



Living kidney donation among ethnic minorities:

A Dutch qualitative study on attitudes, communication, knowledge and needs of kidney patients

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A report on the basis of the cooperation of the Kidney Transplant Unit of the Erasmus

MC and the Department of Medical Psychology and Psychotherapy of the Erasmus MC

Disclaimer report

This report is the first document to describe our focus group investigation and in-depth interviews in order to gain insight in the attitudes, (non-)communication and knowledge of our non-European patients regarding living donor kidney transplantation. The report is a detailed description of our investigation and was made directly after the data collection, in order to allow fast communication between researchers and/or clinicians. As such, this report provides technical details about the methodology and extensive tables of the data.

Although the report will probably remain the most detailed description of our research effort, it must not be seen as the final interpretation of the results. The report will serve as an easy referable and accessible collection of the (almost) raw research data, on which basis we hope to write peer-reviewed articles. This original report will remain available on request, for those researchers who would like to have a detailed description of our first research steps and the accompanying data. Note that parts of the report still reveal our early thoughts and interpretations, which are characteristic for a first report written just after finishing the data collection.

Living kidney donation among ethnic minorities: A Dutch qualitative study on attitudes, communication, knowledge and needs of kidney patients.

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Abstract

Background Terminal kidney patients are faced with lower quality of life during dialysis treatment, restricted diets and high morbidity and mortality rates while waiting for a deceased donor kidney transplantation. Fortunately, living donor kidney transplantation offers an alternative with considerable advantages in terms of waiting time and graft survival rates. Nevertheless, we observed an inequality in the proportion of living kidney transplantations performed between the non-European patients and the European patients in our centre. To date little is known about the factors contributing towards this racial disparity. Previous research from our centre did not find any medical reasons to explain this racial disparity. We believe that non-medical psychosocial and cultural factors predominantly account for this discrepancy.

Purpose Focus group discussions and in-depth interviews were conducted in order to gain insight in the attitudes, (non-)communication and knowledge of our non-European patients (compared to European patients) regarding living donor kidney transplantation (LDKT). Additionally, we investigated their attitudes towards professional support in finding an eligible living donor.

Methods The interviews were held in line with the focus group method and analyzed according to the grounded theory. The interviews were focused on six main topics (kidney

transplantation, living kidney donation, communication, information, knowledge and intervention needs). European patients were included as a comparison group. The qualitative data analyses were performed in Atlas.ti.

Results

We found nearly all our patient to be in favour of a living kidney transplantation (96%). However multiple prohibiting intertwined factors play a role when actually considering a living donor. We found four major barriers to the living donor transplantation process in our non-European patients: 1) not (so easily) comprehensible non-patient-centred information 2) cognitions and emotions (based on fears, concerns and misconceptions) 3) a state of basically non-communication with the potential donor(s) on this issue (as a consequence of personal and cultural beliefs) 4) and social influences. We also found some similar factors playing a role in the donation course of our European patients without a living donor. Finally, our patients held a welcoming attitude towards an intervention aimed at assisting them getting through the living donation program.

Discussion

This study has identified several modifiable determinants underlying racial disparity in our living donor kidney transplantation program and investigated patients' attitude towards two interventions aimed at alleviating this inequality. We realize that our list of barriers may not be thorough enough and surely more is to be said on this topic, the findings offer possible targets for intervention. In accordance with our patients' preference, we argue that a home-based education best suits the complexity of issues and patients' personal needs.

Keywords Attitudes, communication, ethnicity, knowledge, living kidney donor, transplantation.

Introduction

In the Netherlands the average waiting time for a deceased kidney transplantation is 3.9 years and even 5 years for blood type O, with currently approximately 900 patients on the waiting list (1). In the meantime patients are dependent on dialysis treatment which is unfortunately accompanied with lower quality of life, increased morbidity and mortality and lower graft survival rates (2). Kidney patients are required to visit the dialysis clinic two or three times a week for several hours (3-4 hours). This is combined with a restricted diet and fluid intake (800cc a day). Eventually, only three out of the four patients are alive when a deceased kidney becomes available for them. These facts along with the increasing shortage of deceased kidney donors has created the need for exploring alternative treatment options.

Living donor kidney transplantation (LDKT) has become a successful commonplace treatment option since the first LDKT in our centre in 1981. In this practice a living healthy person donates one of his/her kidneys to a patient with end-stage renal failure. This person is often a family member but can also be a friend, an acquaintance or even anonymous donor (3). This has led to a broadened range of potential living donors. In our centre 1000 LDKT have been performed to date (August 2010). Since the deceased kidney pool is not (and is not going to be) sufficient enough to provide all our terminal kidney patients with a (compatible) kidney, LDKT has become a popular and indispensable treatment option. Especially with the knowledge that the graft survival rates of LDKT are better than those of the deceased transplantation (4). In general the donor does not have to change his lifestyle after the operation, will stay on average three days in the hospital, will be able to pursue his preoperative social and professional occupations within six week on average and the perceived quality of life after one year is equivalent to that before the operation (5-6). There are even some positive outcomes identified for the donor, such as enhanced self-esteem (7).

Living kidney transplantation rates have been increasing and now exceed those of deceased kidney transplantation in the Netherlands (8). However, there seems to be an inequality in the number of living kidney transplantations between the European and the non-European patients. In our centre we have 44% non-European patients with terminal kidney failure who are on the waiting list for deceased kidney transplantation whereas only 17% of the patients who underwent a living donor kidney transplantation were non-European (period: 2000-2009). In the same centre and period European patients made up 83% of all the living kidney transplantations. This qualitative study explores factors that underlie the relative under-representation of non-European patients in our living donor kidney transplantation program (LDKP).

To date little is known about whether beliefs and/or communication about living donor transplantation vary across different ethnic groups in the Netherlands and whether these factors can explain the difference in participation in the living donor transplant programs. Still uncertain is the role factors such as shortcomings in knowledge (9), attitudes towards disease and treatment (10) and cultural and religious beliefs (11-13) play. Davis and Randhawa highlighted the deficiency in knowledge in ethnic minority groups regarding organ donation and transplantation. Other research conducted on an ethnic minority in the UK also stated that culture-specific issues can interfere with equality in health access (12). Therefore these factors should be unraveled considering the ethnic minority in question and tackled if possible.

Research in our centre, conducted on European as well as non-European patients, has shown that the communication between the patient and the potential donor and the quality of their relationship are significant factors in the living donor transplantation process. 78% of the patients on the waiting list are in favor of transplantation with the kidney from a living donor (14). However they do not actively pursue this treatment option because of reluctance to discuss the matter with potential donor(s). Moreover, 80% of the patients stated that they

would not or probably would not actively approach a potential donor to 'ask' for a kidney. Following this a state of non-communication on the subject of living donor transplantation has evolved, which in turn is interpreted by the patients as a refusal to donate on the side of the potential donors (15). Fortunately, the same study found a third of the potential donors to be positive about donating their kidney and a similar amount whom had not decided yet.

