

Religious attitudes towards living kidney donation among Dutch renal patients

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Published online: 22 April 2011

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Abstract Terminal kidney patients are faced with lower quality of life, restricted diets and higher morbidity and mortality rates while waiting for deceased donor kidney transplantation. Fortunately, living kidney donation has proven to be a better treatment alternative (e.g. in terms of waiting time and graft survival rates). We observed an inequality in the number of living kidney transplantations performed between the non-European and the European patients in our center. Such inequality has been also observed elsewhere in this field and it has been suggested that this inequality relates to, among other things, attitude differences towards donation based on religious beliefs. In this qualitative research we investigated whether religion might indeed (partly) be the explanation of the inequalities in living donor kidney transplants (LDKT) among non-European patients. Fifty patients participated in focus group discussions and in-depth interviews. The interviews were conducted following the focus group method and analyzed in line with Grounded Theory. The qualitative data analyses were performed in Atlas.ti. We found that

religion is not perceived as an obstacle to living donation and that religion actually promotes helping and saving the life of a person. Issues such as integrity of the body were not seen as barriers to LDKT. We observed also that there are still uncertainties and a lack of awareness about the position of religion regarding living organ donation within communities, confusion due to varying interpretations of Holy Scriptures and misconceptions regarding the process of donation. Faith leaders play an important educational role and their opinion is influential. This study has identified modifiable factors which may contribute to the ethnic disparity in our living donation program. We argue that we need to strive for more clarity and awareness regarding the stance of religion on the issue of living donation in the local community. Faith leaders could be key figures in increasing awareness and alleviating uncertainty regarding living donation and transplantation.

Keywords Attitudes · Communication · Ethnicity · Kidney transplantation · Organ donation · Religion

This paper is part of the Thematic Section on Organ Donation and Muslims in Europe.

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Introduction

Living donor kidney transplantation (LDKT) is associated with significant patient and graft survival benefits when compared to deceased donor kidney transplantation (DDKT) (Lamb et al. 2010). Furthermore, undergoing LDKT can avoid or minimize the negative physical, social and emotional consequences of long term dialysis. However, there is evidence to suggest disparities in access to LDKT programmes among diverse ethnic groups (Roodnat et al. 2010).

As disparities in access to LDKT may translate into higher morbidity and mortality for patients from ethnically

diverse backgrounds, an important line of investigation is exploring possible factors that play a role in this disparity. In kidney patients various factors are likely to contribute to this disparity including a higher susceptibility to renal disease due to high levels of diabetes and blood pressure (Bindraban et al. 2008) and allocation rules based on Caucasian blood distribution and HLA makeup (Rudge et al. 2007). In addition psychosocial and cultural factors may also be of influence. How do patients from ethnically diverse backgrounds view living donor transplantation? Our aim was to gain insight into why we have observed disparities in the number of patients being transplanted with a living donor kidney.

Research into attitudes towards deceased organ donation has highlighted many potential barriers to organ donation such as cultural rituals surrounding death, alienation from or distrust in the health care system, discrimination and exclusion from mainstream society, and lack of awareness of the organ shortage issue and donor registration (Alkhawari et al. 2005; Darr and Randhawa 1999; Davis and Randhawa 2004; Exley et al. 1996; Morgan et al. 2008). Although the various religions do not appear to prohibit the giving and receiving of living or deceased donor organs, objections to both are often made on religious grounds (Bruzzone 2008). Some of these objections relate to sacredness of the body, desecration of the body after death, trusteeship of the body from God, fatalism towards the issue of illness and death, the body remaining intact for resurrection, organs acting as witnesses on Judgement Day and concerns regarding the conduct and religion of the recipient (Alkhawari et al. 2005; Bruzzone 2008). One source of difficulty is that organ transplantation is not explicitly discussed in holy scriptures such as the Bible or the Qur'an, which has resulted in varying opinions on the issue among scholars, faith leaders and their followers.

Although previous studies give insights into attitudes within ethnically diverse communities towards organ donation *after death*, there is little research on attitudes towards *living donation*. The study by Alkhawari et al. describes their participants voicing 'great disquiet' about living donation, although these concerns were quantitatively fewer than for deceased donation. Religious issues among ethnic groups hindering the LDKT process need to be sorted out, so that tailored interventions could be offered to these groups, which are—as research has shown—overrepresented on the deceased donor waiting list (Roodnat et al. 2010). The main aim of this study was to investigate the attitudes of End Stage Renal Disease (ESRD) patients regarding living donor transplantation and religion. This paper focuses specifically on the role of religion in attitudes towards LDKT; other barriers to LDKT are discussed elsewhere (Ismail et al. 2010).

