control group on the three secondary outcome variables. This model enriches the analysis by incorporating covariates (table 2 plus all primary outcomes) in a backwards fashion in the regression equation. All analyses were completed for each of the three secondary outcomes separately (LDKT inquiries, LDKT evaluations and actual LDKT). The event in the three analyses was defined as the occurrence of one of the three LDKT pursuit behaviors. Patients who were lost to follow-up were regarded as censored at their last contact and patients who continued dialysis were regarded as censored at the end of the study. DDKT is modeled as a competing event and therefore patients who received this treatment were censored at date of DDKT. Also, a time-to-event graph was generated for only the actual LDKT rates since this was regarded as the most essential outcome compared to the inquiries and evaluations (Figure 2). Additionally, actual numbers and proportion on the secondary outcomes were reported (Figure 1).

Figure 1. A flowchart of the Kidney Team at Home-Study



Legend to figure 1 - A flowchart of the randomized controlled trial on the Kidney Team at Home-Study. RT=Renal Transplantation. DDKT=Deceased Donor Kidney Transplantation. LDKT=Living Donor Kidney Transplantation.

Results

The only difference in socio-demographics between participants and non-participants (8.9%) is that the latter group is significantly older (yrs= 77.8, sd= 4.3). Of the 163 patients that were included in the trial, 84 were randomized to the experimental group and 79 to the control group. No significant differences were found between the two study groups at baseline on the socio-demographical variables (see Table 1). The dropout rate in the experimental group was 8/84 compared to 0/79 in the control group (*p*=0.004). The majority of the dropouts (75%) left the study after the first home visit. The reasons for drop-out were either that patients were unable to find individuals in their social network to be present during the educational session or that patients received a DDKT before receiving the educational session (2/8). The mean number of visits was 2.2 with a maximum of 5 (SD= 0.69). On average 5.0 invitees attended the educational session (SD: 3.4) for the second educational session. The 246 invitees were on average 39.4 (SD: 14.6) years old, the majority was female (55.7%), Western (58.3%), had completed high school (+some college) (39%), were never screened for LDKT before (79.7%) and the majority were either the partner (21%), the child (29.1%) or the sibling (17.7%) of the patient.

Table 1. Socio-demographic characteristics

Characteristics	Control (N=79)	Experimental (N=84)	p-value
Gender (male / female)	47/32	46/38	0.542
Mean age in years (SD)	54.5 (13.5)	54.9 (13.0)	0.828
Married or living together (%)	47 (59.5)	49 (58.3)	0.256
Western / non-Western	40/39	32/52	0.076
Dutch (%)	38 (48.1)	27 (32.1)	
Antillean (%)	13 (16.5)	16 (19.0)	
Moroccan (%)	7 (8.9)	10 (11.9)	
Turkish (%)	4 (5.1)	11 (13.1)	
Cape Verdean (%)	1 (1.3)	6 (7.1)	
Asian (%)	9 (11.4)	6 (7.1)	
Other (%)	7 (8.9)	8 (9.5)	
Educational level (%)*			0.190
Low	25.3	35.7	
Average	43.0	32.1	
High	8.9	13.1	
Employment (full or part-time %)	11 (13.9)	9 (10.7)	0.548
Dialysis modality (%)			0.351
No Dialysis	10 (12.7)	10 (11.9)	
PD	17 (21.6)	15 (17.9)	
HD	52 (65.9)	59 (70.3)	
Mean months on dialysis (SD)	26.1 (19.5)	26.5 (20.2)	
A history of RT (%)	27 (34.2)	20 (23.8)	
History of LDKT (%)	9 (11.4)	9 (10.7)	0.806
PRA maximum >10% (%)	20 (25.3)	18 (21.4)	0.416
Blood type (%)			0.643
O	40 (50.6)	46 (54.8)	0.891
A	23 (29.1)	22 (26.2)	0.935
B	13 (16.5)	14 (16.7)	
AB	3 (3.8)	2 (2.4)	

Values in the table are presented as *n* with the percentage in parentheses or mean values with ±SD in parentheses. *The educational level was valued at three levels; Low= elementary school, Average= high school (+ some college) and High= college degree (+ some postgraduate/professional degree). PD=peritoneal dialysis. HD=hemodialysis. RT=Renal Transplantation. LDKT=Living Donor Kidney Transplantation. PRA= panel-reactive antibody.

Primary outcomes

Inspecting the data for missingness prior to analyses showed that less than one percent of the primary outcome measures was found missing.

Patients: There was a significantly greater increase in knowledge in the experimental group than in the control group. Non-western participants started at a lower level and had a larger gain from the treatment, though they did not catch up completely with their Western counterparts (Table 2). Men demonstrated a medium decrease in perception of risks associated with living donation, but there was no change among women. The treatment resulted in a small increase in the frequency of communication on renal replacement therapies. No significant changes were found for self-efficacy, attitude towards communication about LDKT, subjective norm, and willingness to accept LDKT.

Invitees: Invitees with a Western background scored significantly higher on knowledge than invitees with a non-Western background on the pre- and post-measurements. Both Western and non-Western invitees showed equally large improvements in their knowledge. Men scored 1.5 lower on knowledge than women (*p*=0.011, not in Table). Invitees also had a small but significant increase in their self-efficacy to discuss renal replacement therapies with the patient, positive attitude towards donating a kidney and intention to donate a kidney to the patient, and a decrease in risk perception. No differences between the pre-post measurement were found on the frequency of communication about renal replacement therapies and their subjective norm. Table 3 shows the scores of the different primary outcome measures between the two study groups for patients and invitees.