At this moment we do not actually know what causes the differences between the European and the non-European in attending our LDKP. Therefore the main aim of this study is to explore which factors contribute to/play a role in the inequality in accessing the LDKP. From previous studies and best practice we already know that non-communication plays a role in the general population (15). Present study will investigate whether this also holds for our non-European patients and whether other factors might appear to be influential as well.

Another very recent study on our patient population has investigated donor declination reasons between the Europeans and the non-Europeans. They found nonmedical reasons to be more common in the non-European patients (16). No other group-specific medical reasons were found to explain the disparity with regard to accessing LDKP. Therefore in our focus group discussions and in-depth individual interviews we focused predominantly on non-medical reasons (i.e. more psychosocial and culture-specific determinants). Our hypotheses hold that the influential factors may include attitude towards kidney transplantation in general, attitude towards LDKT, views on religion/belief and LDKT, attitudes towards the communication on kidney disease and LDKT and/or knowledge with regard to LDKT.

Finally, as we were interested in how we can improve care, we also investigated patients' attitudes towards two different intervention methods. The first one was the Norwegian approach; if the patient agrees, the physician contacts a potential donor by telephone to invite them for a consultation to discuss LDKT options (17). The other intervention was the American home-based educational intervention. In this healthcare

educators inform the patient and his/her significant others (i.e. potential donors) about LDKT at the patient's home (18).

In short we aimed at investigating factors contributing to the racial disparity in health care access regarding the LDKP. We set out hypotheses to explore whether psychosocial and cultural factors may help account for this inequality. Therefore, we focused on patients' attitudes towards (living) transplantation, religion, communication patterns and/or knowledge. Additionally, we looked into their attitudes on two different forms of intervention strategies (aimed at improving health care access).

Method

We employed a focus group approach which is a technique of group interviewing that generates data through people's knowledge and experiences. 'Focus groups are unstructured interviews with small groups of people who interact with each other and the group leader. They 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.

The focus groups method was an effective way of collecting qualitative data on knowledge, attitudes and subsequent communication of our patients regarding their understanding and behaviour in relation to (sensitive) health issues. Organ donation and transplantation are topics that are rarely discussed in daily life and can be considered delicate issues due to the involvement of the body and association with death. Collecting data by using focus group interviews allows exploration of such topics within a specific cultural context. This methodology has been demonstrated to be effective in exploring opinions related to kidney donation and transplantation among ethnic minorities in the United Kingdom (19-20). Focus group discussions offer the particular advantage that individuals can participate who

may be excluded from written assessments due to language or literacy barriers (21). The procedure to be employed as described below follows the recommendations of Randhawa and Darr (2001).

Familiarization with our groups of interest

In the preparation stage a number of experts were consulted in order to develop an extensive topic list for the focus group meetings. The expert steering group consisted of individuals who have specialized knowledge in health care and/or transplantation issues in relation to ethnic minorities in our region as well as experts in conducting focus groups (i.e. nephrologists, (transplant) coordinators, social worker, researchers, spiritual counsellor and policy employees). In addition to these experts a number of non-European dialysis patients who do not have a living donor were interviewed about their personal experiences and attitudes towards living donor transplantation. During consultation with these expert advisors and patients, a suggested topic list generated from the literature was discussed. Any additional topics were added and thereafter the list became more refined. Furthermore practical aspects of conducting focus groups among these specific populations were discussed (e.g. how best to approach patients, convenient locations, customs and language). In this way we hope to maximize cultural sensitivity and acceptability of the group interviews (22).

Choosing and approaching the study sample

We focused on those patients on the waiting list with a non-European ethnicity. To shed some light on the specific facilitators and barriers in donation and transplantation among ethnically diverse patients, we focused on those patients on the waiting list with a non-European ethnicity. We also included a comparison group of European patients. All patients who attended this study were registered at the pretransplantation clinic of Erasmus MC, University

Hospital Rotterdam, between January 1, 2000, and July 31, 2010. The exploration and approaching of eligible patients was done between August 1, 2009, and July 31, 2010 (i.e. the study period). We specifically focused on the largest ethnic groups living in the Rotterdam area. Following this, men and women from the Moroccan, Turkish, Surinamese, Antillean and Cape Verdean communities were invited to participate. On advice of the expert steering group, Turkish and Moroccan men and women were interviewed separately. For Surinamese, Antillean, Cape Verdean and European groups men and women were interviewed together. There was no restriction according to age, gender and country of birth (if this is different from the ethnic origin). To increase personal contact and maximise likelihood of participation, attempts were made to introduce ourselves to the potential participants when they attend the outpatient clinics and to inform them that they will be sent an information pack about the study. They then received a letter in Dutch, Turkish or Arabic for the respective groups (in the case they did not speak or read sufficient Dutch). This was followed up with a telephone call within one week. Participants were sent a confirmation of the appointment and directions to the location (if appropriate) approximately one week prior to the meeting. To promote maximum attendance all individuals received a phone call to check whether there were any questions left and to confirm participation, one day prior to the interview. We took national and religious holidays and prayer times into consideration in planning the sessions and held the meetings at times outside school hours. Following this process of data sampling 41 patients, with 6 to 12 participants per ethnic background participated in this study.

Data collection

The focus groups were lead by a moderator of the same ethnic background as the group in presence of a research psychologist (for all groups). The moderators were selected in such a way that the participants could easily communicate with them (22). In order to make the

communication easily moderators should natively speak the language and have a clear voice.

In line with this, if this was the wish of the participants, the interviews were held in the mother tongue of the participants, and the leader was fluent in both this and the Dutch language.

The moderators were trained to ensure familiarity with the topic, the topic-list and the procedure. This also ensured consistency in methodology between groups. A practice focus group session was held with experienced focus group researchers and colleagues from the transplant unit as participants to give feedback on technique and content. Moderators were responsible for piloting the topic list and terminology to be used in their respective languages through informal discussions with members of their community.

Focus group interviews were either held in an office environment at the medical centre (Erasmus MC) or at the local community depending on the preference of the participants (since the participants are patients we expected that the hospital would a familiar environment).

At the site the moderator welcomed the participants and allowed everyone to introduce him or herself while providing refreshments. This informal welcome was intended to create a relaxed ambience while not directly discussing the subject at hand. Each participant was given a name-tag indicating the first name only in order to ensure privacy. The seats were arranged in a circle around a table.