Methods

Participants

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

Procedure

Focus groups were used to collect data on attitudes towards living donor transplantation. When the patient was not able to travel or if they preferred not to participate in a group discussion an in-depth interview was conducted. In the focus group discussions as well as in the in-depth interviews, the patients were free to mention anything on the topic at hand. Focus group discussions have the additional advantage of stimulating a group discussion on the topic compared to the individual interview. Thus, we chose not to ask our patients about their attitude towards predefined barriers. Consequently all the results are generated by a bottom-up process and may (widely) differ across patients or not be addressed to by all patients. The procedure is discussed in greater detail elsewhere (Ismail et al. 2010) and is based on the methodology of Randhawa et al. (1998).

Preparation

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

Moderator recruitment

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

LC). Moderators were trained by the researchers in the aims of the study and use of the topic list.

Participant recruitment

The deceased donor waiting list was reviewed and patients from Turkish, Moroccan, Surinamese, Dutch Antillean and Cape Verdean origin were approached preferably during their regular visit to the out-patient clinic. A comparison group of patients with a Dutch origin was also invited to participate. All patients invited to participate received written information on the study via the post in Dutch plus Turkish or Arabic for the respective groups. This was a convenience sample and may not be representative of all opinions, particularly of those we were unable to contact and those who did not want to participate. Patients were contacted within 1 week of receiving the study information pack to ascertain participation. Those who chose to participate were sent written confirmation of the appointment along with logistical information such as location. To maximize attendance all participants were contacted by telephone on the day prior to the interview.

Data collection

Focus groups were held in a classroom or meeting room at the hospital. On the advice of the steering group discussions were held separately for men and women of Turkish and Moroccan origin but this was not felt to be necessary for the other ethnicities. The patients were allocated to a focus group with patients from the same ethnic background. First names only were used to protect anonymity. All participants gave written informed consent. The interview commenced with a description of a case study and the questions then followed a pre-devised topic list. The hypothetical case study was used as a less personal spring board to get the discussion started. Participants were encouraged to be honest, to react to each other's answers and to discuss any disagreements or inconsistencies if they arose. Techniques that were employed during the focus groups included 5-s pauses, probing, playing devils advocate and asking questions by proxy (Slocum 2005). The meetings lasted between 1 and 2 h. All participants received a €20 voucher and travel expenses were reimbursed or the transportation was arranged by the researchers.

Analysis

All interviews were audio recorded and transcribed verbatim. Sections of the interviews spoken in languages other than Dutch were translated immediately into Dutch by the respective moderator during transcription. Data were

analysed in the Atlas.ti software package using the principles of Grounded Theory (Strauss and Corbin 1994). Words or phrases were combined together in order to generate categories. This process continued until all transcripts were analysed and no new categories emerged. Subsequently, the content of the categories was analysed for overlapping or linking content. The categories were then compressed and clustered together into themes. Finally, the themes were evaluated across the different ethnic groups to search for similarities and differences in these themes.

Results

In total 50 patients participated in the study (26 males; 24 females). Age ranged from 21 to 74 ($M = 54.2$, $SD = 12.2$). Muslim patients were included in three groups: Moroccan ($n = 7$), Turkish ($n = 10$) and Surinamese ($n = 2$). Christian patients were included in four groups: Surinamese ($n = 4$), Antillean ($n = 7$), Cape Verdean ($n = 6$) and Dutch ($n = 7$). Four Surinamese patients were Buddhist and three Dutch patients were Atheist (coded as no religious affiliation).

Patients' perception of religion and LDKT

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

Helping others

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

Save a life

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

Possible religious objections

Possible objections for living organ donation and transplantation were raised and discussed by the patients. One

Table 1 Reasons to donate a living kidney—helping one another

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

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

Table 2 Reasons to donate a living kidney—save a life

Saving one life is saving a thousand lives	Muslim, Turkish
Saving someone means saving everyone, according to our prophet (peace be upon him). the other way round, if you let someone die, it means letting everyone die	Muslim, Turkish
The Islam is for the improvement of people's lives. If kidney transplantation or transplantation in general can contribute towards this then it's also welcome!	Muslim, Moroccan
You save someone's life, no problem whether it's Catholic or otherwise, it doesn't matter. It's a life, they are all people	Muslim, Moroccan
If you are able to help someone stay alive by giving a part of yourself than you should do that! God will reward you for this act	Muslim, Moroccan
The religion supports it. If you can save someone, why not?	Muslim, Moroccan
In Buddhism it's literally stated that you should save a life when you get the chance	Buddhism, Surinamese
You should take and give anything that is good for a human life	Christian, Antillean

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

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

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

Table 3 Possible religious objections—integrity of the body

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

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

Patients' view on the attitude of the community

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

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

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

Finally, there are varying (mis)interpretations within the community regarding the viewpoint of religion with respect to organ donation. A Turkish patient reported that, for example, people from the Muslim community believe that their religion would disapprove of exchanging blood with a non-blood relative (this implies that they think blood exchange occurs when an organ is transplanted). A Turkish Muslim: "People think for example that if you receive a kidney from someone else you also take on their blood and become part of their family." However, this scenario is undesirable only in the case that the donor is either a non-Muslim or a non-Believer. Another Turkish patient who is also an Imam stated that a minority of the Muslim community (approximately 20%) believes in the preservation

of the body after death. He explicitly stated and preaches in the mosque that this is a misunderstanding: "Some people think that religion (Islam) forbids it. They think that you have to be complete when you die. This isn't in the Qur'an, in fact, it's the soul that ascends and not the body."