Table 2. Estimated means (SEM) and effect sizes between groups of the primary outcomes

Measure (scale range)	Control		Experimental		Effect Size (p-value)
	Pre	Post	Pre	Post	
Patients					
Knowledge (1-21)					
Western	14.9±0.6	15.3±0.6	16.3±0.7	18.1±0.8	0.40 (0.053)
Non-Western	11.7±0.6	11.9±0.6	11.2±0.5	14.8±0.5	0.92 (<0.001)
					0.52 (0.043)*
Risk perception (14-70)					
Men	31.9±1.4	31.5±1.4	32.6±1.4	27.3±1.4	-0.51 (0.001)
Women	36.2±1.7	35.6±1.7	36.6±1.6	36.9±1.6	0.10 (0.582)
					-0.61 (0.009)*
Self-efficacy (3-15)	9.7 ±0.4	9.6 ±0.4	10.3±0.5	10.9±0.5	0.22 (0.116)
Attitude towards communication (6-42)	30.6±0.9	30.2±0.7	30.1±1.3	31.3±1.1	0.18 (0.137)
Communication on RRT's (4-20)	8.5 ±0.4	8.3 ±0.3	8.6 ±0.5	9.4 ±0.4	0.33 (0.012)
Subjective norm (3-21)	15.3±0.4	15.4±0.4	16.3±0.6	16.5±0.5	-0.07 (0.671)
Willingness to accept LDKT (2-14)	8.3 ±0.4	8.6 ±0.3	9.7 ±0.5	9.7 ±0.4	-0.09 (0.408)
Invitees					
Knowledge (1-21)					
Western			12.4 ±0.5	18.5±0.6	1.42 (<0.001)
Non-Western			9.7 ±0.5	15.8±0.5	1.42 (<0.001)
Risk perception (14-70)			33.7 ±0.7	30.6 ±0.8	-0.40 (0.001)
Self-efficacy (3-15)			10.8±0.3	11.5±0.4	0.33 (0.010)
Attitude towards communication (6-42)			29.9±0.9	33.3±1.4	0.25 (0.006)
Communication on RRTs (4-20)			8.1 ±0.6	8.6 ±0.5	0.12 (0.187)
Subjective norm (2-14)			10.3±0.3	10.8±0.5	0.21 (0.080)
Attitude towards LDKT (6-42)			28.7±1.0	32.2±1.5	0.25 (0.003)
Willingness to give LDKT (2-14)			8.8 ±0.5	9.8 ±0.5	0.24 (0.027)

Values in the table are presented as mean estimates of fixed effects with standard error means with ± (SEM) in brackets obtained from the different mixed models. The last column shows the difference in effect size of the pre-post measurement between the study groups. * Significant difference between subgroups. RRT=Renal Replacement Therapy. LDKT=Living Donor Kidney Transplantation.

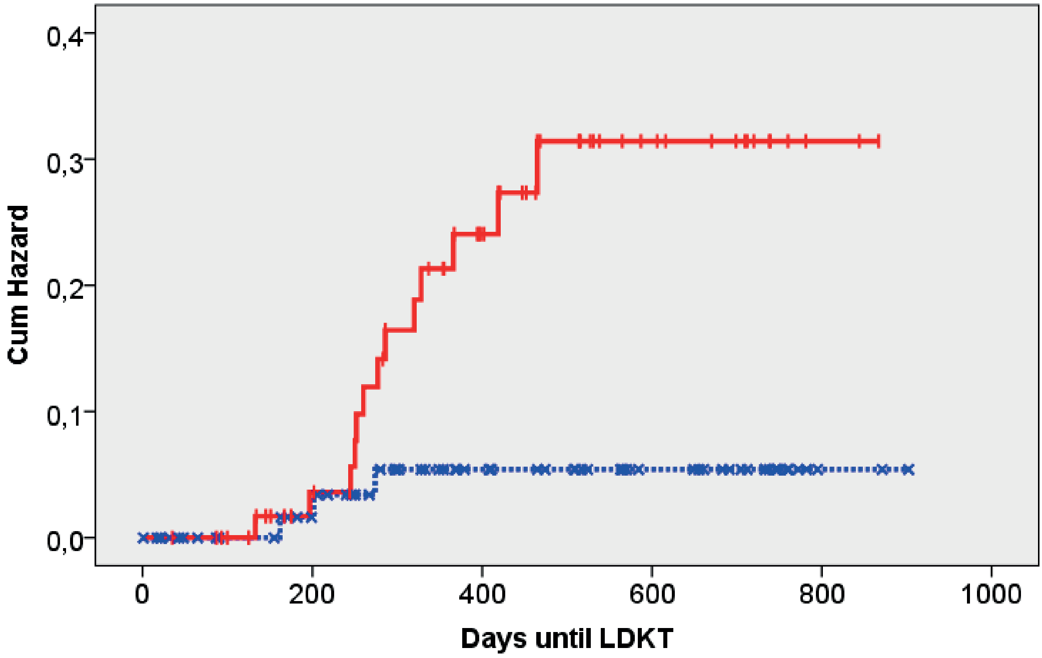
Secondary outcomes

Intention to treat analysis showed significantly more inquiries for LDKT in the experimental group compared to the control group, (HR: 3.3, $CI_{95\%}$: 1.86-5.89), more evaluations, (HR: 4.7, $CI_{95\%}$: 2.07-10.67) and more LDKTs, (HR: 5.3, $CI_{95\%}$: 1.53-17.84). Log-rank tests showed respectively: $Chi^2_{(1)} = 21.97$: $p < 0.001$; $Chi^2_{(1)} = 16.56$: $p < 0.001$; $Chi^2_{(1)} = 8.72$: $p = 0.003$. Figure 2 plots the event-times for the actual LDKTs. As described above, after randomization, 76/84 patients of the experimental group completed the intervention. The death rate was five in both study groups, of which the majority were men (7/10) and above the age of 48 (range: 27-77). The number of patients that received a DDKT in the study period was not significantly different between the experimental (32/71) and control (33/74) condition. Discounting these patients and those that died during the study period, 39 remained in the experimental group versus 41 in the control group. For the remaining patients holds that more inquiries for LDKT were registered in the experimental group compared to the control group 29/39 (74.4%) versus 13/41 (31.7%), more evaluations 25/39 (64.1%) versus 7/41 (17.1%), and more LDKTs 17/39 (43.6%) versus 4/41 (9.8%). None of the 8 dropouts received a LDKT, although 3 had a donor inquiry of which 1 resulted in LDKT evaluation by the end of the follow-up period.

Of the patients who received a living donation inquiry 12/29 have not (yet) donated in the experimental group. This proportion of ‘lost potential donors’ is higher in the control group 9/13. Of these donor evaluation procedures 7/15 in the experimental group and 4/9 in the control group were terminated based on medical contra-indications (e.g. diabetes, obesity). The other reasons were social, for example, the potential donor experienced ambivalence regarding the donation, the patient changed his mind about receiving a kidney from his/her child.

Patients who had a donor that underwent the medical screening for donation showed a main effect of risk perception on the event-times till evaluation. Significantly lower scores in perception of risks associated with living donation were related to significantly earlier commencement of donor screening compared to average scores on the risk perception (HR: 1.56, $CI_{95\%}$: 1.09-2.24, $Chi^2_{(1)} = 5.75$: p=0.016). No other main or interaction effects were found for the primary outcomes on the event-times of living donation inquiries, evaluations and actual donation rates.