The focus group started with explaining the aims and nature of the meeting. The moderator emphasized that this is a chance for participants to express their opinions and for the researchers to learn from them (23). Furthermore, the moderator explained the purpose of the study and that the data will be used to gain a (broader) view on their opinions with regard to LDKT issues.

During the introduction a number of ethical issues were emphasized including that all information will be used anonymously (no names will be used in the final report) and in the strictest confidence, that participation will in no way affect their treatment, that they are free to withdraw at any point and that there are no correct or incorrect answers. Participants were encouraged to allow one person to speak at a time and to respect each others opinions. Permission was also given with regard to audio recording the session so that all comments are correctly registered. The sessions were tape recorded and translated into Dutch for purposes of analysis and comparison. Finally, the informed consent was explained verbally in the group and participants were asked to sign the form.

The focus group then proceeded guided by a predefined topic list constructed into a set of open-ended questions (see Table 1). This allowed participants to explore the issues surrounding transplantation in their own words. Interaction between participants, exchange of experiences and views and comments were encouraged rather than each participant responding individually to the moderator's questions (21, 24). Participants were encouraged to discuss inconsistencies and disagreements between participants' opinions and ones own thinking (21). It was required that questions raised by the participants would not be answered during the focus group discussions in order not to influence their knowledge and attitude. Based on discussions with the expert steering group we decided to use a patient case to encourage contributions as this was considered to be less direct and personal. Additionally participants could offer their personal experience if they wish to. At the end patients were requested to answer six very general true-or-false living donor transplantation related questions (see Table 2).

Table 1

Interview topics and questions

Topic	Questions
Demographic characteristics	<p>Which renal replacement therapy (RRT) are you undergoing? If you do have RRT, for how long?</p> <p>What is your highest level of education?</p> <p>What do you regard as your ethnicity?</p> <p>What is your religion?</p>
Personal medical history	<p>Could you shortly describe your kidney disease?</p> <p>Are you on the waiting list? If yes, for how long?</p>
Attitudes towards kidney transplantation	<p>If you would get a new kidney, how do you think this will influence you life? Could you name a couple advantages and disadvantages?</p>
Attitudes towards LDKT	<p>What is your personal stance towards getting LDKT from a family-member or a friend?</p> <p>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?</p> <p>Would you donate a kidney if the roles were the other way round?</p>
Religion on LKDT	<p>Does religion play a role in accepting and declining a living kidney? And is this culture specific?</p>
(Non-)communication on kidney disease	<p>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?</p>
(Non-)communication on LDKT	<p>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?</p> <p>Did you ever directly asked somebody to give you a kidney? Or did somebody ever offer you one?</p> <p>How 'should' it be: asking someone or getting an offer?</p>
Attitudes towards obtaining and providing information	<p>Are you satisfied about the given information on kidney transplantations and donation at your centre?</p> <p>Do you understand everything?</p> <p>Do you ask your physician questions?</p>
Norwegian approach	<p>In Norway the physician asks the patient about potential donors. Afterwards, if the patient agrees, the physician telephones the potential donors to invite them over for a consultation about living kidney donor transplantation. What do you think of the Norwegian approach?</p>
Home-based educational intervention	<p>In America, health care educators visited patients and their potential donors at their homes, and informed 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?</p> <p>What would you like to discuss during such a meeting?</p> <p>Do you think that people in your community would be open for this intervention?</p>

argument than that just offered. Questions by proxy were used to ask whether others would also think or act in the same way. The expert steering group also suggested working with statements and cards, e.g. true/false or agree/disagree. This technique was used for the knowledge section.

The meetings lasted between one and two hours. All participants received a €20 voucher and travel expenses were reimbursed. In some cases, the transportation from home to the venue was provided by the researchers.

Qualitative data analysis

Immediately after the session the leader and assistant made a debriefing to make a note of initial impressions. Shortly after the session, the taped interviews were transcribed verbatim with participants names replaced with identification codes. In this way anonymity was generated. Transcripts were then translated into Dutch. Data from the focus groups was analysed in a thematic manner using the principles of the Grounded Theory (25-26) whereby content themes from the interviews were grouped together rather than analyzing individual responses. The software package Atlas.ti was used in performing analysis as it appears to be more efficient and reliable than by paper and pencil (27).

The analysis of the focus group transcripts was employed in manner similar to O'Brien's (28). Firstly, we generated a grid according to Miles and Huberman's method (as described in Halcomb et al., 2007) in order to be able to compare the data between the groups (29). Two researchers read though the transcripts twice while listening to the tape recordings and organized them into a table. The first time was primarily to get a feeling for what people said. During the second time the researchers were listening with an analytical focus. After translating the transcripts into a grid words or phrases were combined together in order to generate a covering category. This process goes on until the researchers worked though the

whole transcript and data saturation has been reached (i.e. when no new categories emerge). Subsequently, we worked through the categories separately; How many unique comments are in each? How detailed are these comments? How strongly are they stated? Following this we generated a list of important and less important categories. The categories were then compressed and clustered together into themes. Thereby, generating the underlying uniformities of the categories and further sharpening the conceptual structure. If necessary the emerging themes were further broken down into subthemes. Finally, the themes were evaluated across the different subgroups to search for similarities and differences in these emerged themes.

Results

A total of 50 end stage renal disease patients with different ethnic backgrounds participated in this study. Their demographic characteristics can be found in table 3. The male/female ratio is equally distributed in the groups, except for Antillean. This skewed distribution for the latter group also holds for the whole pretransplantation clinic database (male/female; 3/15). The mean age in years as well as the variation in years is more or less equal for all groups. There are obvious differences in the educational level of the groups. However, considering the nature of the study, we do not regard this variable to be influential.

Except for the Surinamese group all patients within a group were homogeneous with regard to their religious background. In this group the Hindustani Surinamese were either Muslim or Buddhist. The Creole Surinamese in this group were all Christians. The majority of our control patients were Christians, except for three whom were Atheist. Finally we also recorded whether patients were on dialysis and for how long. With the exception of two Moroccan patients and one Dutch patient all patients were on dialysis for various periods of time (ranging from three months to seven years).

Table 3

Demographic Characteristics

	Turkish (N = 10)	Moroccan (N = 7)	Surinamese (N = 10)	Antillean (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 and 1 Full
Patients without Children	2	2	3	1	1	1
Religion	All = Islam	All = Islam	2=Islam 4=Christianity 4=Buddhism	All = Christianity	All = Christianity	7 = Christianity 3 = Atheism
Time on dialyses (months)	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.

1. Knowledge

No differences were found regarding the level of basic knowledge between the different groups. Neither did we find any difference between the Europeans and the non-Europeans. Even the range of correctly answered questions is quite the same between the groups.