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

Discussion

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

We have also identified some barriers to living organ donation from the perspective of the community from a religious point of view. We see that, for example, some of the Muslim patients would not accept blood and/or organs of a non-Muslim. They believe that if they receive non-Muslim bodily substances that they will become (partially) non-Muslim themselves. Bruzzone (2008) has also found that some Islamic scholars propose directed organ donation only to people with the same religion. AlKhawari et al. (2005) refer to the reasoning behind this directed donation since non-Muslim donors may have engaged in acts that are forbidden for Muslims, such as eating pork, drinking alcohol or smoking. However, this line of reasoning would also prohibit the willingness to receive a deceased donor kidney since the recipient can never know from whom the kidney originated and what their colour, creed or behaviour was. Whereas, in living donation the source of the organ is known and generally from a loved one (family member or friend). This issue should not be considered as a barrier to

living donation since the majority of the donors in ethnic minorities are usually of the same faith as the recipients (Roodnat et al. 2010). Because of this we assume that the majority of living donations within families is not faced with the issue of dealing with the donor's religion. This may also partially account for the fact that in Arab countries living donation is the most widely practiced type of donation (Shaheen et al. 2004). Based on present results we do not know whether *giving* blood or organs to a non-Muslim or a non-Believer would also be withheld based on religious grounds.

In the present study our Muslim patients shed more light on the issue regarding the bodily integrity of a Muslim person. The conception of bodily integrity is widely accepted within and outside medicine, discussed and contested in philosophy, and part of international law, that aims to protect individuals against undue interference with the body. Integrity of the body is not perceived as a reason to prohibit living donation among patients but is recognised as a possible barrier within the community. According to our patients there is a minority of people who do believe in the perseveration of the body by death. This can be seen as a belief that takes the accepted idea of bodily integrity one step further. The uncertainty regarding the nature of these beliefs and the corresponding misunderstandings are also recognized elsewhere (Callender and Miles 2001) and need to be addressed by the spiritual leaders.

Varying interpretations of Holy Scriptures are common and generate confusion. Widespread lack of awareness and uncertainty regarding the viewpoint of religion regarding living donation may be a consequence of non-communication on this issue at a community level. Both the findings in our study and in the study of Alkhawari et al. (2005) refer to the Imam as an authoritative figure in the community who advises on such issues. Our patients will predominantly practice what their faith leader preaches. However, not all patients seem to know what their faith leader thinks about this topic. Positive messages had been disseminated by major faith leaders (e.g. the Pope Benedict XVI; Daar and al Khitamy 2001; Exley et al. 1996; Randhawa et al. 2010). In the Islam, for example, the earliest discussions on transplantation of solid organs date back to 1982 following a meeting in Jeddah when the Saudi Grand Ulema (Islamic scholar) gave a *fatwa* (religious edict) on permitting both living and deceased donation according to the Shari'a (Islamic law) (Ebrahim 1995; Einollahi et al. 2007). Permissibility was granted on reasons such as the duty to help/save a life when possible, and the sanctity of human life. Nowadays, the Islamic Fiqh Academy (IFA), Muslim World League (MWL) headquartered in Mecca embodies the strict interpretation of the

fiqh (Islamic jurisprudence) by the rules of the Shari'a. They have ruled that living kidney donation is permissible in the light of Shari'a as long as there is (a) no significant harm for the donor (b) and the donation is voluntarily and without any form of coercion (Al Sayyari 2008; Quadri 2004). Despite these clear rulings there is often, at the grass-root level, a lack of consensus. One could consider reaching out to faith leaders to put this topic on their agenda when preaching to their community. One study has demonstrated a need for such an approach as many spiritual leaders know little about the organ donation program (Alkhawari et al. 2005). This approach is in line with recent findings indicating that the faith leaders too are in favour of organ donation and some even actively promote this practice (Randhawa et al. 2010).

Although patients' beliefs regarding religion do not appear to form a barrier for living donation, our findings indicate that raising awareness in the community regarding LDKT from a religious perspective could be very useful. A possible target for intervention would be to educate the family and close network of the patient, since living donation is not a solely activity. This social approach would also be in line with tackling a social factor that we have discussed elsewhere, which is identified as 'social influence' (Ismail et al. 2010). Using this approach, health care professionals could start with assisting patients and their families in dealing with misunderstandings and communication issues. This approach would be consistent with Randhawa's grass-root approach. As health care professionals we can address multifaceted issues in living organ donation by taking on this out-reaching approach at a local level (Randhawa 2003).

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

Acknowledgments This study is part of research funded by the Dutch Kidney Foundation (Nierstichting Nederland). We wish to thank the foundation for funding this study.

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