

BMJ Open Sikh and Muslim perspectives on kidney transplantation: phase 1 of the DiGiT project – a qualitative descriptive study

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ABSTRACT

Objectives Kidney transplantation offers patients better quality of life and survival compared with dialysis. The risk of end stage renal disease is higher among ethnic minorities and they experience longer wait times on transplant lists. This inequality stems from a high need for kidney transplantation combined with a low rate of deceased donation among ethnic minority groups. This study aimed to explore the perspectives around living donor kidney transplantation of members of the Sikh and Muslim communities with an aim to develop a digital intervention to overcome any barriers.

Design A qualitative descriptive study using in person focus groups.

Setting University Teaching Hospital and Transplant Centre.

Participants Convenience sampling of participants from the transplant population. Three focus groups were held with 20 participants, all were of South Asian ethnicity belonging to the Sikh and Muslim communities.

Methods Interviews were digitally audio-recorded and transcribed verbatim; transcripts were analysed thematically.

Results Four themes were identified: (a) religious issues; (b) lack of knowledge within the community; (c) time; (d) cultural identification with transplantation.

Conclusions Not only is the information given and when it is delivered important, but also the person giving the information is crucial to enhance consideration of live donor kidney transplantation. Information should be in a first language where possible and overtly align to religious considerations. A more integrated approach to transplantation counselling should be adopted which includes healthcare professionals and credible members of the target cultural group.

Trial registration number NCT04327167.

BACKGROUND

Kidney transplantation offers patients with end stage renal disease (ESRD) better survival when compared with dialysis for those who are well enough to undergo the procedure.¹ The risk of ESRD is higher among ethnic minorities.² Typically, ethnic minorities experience longer waiting times on transplant

STRENGTHS AND LIMITATIONS OF THIS STUDY

- ⇒ Participants were from the Sikh and Muslim communities which are the two largest ethnic minority groups in the East of England.
- ⇒ Cultural group specific focus groups allowed identification of culturally or religiously specific perceptions which did not extend across groups.
- ⇒ Important perceptions regarding organ donation have been identified, which will inform the design of a digital intervention tool to promote and encourage consideration of live kidney donation.
- ⇒ Those taking part were primarily those who had engaged with the kidney transplantation process in some way and therefore were largely advocates of this as an effective treatment. Views of those who chose not to pursue transplantation may differ and be less positive about the transplantation process.
- ⇒ Language was a limitation as the focus groups were nominally held in English. This meant that some potential participants were excluded from participating, but some participants whose English was limited, brought family members with them to translate. This will have impact on the ability both for participants to express their views in their first language, but also for those whose contributions were translated for their responses to be directly transcribed and used as data.

lists in comparison to Caucasian patients.³ It is believed that this inequality stems from a particularly high need for kidney transplantation combined with a low rate of deceased donation among ethnic minority groups.⁴ This is in addition to blood group and tissue incompatibility with the majority of donors who in the UK, are of Caucasian origin.

In comparison to deceased kidney donation, living donor kidney transplantation (LDKT) increases the chances of a successful transplant and plays a vital role in saving and improving lives.⁵ Despite the documented benefits, LDKT rates are low among UK ethnic minority communities in comparison



to Caucasians.⁴ Research indicates that ethnic minorities experience a number of barriers to LDKT⁶⁻¹²; notably, patients' reluctance to initiate conversations about LDKT,⁸ and insufficient information about donation and surgery.¹³ The median waiting times for a kidney transplant is 965 days for black patients and 830 for Asian (Indian subcontinent) patients compared with 640 days for white patients.¹⁴ This inequity stems from the fact that ethnic minorities have different tissue types and blood group incompatibility with the majority of the donors in the UK who are of Caucasian origin.⁸ An LDKT not only would offer better longer-term graft survival in such circumstances but also avoid the need to wait on a waitlist which carries morbidity and mortality risks.^{15 16}

In the USA, for example, members of the Hispanic and black communities face barriers to entry on the wait list, organ acceptance and transplantation,¹⁷ some of the barriers highlighted in a scoping review included lack of knowledge, perceived discrimination, mistrust, fear of organ rejection among others.¹⁸ It is unknown whether similar barriers exist in the UK. Interventions to overcome these barriers have focused on education and awareness, however, to date no comprehensive study has been done on the use of digital intervention.¹⁹⁻²¹

This study aimed to explore the views and perspectives around living kidney transplantation of members of the Muslim and Sikh communities, as two of the largest cultural or religious groups in the potential LDKT population. This was phase 1 of the Digital Intervention for Ethnic Minorities in Transplantation study (DiGiT) which aims to develop a digital intervention to support and encourage members of the ethnic minority communities to consider and potentially participate in live kidney donation as an option for the treatment of ESRD. This study included two ethnic minority groups in order to explore whether there were perceptions which spanned cultural and religious groups, with the opportunity of identifying any issues which may be unique to a particular group. Focus groups are an appropriate approach to exploring and identifying perceptions of organ donation as this decision often has a cultural group aspect as well as it being an individualised personal decision.

METHODS

The study used a qualitative descriptive approach. Focus groups were conducted in the Sikh and Muslim communities which are the two largest ethnic minority groups in the East Midlands region of UK where the study was conducted. Convenience sampling of participants from the transplant population of a large regional transplant centre was used.