2. Attitude towards kidney transplantation

All our patients adopted a positive attitude towards kidney transplantation in general. Patients from all ethnic backgrounds reported two reasons for favouring kidney transplantation over their current treatment (dialysis). These two reasons were: having a normal life again (24/50) and having a higher quality of life (23/50). However patients also reported a several downsides on having a kidney transplantation such as, the insecurity about the graft survival, the changing of their lifestyle after transplantation and missing the contacts they have with other patients at the dialysis centre.

Insecurity about the graft survival is a more dominant theme in the Turkish patients, compared to the other groups. *“I am uncertain about how long it will take before my body rejects the donor kidney.”* The social contacts at the dialysis centre is also influential. *“The fact that I go three times a week there to see my friends makes me not eagerly willing to undergo a kidney transplantation.”* Whereas others report the negative aspects of the dialysis, such as: *“I have a restricted diet and I am always tired.”* The majority of the Turkish patients reported the positive aspects of transplantations namely, that they are expecting to regain a normal life. *“I would live again; feel reborn! I would go and enjoy life again; working, eating, drinking and exercising!”*

The Moroccan patients mainly report the regaining of a ‘normal’ life and the low quality of life they experience while being on dialysis. *“A kidney transplantation would be a*

dream come true for me! I will be able to function normal again.” “I would be able to care for my children again!”

Surinamese patients are on this topic more like the Turkish patients and have merely issues with the graft survival. *“I am afraid whether my body will accept the kidney.”* This group also reported ‘the quality of life while on dialysis’ facet as the dominant topic. They have also the highest rates on the other positive issue on kidney transplantation (getting a normal life). *“I hope to be able to get back to my old life and start having a family.” “Having a new kidney would feel like living in paradise”*. One patient also had worries about drinking approximately two litres of water per day after transplantation.

All Antillean patients mention the regaining of a better quality of life a positive aspect of having a new kidney. *“I am tired of that whole dialysis thing. I hate those needles and such; sometimes it hurts so much that I do not want to go to the dialysis centre anymore. A kidney transplantation would put me out of that misery”*. *“I cannot take a normal shower or wear normal clothes with that catheter.* This group also reported that they think they will get a normal life. *“After transplantation I hope to be able to live like a normal person and be happy again.”*

The Cape Verdean patients mainly report the lower quality of life during dialysis treatment. *“People do not see that I am tired and if I tell them they do not understand it”*.

Our comparative group is on this topic not much different than our non-European patients. They also mainly report on the lower quality of life and having a normal life again. *“My whole social life is put on hold by the dialysis”*. *“I hope to be able to live my own life again”*. This group did however exclusively mentioned worries with regard to the immunosuppressive medication after transplantation. *“You have to take lifetime medication”*. *“You will get marks on your face and your hair will fall out by the medication after transplantation.*

3.1 Attitudes towards accepting living kidney donor and the (non-)ideal donor

All but two of our patients held a positive attitude towards LDKT. Two patients did report an absolute negative attitude towards LDKT. Twelve patients did however say that they would only approve a LDKT if it would not jeopardise the health of the donor. The reported advantages for getting a living donor are; better graft survival rates, shorter waiting times for transplantation and the belief that the preparatory examinations are better when undergoing a LDKT than a deceased transplantation. Our patients provided us also with the reasons why their potential donors did not become actual donors so far. These reasons were being afraid of dying, being afraid of the operation, sparing the kidney for a younger family member who is having kidney problems already, the potential donor being influenced by other family members, expected familial problems after donating the kidney, not having a family and family members living abroad.

Six of the ten Turkish patients stated only to accept a LDKT if it would not harm the donor afterwards. *“I do not want to lose you in the process”*. *“I do not want the (future) health of the donor to be jeopardized”*. A patient also mentioned that the graft survival rates in the case of a living donor are better compared to the deceased donor. All the reasons (see above) for not going through with a potential living donor were mentioned by this patient population. *“I do not have any family members and no other Turkish people to talk to”*. *“The husband of my sister discouraged her to donate a kidney for me”*. *“A friend of mine backed out last minute because he was afraid of the operation”*. *“My sisters said that they do not want to have family problems in the future because of the donation”*.

The attitudes of the Moroccan patients did not really differ on this topic from the Turkish patients. They also would welcome a LDKT because it has better survival rates than the deceased transplantation, but only if it does not harm the donor. *“One can keep the kidney*

from a living donor longer than that of a deceased". 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"*. Just like the Turkish patients is this group also confronted with the fact that potential donors will not donate because they fear familial problems in the future.

A Surinamese patient reported that she would not go through with the living donor if it would be harmful to the donor. Other Surinamese patients also had two exclusive reasons for pursuing a living donor. One patient reported that the shorter waiting time in LDKT was the reason for choosing a living donor. Another patient also had favoured LDKP because of the belief that preparatory examinations were better in the LDKP than in the case of a deceased transplantation. Also exclusive to this group was the reason why a potential donor always should go through. Apparently the close bond between child and parent creates a self-evident situation in which parents and children ought to mutually donate. *"In our community children and parents are very close. So if they can donate they will donate! This works both ways"*. The major reasons for not having a LDKT were that the donor was afraid of dying or afraid of the operation. Another reason was not having a family here or any family members living close at hand.

Our Antillean patients did not have any reasons for pursuing a living donor. One patient however did also mention only going through with the procedure if it was not harmful for the donor. Together with the Surinamese patients they also reported that the reason for not getting a living donor was that their potential donors were afraid of dying. Furthermore, this group had the highest rate of the potential donor being influenced by other family members. *"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"*. Another familial reason for not accepting a living donor was that the kidney from the partner of the patient will be saved for the child who is already having kidney problems.

Exclusive to this group for not enrolling in the LDKP was the belief that the donor would become a kidney patient and that the donor has to change his lifestyle. *“My daughter said that she heard on the television that you can not drink any drinks containing alcohol after donating a kidney”*. This also implicated that the media can give misleading messages which discourages a LDKT.

The two patients holding a negative attitude towards LDKT were Cape Verdean. *“Even if they themselves would give me a kidney I would not accept it”*. *“My daughter called me about living donation but I just do not want it!”* No further declaration was provided. Two other patients did not participate in the LDKP because their potential donors were afraid of the operation. *“It is terrible though, I would be afraid of getting a surgery too!”* *“He does not have the courage to go into surgery”*.