Figure 2. A time-to-event cumulative hazard plot for the Living Donor Kidney Transplantation (LDKT) rates comparing the experimental (solid line) and control (dashed line) group



Number of patietns at risk:

Days	0	100	200	300	400	500	600	700	800
Experimental group:	84	77	66	55	41	29	20	15	5
Control group:	79	68	63	48	39	32	23	18	2

Legend to figure 2 - This graph depicts the cumulative hazard plot time-to-event data for the LDKT rates for the separate study groups of a randomized controlled trial on an home-based educational intervention. Experimental group received an home-based education and the control group received the standard hospital-based education.

Intervention evaluation

Overall, patients were very satisfied with the content (81.7%) and the process (77.0%) of the intervention. Professionalism (86.5%) and the communication skills (81.0%) of the educators were rated the highest, whereas, the accessibility (57.9%) and the degree in which the goals were achieved (60.3%) scored lower. The lower scores on the accessibility reflected mainly dissatisfaction with the availability of the educators by telephone. Most of the patients that had low ratings regarding achievement of intervention goals reported that they were disappointed that the intervention did not yield a living donor. The intervention was rated approximately the same by the invitees: content (81.9%) and process (88.6%). The figures on dialysis-related mortality and morbidity and the questionnaire were experienced as taxing by the majority of the invitees.

Discussion

This study describes the first application of home-based family education on living donation tailored to a European population without a (potential) living kidney donor. The home-based educational intervention in this study was shown to be effective in bringing about change in knowledge and communication among patients. These changes support well-informed decision-making in favor of living donation, which can be seen in the changes observed in the secondary outcomes: significant increases in LDKT pursuit behaviors in the experimental group compared to the control group.

These findings should be interpreted in light of a number of limitations. A comment should be made with regard to the use of Likert-scales in a cross-cultural setting. Research has indicated that response patterns may be affected by culture (26). The reasons given for prematurely ending the treatment (6/84) were related to a limited social network, which suggests that the intervention might be less effective in patients with a limited social network. Yet, these are the particularly hard to reach patients for whom living donation is difficult to realize. Additional data on drop-out patients should be collected in future studies in order to specify this group further. Although, carefully selected via literature, expert opinions and theory except for knowledge the items measuring the other primary outcomes were not validated. Therefore, it could be that what those concepts are measuring does not completely reflect reality (i.e. dependability is compromised).

Notwithstanding these limitations, dialysis patients and their significant others benefit from an outreaching, patient-centered approach to education on kidney disease and renal replacement therapies. This need for a more active approach has been identified in the literature (27-28). This study is complementary to the earlier study on home-based education (15). The main extension of our intervention is the inclusion of only those patients who have not previously been able to find a living donor. We hold the view that only transplant candidates that do not find a living donor following standard education should receive this home-based intervention. Additionally, the home-based intervention is exceptionally well-suited for those patients for whom the standard education/guidance is not accessible (e.g.

patients with language or literacy barriers, patients with large (nuclear) families, patients who find it difficult to discuss their treatment options with significant others).

Previous research among Western and non-Western dialysis patients has shown that communication between patients and potential donors plays a role in the access to LDKT (29). In that study the majority of patients stated that they would not actively approach a potential donor to 'ask' for a kidney. Following this, a state of non-communication on the subject emerges and may be interpreted by patients as a refusal of the potential donors to donate: a state of passive deadlock. The current study highlights the beneficial value of stimulating and supporting the communication and thus the decision-making process between patients and their family and friends (30). This promising change, together with the increase in knowledge and the decrease in perception of risks associated with living donation, support the shared decision-making for the pursuit of LDKT. Not all primary outcomes explain the higher increase in living donation rates. In line with our theoretical model (Attitude-Social influence-Efficacy-model), the clinical relevance of the statistical differences in these factors (e.g. knowledge, communication) lies mainly in their contribution to a better shared decision-making.

This trial took place at the Erasmus Medical Centre, Rotterdam, where extensive efforts are made as part of the standard care to promote LDKT (31), including for example a national exchange program, ABO incompatible transplantation, and unspecified donation (32). As a result the rate of living donation in Rotterdam is high (>70% (33)) and the patients included here were those who had very minimal chances of a living donor transplant prior to the intervention. It is therefore likely that the success of this home-based family intervention will even be higher in transplant centers with less intensive promotion of living donation as part of standard care.

The favorable results in the primary and secondary outcomes of this intervention are also reflected in the subjective evaluation of the intervention by patients and their family and friends. One of the concerns with home-based interventions is that they may induce unacceptable pressure on the family/friends to donate a kidney. However, this was not reported by either patients or by individuals from their social network. On the contrary, some patients reported disappointment that the intervention did not result in a LDKT. It is therefore crucial to explicitly formulate the goals of the intervention, which are information provision and communication support, and to manage patients' expectations regarding the outcome. This is also documented as one of the initial conditions in order to implement an ethically justified intervention (34). Yet, patients and invitees seem to appreciate the effort of the educators in the support of the LDKT discussion. Therefore, home-based educators should not be reserved in addressing the possibilities of LDKT with patients and their family and friends. Nonetheless, the discussion of a delicate subject such as LDKT within families should be undertaken in way that is sensitive to the family dynamics and with respect for the ethical conditions for a home-based intervention (35). Information should be honest and complete (35). Intervention techniques drawn from multisystemic therapy were experienced as useful by the educators as they offer communication skills to sensitively address family-specific stressors and to support the discussion regarding LDKT.

In conclusion, current findings support further implementation of this educational program into standard care in an interactive, culturally sensitive, patient tailored and out-reaching way to stimulate an overall increase in the numbers of LDKT.

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Disclosure

The authors declare that they have no conflicts of interest to disclosure as described by the *American Journal of Transplantation*.

