Patient Perception, Preference and Participation

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, and (4) 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.

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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 1950s, Moroccans and Turkish in the 1960s, Surinamese, Caribbean and Africans in the 1970s. 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 center reported that medical, socioeconomic 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

2.1. 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 and 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, 50 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.

2.2. 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 educational 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.

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 h participation. Ethical approval was sought but was deemed unnecessary for this kind of non-interventional research according to our medical ethical committee.

2.3. 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

Table 1
Socio-demographic characteristics.

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

a 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).
Table 2
Interview topics and questions.

<table>
<thead>
<tr>
<th>Topic</th>
<th>Questions</th>
</tr>
</thead>
<tbody>
<tr>
<td>Demographic characteristics</td>
<td>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? Are you on the waiting list? If yes, for how long?</td>
</tr>
<tr>
<td>Personal medical history</td>
<td>Could you shortly describe your kidney disease?</td>
</tr>
<tr>
<td>Attitudes towards kidney transplantation</td>
<td>If you would get a new kidney, how do you think this will influence you life? Could you name a couple advantages and disadvantages?</td>
</tr>
<tr>
<td>Attitudes towards LDKT</td>
<td>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 whom would you and from who would you not? Would you donate a kidney if the roles were the other way round?</td>
</tr>
<tr>
<td>Religion on LDKT</td>
<td>Does religion play a role in accepting and declining a living kidney? And is this culture specific?</td>
</tr>
<tr>
<td>(Non-)communication on kidney disease</td>
<td>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?</td>
</tr>
<tr>
<td>(Non-)communication on LDKT</td>
<td>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?</td>
</tr>
<tr>
<td>Attitudes towards obtaining and providing information</td>
<td>Are you satisfied about the given information on kidney transplantations and donation at your center? Do you understand everything? Do you ask your physician questions?</td>
</tr>
<tr>
<td>Norwegian approach</td>
<td>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?</td>
</tr>
<tr>
<td>Home-based educational intervention</td>
<td>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?</td>
</tr>
</tbody>
</table>

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.

According to Miles and Huberman’s method in order to be able to compare the data between the groups [20]. Two researchers read through the transcripts twice while listening to the tape recordings and organized them into a table. Fig. 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.

### 3. Results

#### 3.1. 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 12 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.
3.2. 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.

3.2.1. 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 wait-listed patients were satisfied with the hospital information provided in our center, an equal number were unsatisfied, and 20% 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-thirds 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”.

3.2.2. 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 DDST 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 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”.

3.2.3. 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”.

3.2.4. 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 cannot 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, 30% 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 cannot just wait for someone to give his kidney away. You should promote yourself and get to the point!”.

3.3. Intervention options

3.3.1. 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”.

3.3.2. 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 favor 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 behavior, 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 Fig. 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.

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, and (4) 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 health 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 60% 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 Fig. 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.

Conflict of interest

The authors declare ‘no conflict of interest’.

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