In our comparison group we see a rather similar pattern. One patients would only accept a living donor transplantation if it would not harm the health of the donor. *“I want a great deal of certainty that my donor is going to be ok”*. Reasons for not getting through with the LDKP were that the donor was afraid of the operation, that the patient did not have any family or that they wanted to spare the kidney of the partner for their own child who is also having kidney problems. *“My son is also having kidney problems therefore I will not accept a kidney from my wife”*. Exclusive for this group is the fear of getting blamed by the donor if something goes wrong during the donation process. Another reason for not pursuing a living donor kidney was that they believed that the potential donor will become a kidney patient too.

We also investigated who patients would regard as ideal or less ideal as a living donor. The two most frequently mentioned choices in most groups were having a direct family member as a donor and not having an ideal donor. The latter was not mentioned by our European group. This group did however mention exclusively that they would ideally have an anonymous donor. Cape Verdean patients did not mention anything about having an ideal

donor. The other non-European patients were equally distributed of either having ideally a direct family member as a living donor or not having a preference at all. In all groups children were viewed, by the majority of our patients (27/50), as not the ideal donor. *“The children have their whole life ahead” “They have to take care of their own family” “My son is still young (19yrs), maybe when he turns 21”*. Children were closely followed by potential donors with a medical background or with a (long) history of unhealthy behaviours and the partners of the patients whom must stay healthy for the children. The latter reason was not mentioned by the Cape Verdean patients.

3.2 Attitudes towards being a living kidney donor

A great majority of our patients (40/50) would donate their kidney if they were healthy. A loved one had a fifty percent more chance of becoming a recipient than any other random person. All but one of our Turkish patients would donate a kidney if they were in the position. *“I would be honoured to give a kidney to my wife or children”*. All our Moroccan and Antillean would also donate their kidney. *“You should always donate to a family member” “God would reward you if helped someone to live longer; two Moroccan patients. “As a mother you should donate to your children and other family members”*; an Antillean patient. These two groups were not different from our European group in which also all patients would donate their kidney if they could. This group did however exclusively report that they would be more likely to donate to a loved one than a stranger. *“I would not give to a stranger, but to family and friend? Yes!” “I would do anything for my family”*. Only one of the Cape Verdean patients did however mention to be willing to donate. There was no data on those who did not want to be a living kidney donor if they were healthy.

4. Patients’ religion on LDKT

The majority of our patients with a religious background reported that their regions' standpoint with regard to LDKT was in favour of living donor transplantation (41/47). This holds for all faith or belief groups; European as well as non-European. Three patients did not report a religious affiliation. One can find the distribution of the religious background of our patients in Table 1. A more elaborated view on religion with regard to LDKT see our other article (Ismail, Massey et al., in preparation).

5.1. (Non)-communication with regard to LKD

We investigated the communication patterns with respect to pursuing a living donor. We see that in each group almost all patients were in favour of an 'wait-and-see' attitude (36/50). They all reported that as a kidney patient they should wait for a kidney offer from their potential donor. The remaining third said that they would indirectly 'ask' for a kidney (indirect approach). They do this by cautiously discussing the topic and showing the other that they prefer the living donor transplantation option. And a minority was in favour of directly asking for a kidney from a potential donor (direct approach). Main reasons for upholding a waiting approach was the fear of rejection and anticipated regret after the donation process. We also asked our patients whether their community would appreciate a waiting or an active attitude approach when it comes to asking for a kidney. All the non-European patients who did answer or had an opinion on this matter stated that their community would appreciate a waiting approach towards the issue. This latter topic was not discussed in the European group.

Almost all Turkish, Moroccan, Antillean and the Cape Verdean patients were in favour of a waiting approach. *"A person should be able to decide for himself if 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 Antillean 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 (1-3 patients per group) would actually prefer a more indirect style of asking. *"I cautiously dropped the subject during a meeting with 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 style of pursuing a kidney.

Two Turkish patients also did mention that they would provide the donor with a house and/or a marriage in Turkey. *"Last I said to a young acquaintance that if he would donate his kidney to me, I would arrange a marriage and buy a house for him in Turkey"*. Also exclusive to this group was that one patient mentioned that as a recipient you have no right saying anything about someone else's body. Another patient said that he would have asked if he had more information on living transplantation. Feelings of anticipated regret and fear of rejection after having asked for a kidney were other common reasons in this group for not actively and directly pursuing a kidney. *"I would never forgive myself if something goes wrong with the donor"*. *"I get a no from a potential donor I would be devastated. You can not imagine how much that would hurt"*. These latter two reasons were also mentioned by the Antillean and the Cape Verdean patients. *"I am afraid that the donor someday will ask for his kidney 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 used an indirect style of asking. The Moroccan patients have not reported any reasons for favouring a waiting approach.

The Surinamese and the control patients were quite similar 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. Secondly, roughly half of the patients from both groups 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 minority of these groups also exclusively and in an equal ratio reported to be approving a direct way of asking for a living donor. *"You can not 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 can not turn down your request"*; a Dutch patient.

The reasons behind the Surinamese and Dutch asking style were fear of rejection and anticipated regret. Half of the Dutch patients who asked directly for a kidney got a negative response from their potential donor. The other half used an indirect style of asking. *"The people I asked do not want to put their life in the fire line"*; a Dutch patient. The Surinamese patients who used the indirect approach did not still get an answer so far.

Finally, we focused on the general opinion of the community of our patients regarding the request to the potential donors. All non-European patients, who had an opinion on this topic, reported that their community would approve a waiting approach when it comes to asking for a kidney. This topic was not put forward in the control group.

5.2. (Non)-communication with regard to kidney disease

Half of our patients, distributed over all groups, do not talk about their disease in their social environment. However, nearly forty percent do talk about their diseases. This distribution also holds within groups for the Turkish, Moroccan, Surinamese and Antillean patients. The Cape Verdean and the Dutch patients showed a 20/80% distribution in favour of not talking about their disease. The reasons for not willing to talk about their disease are self-generated optimism, not wanting to be seen as a pathetic and not wanting to become emotional.

The Turkish patients mentioned all three above listed reasons for not talking about their disease. *“I do not want to be seen as pathetic. It does not get me anywhere. So I rather keep my mouth shut”*. *I am positive about anything, why should I start complaining”? None of the Moroccan patients mentioned any reason for not communicated about their diseases. A couple of Surinamese patients reported not wanting to be seen as pathetic by talking about their disease. “I do not want to be seen as a patient”*. This group also mentioned that it is somehow easier to talk to a stranger about their disease than to a loved one. *“Talking to family and friends is awkward because they think you always need something from them”*. The Antillean patients reported the emotions accompanied with talking about the subject and their self-generated optimism as inhibitors to the discussing their disease. *“If you just keep up the positive thinking than everything is going to be alright”*. The Cape Verdean patients also mentioned the accompanied emotions as a reason of their non-communication. *“It just are the emotions which impedes me from communicating”*. Half of these patients also stated that they would more easily talk to a stranger. The control patients only reported the self-generated optimism as an explanation for not talking about their disease. They think that there are a lot of other things to talk about and the disease has become a part of them self.