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Chapter 9

General discussion
&
Clinical implications

General discussion and clinical implications

For many decades, efforts have been undertaken to shorten the wait lists for renal transplantation. In the Netherlands, attempts to increase the deceased donor rate all failed. However, there has been an increase in the number of kidneys from living donors. Nonetheless, a significant proportion of the dialysis patients, largely non-European, neither receive a spontaneous offer from a potential donor nor discuss their treatment options with significant others. More importantly, these patients cannot profit from improved quality of life and survival associated with LDKT. Patients continue to find it difficult to discuss their kidney disease and associated treatment options with significant others. Patients' attempts to discuss living donation are experienced as disappointing (1, 2). Therefore, patients often feel rejected. Investigating such personal feelings and incorporating them in subsequent patient education/counseling should be regarded as a necessity. Such an approach could contribute to tailored patient care which will evoke increased patient satisfaction resulting in better therapy adherence (3). In this thesis the qualitative and quantitative contribution of psychosocial factors in the pursuit of LDKT was investigated. Subsequently, that empirical output was used to develop and test the effectiveness of patient centered intervention.

An effective home-based educational intervention

Research presented in this thesis shows that both knowledge of the various renal replacement therapies and discussing this knowledge with family and friends, plays an important role in finding a living donor (chapter 2, 3 and 5). Also, results show that the presence of these modifiable factors does not vary with patient's ethnic background. This is why our initial These modifiable factors provide health care professionals targets for intervention. However, we take the view that one should not consider these factors as standardized ingredients for an intervention. We rather see it as a point of departure from which a patient-tailored intervention can be provided. Using this knowledge a home-based educational intervention was developed for patients without a living donor (chapter 7).

Results of this home-based educational intervention show favorable effects (chapter 8). Patients and family/friends show a significant improvement in their knowledge and an improvement in their communication regarding the various treatment options. These improvements contributed in better well-informed shared decision-making. Additionally, the home-based intervention resulted in a fivefold increase in the number of living donations. No influence of ethnicity was found for these results. Also, no differences were found in refusal rates, drop-out, death rate and the number of patients transplanted with a kidney from a deceased donor between patients from European and non-European descent. Thus, unlike many other behavioral interventions, the home-based intervention as described in this thesis is applicable to and effective among patients from various cultures. In line with other research (4), results in this thesis show that non-European patients are overrepresented in the group of transplant candidates without a living donor. Therefore, this group could benefit from home-based interventions to a greater extent. If a home-based intervention are implemented in standard transplant care, differences in ethnicity in the access of LDKT could be reduced.

Potential side-effects of home-based interventions

It is conceivable that discussing treatment options, including living donation, could lead to undesirable effects in the relationship between the patient and members of the social network. This can be seen as side effects or 'safety issues' of the intervention. However, chapter nine shows that the side effects of the intervention were limited. In future implementations the side effects will probably remain limited if the quality standards of the intervention are maintained. One of the challenges in implementation is therefore to ensure optimal protocol adherence. This consists of monitoring the interventions on a case-by-case basis and identifying any protocol deviations.

One other possible risk is that discussing topics such as kidney disease and living donation can be emotionally laden for patients and their family/friends. If this burden is not taken into consideration it may jeopardize the effects of the intervention. It is therefore important to train health care educators in 1) recognizing discomfort in patients and their family/friends and in 2) adequately dealing with that discomfort. This is another plea to follow the protocol of the intervention as described in this thesis.

The patient and/or others present during the intervention may not feel able to make autonomous decisions due to the presence of the healthcare educators. In our home-based intervention communication techniques drawn from multisystemic therapy (MST) were used to promote individual autonomy while at the same time guiding patients and their significant others to reach a well-informed decision (chapter 7). Minimizing this risk should be one of the core elements in future interventions.

Another risk could be of ethical origin; does this outreaching effort exert too much pressure on patients and their significant others? The ethical justification of the home-based interventions was evaluated in an earlier study. That study indicated that a proactive intervention, in which living donation is discussed within the social network of the patient, is justifiable (5). In order to maintain ethical justification the intervention must be tailored to the personal and social circumstances of the patient. Thus, again the value of tailoring the intervention with trained educators is stressed. Such an approach is proven to be associated with minimal risks of side effects and maximal favorable changes in outcomes. Chapter seven and eight show that multisystemic therapy provides sufficient tools to tailor the intervention and train educators. These tools and communication techniques drawn from MST arguably contributed to the success of this intervention. Thus, educators conducting the home-based intervention should study the theory of MST and take a practical course in order to learn these techniques. The effects of this initial schooling should be maintained by regular (every 6-8 weeks) meetings with a senior educator and preferably a MST-supervisor. In addition, another study showed that home-based interventions are ethically justified if certain conditions are met (6). Essential conditions are: 1) the purpose and procedure of the intervention must be clear to all participants in advance, 2) participation must be completely voluntary throughout the intervention and 3) the intervention should be free of any unreasonable pressure on the participants. Providing information in a non-persuasive manner is in line with earlier findings (chapter 2). These conditions must be part of the training for the educators that will make the home visits.

Future directions

Given the large effects and the limited side-effects, making this home-based intervention part of standard care could be seen as a duty of every transplant professional. This intervention is in line with transplant professionals´ goal of finding the best treatment option for patients with end-stage renal disease. This does not imply that that all transplant candidates should receive this home-based intervention, but only those that do not find a living donor following standard education. Additionally, this home-based intervention is exceptionally well-suited for those patients for whom the standard education/guidance is not accessible (e.g. patients with language or literacy barriers, patients with large (nuclear) families, patients who find it difficult to discuss their treatment options with significant others). With such a stepped-care model one avoids imposing a relatively 'heavy' intervention on those who access LDKT via 'lighter' educational programs. Also, 'unnecessary' incremental health costs are avoided. Although the cost-effectiveness of this home-based intervention has yet to be investigated, it is likely that the intervention is cost-effective considering the effects and the relatively lower costs associated with LDKT compared to dialysis. A cost-effectiveness study evaluating and quantifying these assumptions is warranted. Such a study could provide information that may support arguments for reimbursement of the incremental costs associated with a home-based intervention.

Although this thesis and earlier studies provide evidence for the effectiveness of home-based interventions, pre-post measurements on factors associated with that effectiveness remain important. This recommendation has two supporting arguments. Firstly, the use of validated questionnaires allows health care educators to identify and quantify ‘problem areas’ that could be targeted rather than leaving them to silently obstruct intervention effects. This is a necessary step towards a patient tailored intervention. Secondly, if such questionnaires are implemented at the end of the intervention as well, the ‘success’ of the intervention can be monitored and feedback provided to health care educators. This idea is consistent with the practice of using questionnaires as instruments for routine outcome monitoring in clinical practice (7). This thesis contains the first validated questionnaire on kidney disease and the various renal treatment options (chapter 6). Recently, a set of questions related to communication on LDKT, fears/concerns regarding LDKT and self-efficacy related to the pursuit of LDKT were validated (8). A combination of the validated knowledge questionnaire (R3K-T) and that set of questions would largely cover the psychosocial factors targeted with this home-based intervention. Further validation of the R3K-T and other questionnaires measuring factors related to the pursuit of LDKT are needed.