With regard to this topic we also investigated the general attitude of the community of our patients. Sixty percent of our patients, distributed over all groups, said that their community would appreciate it if people did not talk about their disease. Our patients believe that the main reason for thinking this way was associated with cultural factors. This was stated by the Turkish, Moroccan, Surinamese and Antillean patients. *“Turkish people are not open for this kind of communication, they are shallow”*; a Turkish patient. *“In general Moroccan people hold a passive attitude on this subject, we just do not talk about it”*; a Moroccan patient. *“We do not talk about disease. Our cultural pride causes this”*; a Surinamese patient. *“It is still a taboo to talk about your illness in the Antillean community”*;

a Antillean patient. A Surinamese patient also mentioned that within their community communication on the patient's disease was depended on the relationship with that certain patient. Only the Surinamese and our control patients actually reported that their community would be in favour of an active communication style regarding the patient's disease. *"Just mention the 'hospital' and people will start talking, they all got their own story"*; a Surinamese patient. *"People actively approach me to ask me about my health status"*; a Dutch patient. A couple of Turkish and Moroccan patients did not know what their community's standing would be on this topic.

6. Attitudes towards clinic education regarding LDKT

Forty percent of all our patients adopted a positive attitude towards the information provided in our centre. An equal number of patients were negative towards the same issue. This latter group was negative because they felt that they need more information and/or personal guidance. The other patients did not mention their opinion. A third of the patients reported comprehending the hospital information. Except for the Surinamese and the control patients another thirty percent of our patients mentioned that they did not comprehend the information. We do not have data on the remaining patients. If we additionally ask how actively involved they themselves are in the information gathering, half of the patients reported to be actively involved (27/50). This was true for patients from all groups. However, approximately a quarter of the patients (all non-European) stated that they were not active information seekers. This same group also reported that it was not common practice to actively search for information. Whereas only patients from our European control group stated that their community is actively involved in searching for information.

Eighty percent of the Turkish population had a negative attitude towards the information from the hospital. They were unsatisfied about the amount of information. Half of

them did not comprehend the provided information but were also not actively seeking out information either. This was irrespective of age. Sixty percent of the patients reported that their community adopted a passive way of searching for information. *“I need more information to understand what my body is going through or what I can do”*. *“The collaboration between the hospital and foreign people is bad; they do not give us all the information we need”*.

The majority of the Moroccan patients were positive about the hospital information but would have liked more information and personal guidance from our staff. Most of them also comprehended the provided information and have also been actively looking out for information. *“I have read the information and everything is clear for me now”*. *“I miss information on some topics”*. However, the people in their community were passive information seekers. *“We just wait and see”*.

Nearly half of the Surinamese patients had a negative attitude towards the provided information. They needed more personal assistance in the LDKP. In this group sixty percent thought the information was comprehensible and seventy percent actively sought information regarding their disease. *“I can not say that the information is good but I can understand it”*.

In the Antillean group seventy percent of the patients held a positive attitude towards the hospital information. Exclusively this group reported high rates of needing personal guidance and to be needing more information. More than half of them comprehended the provided information. Practically all patients in this group had actively sought for information. *“I have had a lot of information and everything was explained to me very well”*.

All Cape Verdean patients were negative about the provided information. They actually needed more information from the hospital. All of them did also mentioned that they did not comprehend the information which was provided so far. On the other hand they

themselves as well as their community do not seek for information. *“I did not get any sufficient information and could not understand the rest of it”*.

The European patients were more positive about the information but could actually also use some extra personal assistance. Ninety percent of them comprehended the information. Moreover they actively searched for the information they needed and so did their community. *“I have read the books and watched the DVD and rest of the questions I have I can ask to the doctor”*.

7. Attitudes towards the Norwegian approach

Nearly half of our patients approved of this way of stimulating the living kidney transplantation (23/50). Eight of them disapproved of it and the rest of them could not decide yet. Those in favour thought that a legitimate person (a physician) will be able to ‘get though’ to the potential donor. The physician could also directly respond to the questions first hand. Patients disapproving the idea reasoned that the potential donors have a will of their own. Therefore it would be unjust to impose them with an idea they did not ask for. Regardless of their personal stance the patients did agree that the physician should not be persuasive.

Half of the Turkish patients did not know what they should think of this idea. However a third of these patients were in favour of this approach. *“It is a good option, but the donor must not feel pressured”*.

The majority of the Moroccan patients welcomed this idea. *“I would love it if my doctor would put such an effort in helping me”*. Two other patients disapproved this idea and stressed that the donor has his own will. *“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 at his own time”*.

Seventy percent of the Surinamese adopted a positive attitude towards this telephone consult. Half of them thought that if a doctor approaches the donor, the donor would evaluate the situation as legitimate. *“It would be wonderful that an objective person would ask it for you”*. *“It would actually work if doctor contacts the donor”*. *“The donor would see the urgency of the situation”*. The other thirty percent did not know what to think yet.

Nearly all Antillean patients were in favour of this approach. *“I would indeed prefer it my doctor asks it for me”*. *“He can do the conversation without getting emotional”*. They did not report any reasons for their opinion.

On the contrary only one Cape Verdean patient was in favour of this idea. *“I do not know what the potential donors think, so this approach would work for me”*. The other had not defined their personal stance yet.

The European patients were the only group in which the majority of patients disapproved this idea. *“A donor has the right to make up his own mind, we can not do that for him”*. A third of the patients in this group were positive towards this suggested intervention. *“It is a good idea, only if it is life threatening”*. *“If a doctor asks it, it would be seen as a legitimate request”*. This was also the group with the highest number of patients mentioning that physician should not pressure the donor.

8. Attitudes towards home-based education

Finally we investigated what our patients would think of a home-based education. This form of intervention was by far favoured over our previous Norwegian intervention. More than eighty percent of our patients (total group) were in favour of this home-based education. Only twelve percent disapproved this intervention. This latter group consisted of only Turkish and European patients. Despite their personal stance our patients shared one major concern namely, that family and friends would not come to the gathering. They could not provide us

suggestions about how this could be avoided. Secondly we asked the patients what they would preferably expect from such a meeting. Two third of them would like to be informed about their personal condition. Thirdly we investigated which conditions needed to be considered before starting such an intervention. The following terms were mentioned the provided information should be of value to the patient, the intervention should not be persuasive and the non-European groups stated that an interpreter is recommended. Finally we asked our patients whether their community would appreciate such a home-based education program. In all non-European groups at least one patient reported that their community would welcome this idea. A couple of patients were neutral on this topic and none of them mentioned that their community would not appreciate this intervention.