Even after successfully implementing the home-based intervention, a certain proportion of the transplant candidates decide to remain on dialysis or will still be unable to identify a living donor. Even in these cases transplant professionals should not rule out the possibility of a living donation in the (near) future. It is recommended to stay in dialogue with patients and their significant others on transplantation and living donation. Transplant professionals could discuss living donation with transplant candidates when they attend the transplant clinic and patients should be able to contact the educator(s) at least by telephone at any time. Yearly appointments with the transplant nephrologist could facilitate this and should be seen as a minimum requirement.

We started this home-based intervention at a time that there was much debate surrounding ethical questions on whether you should counsel transplant candidates in finding a living donor using psychosocial interventions. Given the convincing evidence of this home-based intervention now, time has come that it is unethical to deny transplant candidates access to this home-based intervention. This thesis should inspire transplant professionals to consider a home-based educational intervention to whom it is indicated.

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Chapter 10

Summary in English

Summary

Living donor kidney transplantation is (LDKT) the optimal treatment for patients with end-stage renal disease. However, there is a significant number of patients, predominantly of non-European origin, that do not find a living donor. This thesis investigated potential psychosocial hurdles to LDKT. Subsequently, a home-based intervention was developed and tested if such an intervention would effectively address hurdles to LDKT and increase LDKT rates.

We hypothesized that dialysis patients are most knowledgeable on the psychosocial factors that prevent them from pursuing the most optimal treatment for their kidney disease from their personal experience. Focus groups with patients were carried out to gain insight into the factors that play a role in disease perception, attitudes/worries/fears regarding the various renal replacement therapies (RRT's) and the degree of communication with family and friends regarding RRT's. Four psychosocial factors were identified: 1) a lack of information and guidance, 2) lack of communication with family and friends related to living donation, 3) fears and concerns about a potential LDKT, and 4) social influences from family and friends (chapter 2 and 3). Research suggests that non-modifiable factors also influence the likelihood of finding a living donor, namely medical (anti-HLA antibodies, dialysis modality), socio-economic and ethnic factors. However, these factors cannot be modified with an intervention. When controlling for those non-modifiable factors, chapter 5 shows that knowledge and communication on kidney disease and treatment options are the most important modifiable factors. Indeed these factors were most strongly associated with having a living donor (chapter 5).

These and other psychosocial factors that form hurdles to LDKT have been frequently described in literature. A potential hurdle to LDKT that is less often described is that of religious concerns. Combining religious jurisprudence and patients' views on the potential religious hurdles to LDKT shows that the major faiths and religions worldwide support LDKT (chapter 4). Yet, some religions specify surmountable conditions. Nonetheless, saving a human life remains an overarching and powerful argument that has priority to the 'lower-order' excising contra-arguments. Health care professionals in donation and transplantation should to take knowledge of this positive religious viewpoint and discuss this with those who have religious concerns.

A focus group approach was used to disclose transplant candidates' view on patient-tailored interventions that could target modifiable hurdles to LDKT. A majority would

appreciate an home-based educational intervention (chapter 2). Solving knowledge insufficiencies regarding the various renal replacement therapies would be one of the main goals. Additionally, patients would welcome a discussion on living donation with members of their social network. Such interventions would also be potentially effective in addressing other psychosocial hurdles to LDKT within patients' social network.

Patients report that a non-persuasive approach is appreciated since health care professionals will intrude families' comfort zone (chapter 2). Yet, if the discussion on LDKT is not initiated by those present during the home-intervention, the educator should address the issue in a non-persuasive manner. The way in which the subject of living donation is addressed warrants cultural sensitivity. For instance, cultures in which modesty is a strongly valued tradition an indirect communication style is more appropriate (chapter 3). An indirect communication style would for example be: "Which aspects of the education on renal replacement therapies have drawn your attention specifically?" A more direct style would be: "Has someone in this room ever considered to be a living kidney donor?" Educators should try to tailor the education and the communication style on a case-by-case basis. Therefore, acquiring knowledge on the family values and norms is needed in order to receive optimal family engagement. In addition to a tailored and non-persuasive home-based educational intervention, patients and members of the social network who do not speak the language of the educator would value an independent interpreter. Besides these subtle (communication style) and obvious (use of an interpreter) differences, no further qualitative or quantitative evidence was found for cultural differences in factors hampering the access to LDKT. Neither did patients report on other conditions that need attention before implementing an home-based education.

This thesis and other literature show that knowledge is repeatedly found as one of the important factors for promoting the access to LDKT. Yet, prior to the manuscript in chapter 6 no validated and standardized tests on knowledge among renal patients regarding kidney disease and all treatment options existed. Therefore, part of this thesis was devoted to the development and testing of the psychometric properties of a questionnaire that assesses patients' knowledge on kidney disease and renal replacement therapies. That effort resulted in a 21-item list with two stable dimensions containing items on 'Dialysis and Transplantation' (11 items) and 'Living Donation' (10 items). Such a thorough questionnaire enables reliable testing of patient's knowledge on kidney disease and treatment options. Therefore, this questionnaire was used to test potential changes in knowledge due to the home-based intervention.

Chapter 7 present the development and protocol of the tested home-based intervention. Patients and their family/friends who received the home-based intervention had two home visits in addition to the regular hospital information. The first home with only the patient was intended to get an idea of patient's family and culture. The patient could then invite family and friends for the second home visit (the educational intervention). The aim of the educational intervention was to provide information on kidney disease, dialysis, kidney transplantation and living donation. Central to the intervention was promoting the communication on the different treatment options between the patient and members from his/her social network. For this communication techniques from multisystem therapy were used. This therapy systematically considers the stability of relations and ensures that the conversation takes place within a framework of respect for individual feelings and autonomy. For this the quality system of multisystemic therapy was applied which involves structural supervision and anonymous/independent quality checks.

Results of this home-based educational intervention show favorable effects (chapter 8). The patient and family/friends show a significant improvement in their knowledge and an improvement in their communication regarding the various treatment options. Moreover, analyses showed that the home-based intervention results in a fivefold increase in the number of potential donors tissue typed and actual living donations. Given the success and the limited side-effects of this approach implementation in other transplant centers is strongly recommended for transplant candidates without a living donor. Further research on the generalizability of the intervention and the cost-effectiveness is warranted.