Eighty percent of our Turkish group were in favour of this idea but half of them worried that their family and friend would come to the meeting. *“I do not think that they would come to such a meeting but it would really help them understand my situation”*. Just about all the patients would not like to get more information regarding their disease from a Turkish speaking person. *“I do not comprehend everything the hospital staff tells me so a information meeting for me and my family on my personal situation would be wonderful”*. One patient mentioned that he would prefer peer discussions over this intervention. Half of the patients stated that their community would value this intervention. *“We have a big family and therefore it would be good if everyone could get the information in this way”*.

The majority of our Moroccan patients would be in favour of this intervention. They would like to receive information in their own language. *“A lot of people do not know anything about my condition so it would be better if they get the information in Arabic”*. However they are uncertain about the standing of their community and whether they would come to such a meeting. *“People probably will not appreciate it but I do not know people*

differ on this issue". "I do not know whether my family would come to the meeting" Why not? "I would actually not know".

All but one of the Surinamese patients would appreciate the home-based education. More information on their condition would be welcome. This information should preferably be given in their own language in a non-persuasive manner. "It is really nice to let the information come to you. But people are principally against pushy behaviour, especially in your own house". One patient mentioned an exclusive term namely, that the health educator should not be Surinamese. "But who are these people? Not Surinamese I hope, no please". Those who had an opinion about the standing of the community all said that their community would welcome this intervention.

Just like the Surinamese, all but one of the Antillean patients were in favour of this idea. All patients in this group would also merely want to get information on their disease. However the educators should not push the friends and family. "It would be really nice to discuss every thing with your family. In this way they will get to know your miseries". All of these patients also recommended us to bring an interpreter. "These are very few Antilleans who can speak and understand Dutch". The majority in this group were of the opinion that their community would also appreciate this intervention.

Nearly all the Cape Verdean patients had a positive attitude towards the home-based education. Identical to our other non-European patients this group would also like to receive more information on their condition and recommended to bring an interpreter to such a meeting. "It is a shame that the information is not available in Portuguese". One patient also mentioned that the community would welcome this idea. "I see that family could use some information".

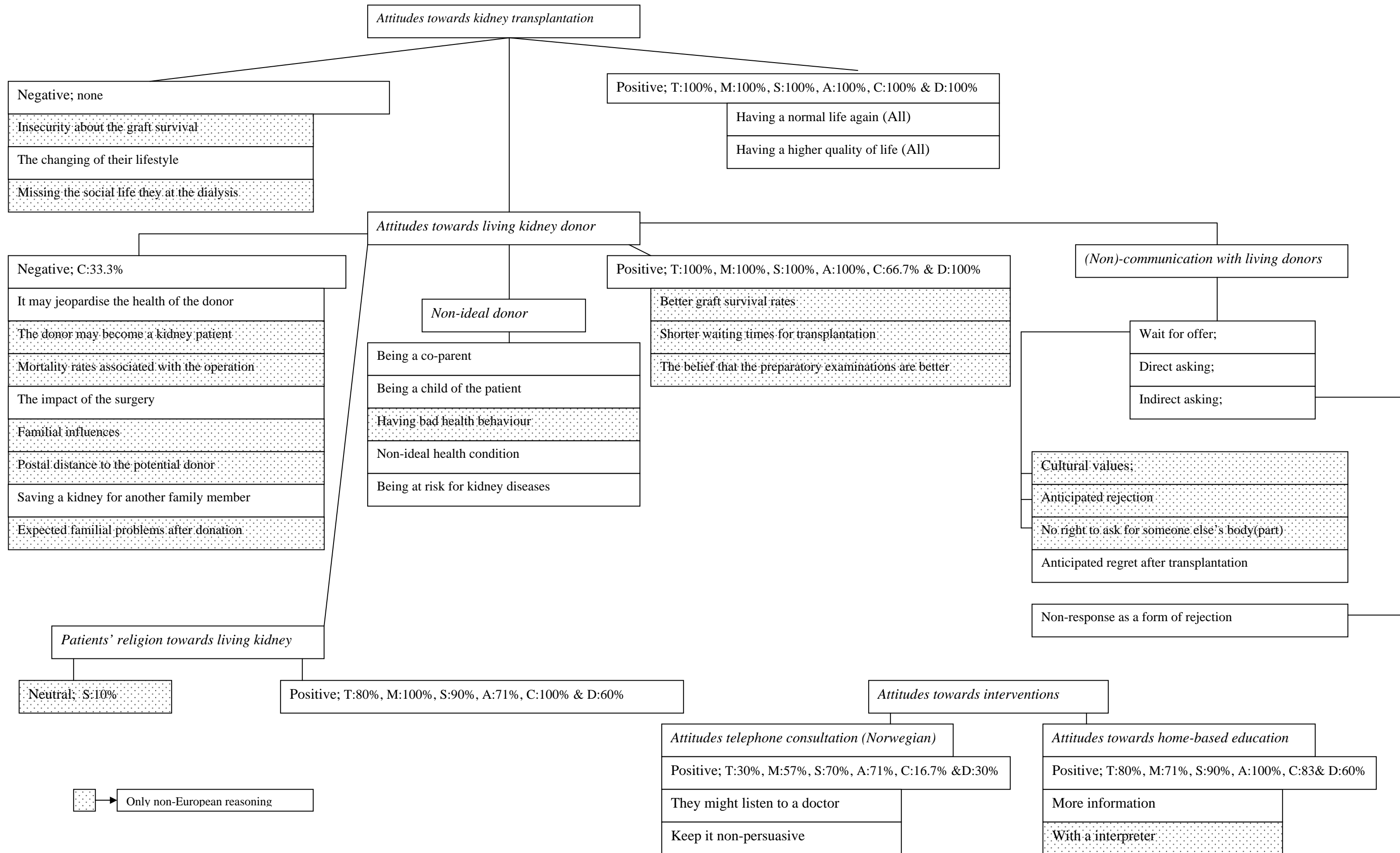
Our European control patients held different attitudes towards this issue. Half of them approved this idea while the other half would not be in favour. "In such a group meeting

everything can easily be discussed". *"In such meetings you will usually keep circling around the same thing and they already know how miserable you are"*. Those who were in favour of this intervention would like to receive more *useful* information in a non-persuasive way. Those not favouring this intervention said that they did not want to be seen as pathetic and others said that they already know everything. *"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"*. One patient said that the Dutch like to talk about everything except for disease. *"They will leave the meeting if it is not, for example, about politics"*.