Chapter 11

Samenvatting in het Nederlands

Samenvatting

Niertransplantatie met een nier van een levende donor is voor de meeste patiënten met eindstadium nierfalen de optimale behandeling. Er bestaat echter een aanzienlijke groep patiënten, voornamelijk van niet-Europese origine, die geen levende nierdonor kan vinden. Uit onderzoek blijkt dat zowel kennis van de verschillende nierfunctievervangende behandelingen, als het bespreken van deze kennis met familie en vrienden hierbij een belangrijke rol spelen. In dit proefschrift wordt het ontwikkelen en het onderzoeken van de effectiviteit van thuisvoorlichtingen bij patiënten zonder een levende donor beschreven.

Aangezien patiënten met een eindstadium nierfalen aan den lijve ondervinden welke factoren hen belemmeren in het vinden van levende nierdonor hebben we met deze patiënten focusgroepbijeenkomsten gehouden. Het doel van deze bijeenkomsten was om inzicht te krijgen in de factoren die een rol spelen bij ziektebeleving, attitude/zorgen/angsten met betrekking tot de verschillende nierfunctievervangende therapieën, de mate van communicatie met familie en vrienden over de verschillende nierfunctievervangende therapieën en of er behoefte is aan meer op maat gesneden voorlichting. Uit dit onderzoek zijn de volgende vier aandachtsgebieden geïdentificeerd: 1) een gebrek aan persoonlijke informatie en begeleiding, 2) gebrek aan communicatie met familie en vrienden met betrekking tot nierdonatie bij leven, 3) angsten en zorgen over een mogelijke nierdonatie bij leven, en 4) sociale invloeden van familieleden en vrienden (hoofdstuk 2 en 3). Onderzoek wijst uit dat niet-veranderbare factoren ook van invloed zijn op de kans op een nierdonatie bij leven, namelijk medische (anti-HLA-antilichamen, dialyse modaliteit), socio-economische en onverklaarde etnische factoren. Deze factoren zijn echter niet met een interventie te omzeilen. Daarom is in hoofdstuk 5 onderzocht of er veranderbare factoren te identificeren zijn die samenhangen met het vinden van een levende donor. Hieruit is gebleken dat kennis en communicatie ten aanzien van nierziekten en de verschillende nierfunctievervangende therapieën een belangrijke rol spelen. Ook bleek dat deze factoren het sterkst geassocieerd zijn met het hebben van een potentiële nierdonor.

Deze en andere psychosociale factoren die nierdonatie bij leven belemmeren zijn vaak beschreven in de literatuur. Religieuze bezwaren kunnen een belemmering vormen en zijn minder vaak omschreven. De combinatie van religieuze jurisprudenties en opvattingen van patiënten aangaande die religieuze bewaren toont aan dat binnen de grote religies en godsdiensten, nierdonatie bij leven is toegestaan (hoofdstuk 4). Bij sommige religies wordt echter een aantal voorwaarden gesteld, zoals de afwezigheid van commerciële belangen. Het redden van een mensenleven blijft een overkoepelend en krachtig argument dat voorrang heeft op ondergeschikte contra-argumenten. Zorgvoorlichters in de donatie- en transplantatiezorg moeten kennis nemen van dit positieve standpunt en dit bespreken met patiënten en naasten die religieuze bezwaren hebben.

Voorts werd met de patiënten besproken hoe zij begeleid willen worden in hun keuze tussen alle nierfunctievervangende therapieën. Hun mening werd gevraagd met betrekking tot in de literatuur beschreven manieren van extra voorlichting/begeleiding. De thuisvoorlichting werd met 88% geprefereerd boven andere op maat gesneden interventies (hoofdstuk 2). Het geven van persoonlijke informatie over de verschillende nierfunctievervangende therapieën zou het hoofddoel van de thuisvoorlichting moeten zijn volgens patiënten. Daarnaast rapporteren patiënten dat thuisvoorlichting bij uitstek geschikt is om de bovengenoemde belemmerende factoren met de patiënt en diens sociaal netwerk adequaat te behandelen.

Patiënten melden dat een niet-persuasieve aanpak wordt gewaardeerd daar thuisvoorlichters de comfort zone van gezinnen zullen betreden (hoofdstuk 2). Desalniettemin zullen de thuisvoorlichters als aanwezigen aan het einde van thuisvoorlichting niet zelf het gesprek over nierdonatie bij leven initiëren, dit onderwerp op een niet-persuasieve wijze aan de orde moeten stellen. De manier waarop de gespreksfocus wordt verplaatst naar een mogelijk concrete donor bij leven, behoeft echter wel culturele sensitiviteit. Bij gezinnen met een cultuur waarin bijvoorbeeld verlegenheid bijzonder wordt gewaardeerd, zou een indirecte communicatiestijl meer passen. Een voorbeeld van een dergelijke communicatiestijl zou zijn: "Welke aspecten van de voorlichting over de verschillende nierfunctievervangende therapieën hebben in het bijzonder uw aandacht getrokken?" Een meer directe communicatiestijl zou zijn: "Heeft iemand van jullie ooit een nierdonatie bij leven overwogen?" Thuisvoorlichters zouden dan ook per casus de voorlichting en de communicatiestijl op maat moeten snijden. Hiervoor is het verkrijgen van informatie over de normen en waarden van het betreffende gezin noodzakelijk. Temeer omdat een dergelijke benadering ook leidt tot betere betrokkenheid/participatie van de betrokkenen. Naast het op maat snijden van de thuisvoorlichting en het zorgen voor een non-persuasieve aanpak wordt door betrokkenen die de Nederlandse taal niet machtig zijn het meebrengen van een onafhankelijke tolk gewaardeerd. Behoudens deze subtiele (communicatiestijl) en duidelijke (het gebruikmaken van tolken) verschillen, is er geen grondslag gevonden voor het bestaan van verschillen tussen culturen in factoren die de toegang tot een transplantatie met een nier van een levende donor belemmeren. Net zo min hebben patiënten in het onderzoek dat in hoofdstuk 2 wordt beschreven andere voorwaarden gerapporteerd die alvorens de thuisinterventie wordt geïmplementeerd, aandacht zouden behoeven.

Uit dit proefschrift en de literatuur blijkt dat kennis herhaaldelijk wordt gevonden als een van de belangrijkste factoren voor het bevorderen van de toegang tot een transplantatie met een nier van een levende donor. Desalniettemin, bestonden er voorafgaand aan het manuscript in hoofdstuk 6, geen gevalideerde en gestandaardiseerde vragenlijsten om kennis bij nierpatiënten met betrekking tot nierziekte en de nierfunctievervangende therapieën te meten. Daarom is een deel van dit proefschrift gewijd aan de ontwikkeling en het testen van de psychometrische eigenschappen van een dergelijke vragenlijst. Die inspanning resulteerde in een 21-itemlijst met twee stabiele dimensies met items over 'Dialyse en Transplantatie' (11 items) en 'Nierdonatie bij leven' (10 items). Zo’n breed meetinstrument maakt het betrouwbaar en valide meten van kennis over nierziekte en alle behandelopties mogelijk. Daarom werd deze vragenlijst gebruikt om veranderingen in de kennis door de thuisvoorlichting over deze zaken te meten.

Hoofdstuk 7 beschrijft het protocol waarmee de thuisinterventies zijn uitgevoerd. Patiënten en hun familieleden/vrienden kregen naast de reguliere ziekenhuisvoorlichting twee huisbezoeken. Het eerste bezoek vond alleen met patiënt en partner plaats en was bedoeld om de familie- en gezinscultuur in kaart te brengen. De patiënt kon vervolgens familie en vrienden uitnodigen voor het tweede thuisbezoek. Dit tweede bezoek had als doel voorlichting te geven over nierziekten, dialyse, niertransplantatie en nierdonatie bij leven met aandacht voor de daarbij komende psychosociale aspecten. Hierbij stond centraal het bevorderen van de communicatie tussen de patiënt en zijn/haar sociale netwerk over de verschillende behandelvormen. Hierbij werd gebruikgemaakt van het communicatiemodel en de vaardigheden zoals die uitgewerkt zijn in de multisysteemtherapie. Deze therapie houdt systematisch rekening met de stabiliteit van relaties en garandeert dat het gesprek gevoerd wordt met respect voor de individuele gevoelens en autonomie. Daarbij werd ook het kwaliteitssysteem van multisysteemtherapie toegepast dat uitgaat van structurele supervisie en anonieme kwaliteitscontroles door een onafhankelijke persoon.

Uit de analyses van het onderzoek blijkt dat de thuisvoorlichting een gunstig effect heeft. De patiënt en familieleden/vrienden die bij de voorlichting aanwezig waren laten een significante verbetering zien in hun kennisniveau, een afname in hun zorgen en angsten met betrekking tot levende donatie en een verbetering in de onderlinge communicatie over de verschillende behandelmogelijkheden. Daarnaast laat analyse zien dat na de thuisvoorlichting er sprake is van een vijfvoudige toename in het aantal nierdonoren dat gedoneerd heeft ten opzichte van de controlegroep. Gegeven het succes van deze aanpak en de lange wachttijd op een postmortale nier is het wenselijk om deze aanpak bij andere transplantatiecentra te implementeren. Vervolgonderzoek naar de generaliseerbaarheid van de thuisinterventies met behoud van kwaliteit, middels het scheppen van een veilig kader en kwaliteitscontroles, is wenselijk. Tevens is aanvullend onderzoek nodig naar de kosteneffectiviteit van de thuisinterventies, om het verzoek voor financiering door de ziektekostenverzekeraar in de nabije toekomst te kunnen onderbouwen.

Chapter 12

PhD Portfolio

Curriculum Vitae

Words of thanks

PhD Portfolio

Name PhD student: Sohal Ismail
Erasmus MC Departments: Psychiatry, Section Medical Psychology and Psychotherapy & Internal Medicine, Section Nephrology and Transplantation
PhD period: 2010-2013
Promotors: Prof. dr. J.J. van Busschbach & Prof. dr. W. Weimar
Co-promotor: Dr. E.K. Massey

1. PhD Training	**Year**
Relevant courses	
Theoretical course in Multisystemictherapy, MST, Oslo	2010
Practical course in Multisystemictherapy, RINO-Groep, Amsterdam	2011
Basic course in Good Clinical Practice guidelines (BROK), Erasmus MC, Rotterdam	2011
Master of Science in Health, Specialization: Epidemiology, Electives: Repeated Measurements in Clinical Studies; Bayesian Statistics; Ethnicity, Health and Health Care; Medical Demography, From Problem to Solution in Public Health, Missing Values in Clinical Research	2011-2013
Family counseling in organ donation after death for physicians (CrD-training)	2013
(Inter)national conferences & Presentations	
ETCO Cardiff, United Kindom: Poster presentation	2010
Education day Nierpatiëntenvereniging Rijnmond Rotterdam, Nederland: Invited speaker	2010
MESOT Tunis, Tunisia: Oral presentation	2010
BOOT Amsterdam, The Netherlands: Oral and poster presentation	2011
ESOT Glasgow, United Kingdom: 2 Oral presentation	2011
ISODP Buenos Aires, Argentina: 2 Oral presentations	2011
BOOT Duiven, The Netherlands: 3 Oral presentations: Best Speaker Award	2013
NND Veldhoven, The Netherlands: Oral presentation: Best Paramedic Award	2013
ELPAT Rotterdam, The Netherlands: 2 Oral presentations	2013
EWOPA Rotterdam, The Neterlands: Invited speaker	2013
NTS Utrecht, The Netherlands: Invited speaker	2013
ESOT Wenen, Oostenrijk: 2 Oral presentations	2013
ELPAT Juan les Pins, France: Invited speaker	2013
Seminars and workshops	
Masterplan organdonation seminar Utrecht, The Netherlands	2010
Member of ELPAT: ‘Psychological care’ & ‘Diversed populations’ workgroup	2010-2013
ISOQOL-NL Pre-conference for WEON-Congress	2011
‘Psychosociaal Onderzoek bij Nierpatienten’ (PON)	2010-2012
Amstelsymposium Renal Transplantation Amsterdam, The Netherlands	2012

2. Teaching	
Lecturing	
Communication & Professionalization for medical students	2010 – 2013
Skill training in patient counseling: Renal care, Genetics, Dysmorphology, Pain	2010 – 2013
Family counseling in organ donation after death for physicians	2013

Workshops

LWTV symposium Utrecht, The Netherlands: Invited speaker	2013
Regionale Nascholing Nefrologen Rotterdam, The Netherlands: Invited speaker	2013
Masterplan orgaandonatie symposium Utrecht, The Netherlands: Invited speaker	2013