One can find a summative figure below (Figure 1). We used this figure to illustrate the patient's view on the major topics. The highlighted areas indicate the aspects which exclusively apply for non-European patients .

Figure 1

A schematic distribution of attitudes and reasoning form Turkish (T), Moroccan (M), Surinamese (S), Antillean (A), Cape Verdean (C) and Dutch (D) terminal kidney patients



Discussion

In present study we aimed to investigate the discriminatory determinants accountable for the inequality in health access between European and non-European terminal kidney patients. We identified through focus group discussions and in-depth interviews that multiple issues are involved rather than a single barrier. All our patients take on a positive attitude towards kidney transplantation in general. This is not a very surprising finding since all our patients are on the waiting list for a post-mortal kidney and in advance had already chosen to get a transplantation. After transplantation the majority of our patients expect to have a 'normal' life again and/or attain a higher quality of life. Additionally, all but two of our patients were in favour of living kidney transplantation. They all correctly expect better graft survival rates and shorter waiting times for the transplantation date in the case of a living donation. The other two patients just could not live with the idea of cutting in the body of a beloved one in order to gain health status for themselves. No other specific differences between them and those in favour were found. Eighty percent of our patients would also become donor themselves if they were in the position of donating. In view of the fact that our patients are willing and preferring a living kidney we will propose our model for not attaining a living kidney donation.

In present study knowledge per se was not found to be barrier; no group differences were found between the European and the non-European. Notwithstanding, forty percent of (predominantly non-European) patients stated that they were unsatisfied about the provided information. They (all non-European) also stated that they do not always comprehend the provided information. As a consequence, patients may lack input and confidence to ask important questions. These two facts (no differences in the level of knowledge and the differences in the perceived sufficiency of the provided information between the groups) can

coexist since we used six very general and well-known questions to measure their current knowledge. However, as one can see in Table 1, not all our patients did answer all the questions correctly. Our results are in line with Pham and Spigner (2004). For discriminatory purposes recommendations regarding a more elaborated questionnaire are to be made. With regard to the hospital information we have also found that our non-European patients themselves and their community passively await for the information to be provided by the hospital staff. This is in contrast to our control patients who actively gather information and ask questions about it. Therefore a more interactive way of reaching out to this group should be considered. Especially, since Pham and Spigner (2004) also found that patients with higher knowledge percentages on the subject were also more likely to be in favour of that certain subject (e.g. living donation). A Moroccan patient even literally stated that he would initiate a conversation about living donation with a potential donor if he had more information. Conclusively, special attention should be paid to assistance at a personal level, involvement of the social network and making the information comprehensible (e.g. consider an interpreter). An intervention providing these requirements is the home-based education discussion advocated by Rodrigue et al. (2008). His research has proven to be successful at reaching out to those patients who adopt an awaiting attitude towards obtaining information and has cultural barriers which should be considered. This intervention is also successful in getting in touch with a passive social network.

Secondly, we observed that our patients held several attitudes which renounced them from a living kidney donor. Uncertainty about graft survival, the life after kidney transplantation, mortality rates associated with the operation, misconceptions regarding the pros and cons of living donation and post-mortal transplantation and the impact of the surgery are procedural factors that withhold predominately our non-European patients from starting a living donation. These factors can easily be overcome by providing the patients more

thorough and personal information on the topic. We also identified psychosocial barriers such as anticipated fears and regrets, familial values and beliefs, anticipated counterwork from other family members and expected familial problems after a living donation. Our patients had generated these beliefs themselves without consulting significant others. Beyond this they even excluded two groups of potential donors beforehand based on their characteristics namely, being a child of the patient and being a co-parent. Ideally these prefixed beliefs and exclusions should at least be considered with the relevant other(s) before jumping to such conclusions, with and without the presence of a health care educator. As we have included European patients without a living donor half of the above listed attitudinal barriers were shared by a proportion of the European patients, particularly the procedural concerns. Including only control patients without a living donor can be regarded as a methodological limitation. On the other hand, we have consciously manipulated the ethnicity of our participants and tried to keep the other variables as equal as possible. Furthermore, previous research in our center already compared European patients with and without a living donor. They found actually the same barriers in both groups (15).

Thirdly, we found that seventy percent of our patients approved an awaiting attitude towards communicating with potential living donors. Some patients (European and non-European) adopted an indirect style of communicating with the donors. Half of them were heard, the other half were actually ignored hoping that the topic would fade away. The patients interpreted this ignoring attitude as a refusal and in response held their silence forever. In addition they were even left with negative emotions. This indirect style of communicating can be seen as a first step in getting in touch with the potential donors. Although this group of patients require some additional empowerment. Only a minority of Surinamese and European patients were in favour of an active approach towards the potential donors. We believe that acculturation with the European health communalities account for the

fact that the Surinamese patients gradually are adopting this European practice. This thought is in line with previous research indicating that non-European patients with the longest duration of stay in a European country of residence were more similar in their attitudes and behaviour to the home-bred civilians (16). However we also observe that this group needs some assistance with optimizing this process. In addition the community of our non-European patients would also merely approve a passive attitude regarding this issue. The main reasons behind this passive attitude are cultural values, anticipated rejection, anticipated regret and the belief that no one has the right to talk about someone else's body(part). We already know from research that discussing such (emotionally loaded) issues with the potential donor(s) has proven to be very difficult for patients (15). This group of patients would benefit from professional assistance which is aimed at enhancing the level of understanding and knowledge while taking the personal stances, feelings and relationships into consideration in an emotionally and culturally secure environment. After all, our patients (predominately the non-European) are in favour of an intervention aimed at promoting living kidney donation. Furthermore, we see that our non-European patients foster strong and traditional family values. In line with other findings, cultural and familial patterns and values are inevitable when providing health care to culturally diverse populations (28). Therefore this factor should somehow be considered when educating these patients. Since the home-based educational intervention is even favoured over a telephone consultation, healthcare educators are provided with the luxury to incorporate family members and cultural values more easily in an environment that is comfortable to the patient.

Other colleagues had already presented the dangers to consider when intervening in patients' health behaviour. They have argued that the intervention should be restricted to patient empowerment (29). This is confirmed by our patients' warnings. They specifically stated that when healthcare educators are about to intervene in patients' lives they should

never try to be persuasive. Especially, when the intervention takes place at the patients' houses (their save heaven). In conclusion we must notify that the attitudes and barriers presented above can vary from one ethnic group to the other (see our result section for group-specific deviations). See also Figure 1 for an overview of our patients' standings and reasoning. We hope that this article will provide healthcare educators and policy developers with some insights and modifiable determinants to work with presented ethnic minorities.

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