3. National publications

Wisselwerking, December	2010
Nederlands tijdschrift voor de geneeskunde, November	2011
Wisselwerking, March	2012
Nier-zine, June	2013
Nierzine, Oktober	2013
Transparant, Oktober	2013
Wisselwerking, Oktober	2013
Telegraaf (front-page national newspaper)	2013-10-14

4. International publications (1-9)

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6. Ismail SY, Luchtenburg AE, Timman R, Zuidema W, Boonstra AC, Weimar W, et al. Home-based Family Intervention Increases Knowledge, Communication and Living Donation Rates: A Randomized Controlled Trial. Manuscript accepted for publication.
7. Ismail SY, Luchtenburg AE, Zuidema WC, Boonstra C, Weimar W, Massey EK, et al. Multisystemic engagement and nephrology based educational intervention: a randomized controlled trial protocol on the KidneyTteam At Home study. BMC Nephrol 2012;13:62-70.
8. Ismail SY, Massey EK, Luchtenburg AE, Claassens L, Zuidema WC, Busschbach JJ, et al. Religious attitudes towards living kidney donation among Dutch renal patients. Med Health Care Philos 2012;15:221-7.
9. Ismail SY, Timmerman L, Timman R, Luchtenburg AE, Smak Gregoor PJ, Nette RW, et al. A psychometric analysis of the Rotterdam Renal Replacement Knowledge-Test (R3K-T) using item response theory. Transpl Int 2013;26:1164-72.

Other publications (1-3):

1. Ismail SY, Luchtenburg AE, Massey EK, Claassens L, Busschbach JJ, Weimar W. Living kidney donation among ethnic minorities: A Dutch qualitative study on attitudes, communication, knowledge and needs of kidney patients. http://repubeurnl/resource/pub_20862/indexhtml 2010.
2. Ismail SY, Knoop MM, Duerinkckx N, Timmerman L, Papachristou C, Aujoulat MS, et al. An ELPAT definition of the concept 'Psychosocial' in the context of Screening Living Organ Donors in Europe: A Concept Mapping approach. 2012; Available from: http://hdl.handle.net/1765/38305.
3. Ismail SY, Massey EK, Luchtenburg AE, Da Silva A, Smak Gregoor PJH, Nette RW, et al. Development of the Rotterdam Renal Knowledge-Test (R3K-T). 2011; Available from: http://repub.eur.nl/res/pub/23968/Manuscript_Development%20of_R3K-T.pdf.

5. Television

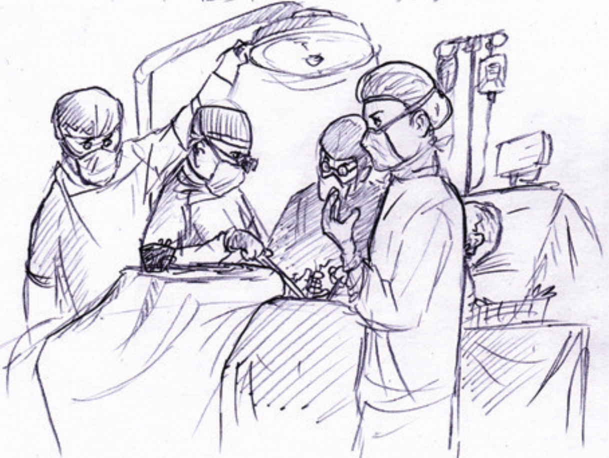
Interview on the television program "De Halve Maan" September: Organ donation & Islam	2011
Interview on Rijnmond TV: Effectiveness of the Kindney Team at Home-Study	2013

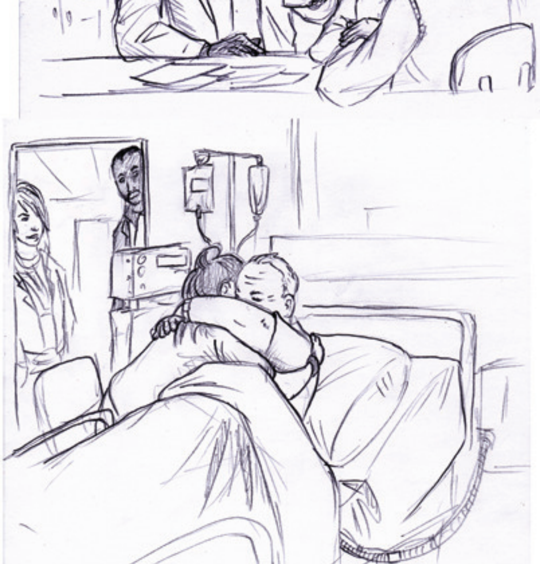
Curriculum Vitae

Sohal Ismail was born on July 1st, 1985 in Erigavo, Republic of Somaliland. After elementary school he graduated from secondary school (Visser ´t Hooft Lyceum, Leiden) in 2004. After attending the Pharmacy school in Utrecht for one year he obtained his Bachelor's degree in Psychology cum laude at the University of Leiden in 2008. His bachelor's thesis was part of the Honors Research program and focused on trauma and hypervigilance in patients with (pseudo) epileptic insults in the Epilepsy Institutes of the Netherlands Foundation. In 2009 he received his Master's degree in Clinical Neuropsychology with honor, after completing his internship at the Leiden University Medical Centre and the regional hospital of Capelle aan den IJssel (IJsselland Ziekenhuis). For his Master's thesis, he conducted a study on the association between white matter lesions and neuropsychological test profiles.

In June 2010, he began his PhD study as described in this thesis at the Department of Psychiatry, Section Medical Psychology and Psychotherapy at the Erasmus Medical Centre in Rotterdam, in collaboration with the Department of Internal Medicine, Section Nephrology and Transplantation. The focus of his research was to test the efficacy of an educational home-based intervention to establish well-informed decision making regarding treatment options for patients with end-stage renal disease. In addition to research, he is involved in teaching medical psychology and effective patient counseling in the medical curriculum at the Erasmus MC. In August 2013 he received his second Master's degree in Clinical Epidemiology at the Netherlands Institute for Health Sciences, Erasmus University.

Since 2010, he is a member of the Ethical, Legal and Psychosocial Aspects of Transplantation organization. In the Working-Group of 'Public Issues' he worked on a paper addressing public engagement in organ donation and in the 'Psychological Care' Working-Group he worked on a couple of papers focusing on psychosocial screening of living organ donors.



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