Inclusion criteria

1. 18 years or over.
2. Identify as Sikh or Muslim.
3. Past live kidney donor, transplant recipient or family member.

Exclusion criteria

1. Unable to speak English or unable to provide a translator.
2. Unable to give informed consent.

Potential participants were invited to participate by the research team or a local community involvement leader with a special interest in promotion of organ donation within ethnic minority groups. We partnered with South Asian Health Action Charity to recruit participants from the community. Response rate from the initial group of contacted participants was 100%. All participants provided written informed consent prior to participating in the study.

Three focus groups were held face to face at a hospital location during December 2018 and January 2019 and were conducted based on a topic guide. The topic guide was informed by the literature regarding perceptions of organ donation by the wider population, but with a view to exploring whether these were reflective of perceptions within the target groups. There was also an opportunity to identify whether there were perceptions which had not been apparent in the general literature which were specific to these particular ethnic groups. The composition of the focus groups was based on the participants who were available and willing to attend, with a view to keeping cultural and religious groups separate. Due to the larger number of Muslim participants, it was possible to keep those with experience of LDKT and deceased donor transplant separate. This was to allow any differences in views to be identified and to allow participants to speak freely in case there was any cultural or religious disagreement regarding whether either live or deceased donor transplantation was most appropriate. The same person conducted all three focus groups and was a researcher who had not been involved in the patients' care. She had a PhD, was a nurse by professional background and extensive experience of conducting a range of qualitative research. The local community involvement leader who had introduced the study to the participants was also in attendance at the focus groups. It was hoped that the presence of a known community member may reassure the participants and encourage honesty in their answers. The facilitator allowed all participants opportunity to give their views on questions and encouraged participants to provide agreement or challenge to any perceptions given within the focus groups.

Focus group topic guide

Recipients

Opening question: How long has it been since your living kidney transplantation surgery?

1. What made you first consider living kidney donation? (Probes: might be the stage of illness, external information from doctors, friends and family influence)
2. Thinking back to the time before your surgery, how did you reach a decision to pursue living kidney donation? (Probes: what sources of information did you seek when making a decision that is, advice from medical

- professionals, influence of friends/family, how useful was this information? format? tailored to culture?)
3. What information was helpful, what was it about the information that was helpful? what was missing? how could it be improved?
 4. How did you communicate your need for a living kidney donor?
(Probes: did you identify donors or did they approach you? did you begin a conversation with the donor? how did it make you feel? expand on the conversation?)
 5. How did you communicate about living kidney donation with your friends and family and how did it make you feel?
(Probes: when did you begin discussions before/after donor was identified, individually or as group, did they have concerns? were they supportive?)
 6. Thinking about any religious or cultural beliefs you have, do you feel your beliefs influenced your feelings towards living kidney transplantation or the ability to discuss the topic with friends and family?
(Probes: aware of religious stance towards donation? is it discussed openly in the community?)
 7. Did you use any tools or information to aid communication on living kidney donation?
(Probes: what were they? how useful were they?)
 8. When considering transplantation options, what do you think would help patients to facilitate a conversation with potential donors?
(Probes: practise with professionals? knowledge on living kidney donation?)

Donors

Opening question: Before you became aware of a need to donate, what were your thoughts towards living kidney donation?

1. What made you first consider living kidney donation?
(Probes: might be the stage of illness, external information from doctors, friends and family influence)
2. How did you reach a decision to become a living kidney donor?
(Probes: what sources of information did you seek when making a decision that is, advice from medical professionals, influence of friends/family, how useful was this information? what was the format? tailored to culture?)
3. How did you find out about the patients need for a kidney and how did it make you feel?
(Probes: did patient approach you? did someone ask on their behalf?)
4. How did you communicate your willingness to be a living kidney donor to the recipient and friends and family?
(Probe: who instigated conversation? decision over time? volunteer? reactions?)
5. Thinking about any religious or cultural beliefs you have, do you feel your beliefs influenced your feelings towards living kidney transplantation or the ability to discuss the topic with friends and family?

- (Probes: aware of religious stance towards donation, is it discussed openly in community)
6. Did you use any tools or information to aid communication on living kidney donation, what information was most useful?
(Probes: why?)
 7. When considering transplantation options, what do you think would help patients and potential donors to facilitate a conversation about living kidney donation?
(Probes: practise with professionals? knowledge on living kidney donation?)
 8. Thinking back to the time before your surgery, what was it about the information was helpful? what was missing? how could it be improved?

The discussion which took place during the focus groups were recorded and transcribed by verbatim. These transcripts were analysed thematically by the researcher who had conducted the focus groups to produce the final themes outlined below. Thematic coding was carried out, looking for repeated patterns across the data,²² and the constant comparative method was employed to ensure existing themes were reviewed in light of new data.²³ Themes were discussed between the research team to ensure agreement that the data was reflected adequately and any amendments were made as required following group discussion. Some themes related particularly to the religious and cultural beliefs of these specific ethnic minority groups, but other themes could be seen to be applicable to any individual involved in the transplantation process irrespective of cultural background. The themes were religious issues, time, lack of knowledge within the community and identification with transplantation.

Patient and public involvement

Patient and public involvement for this study received a favourable opinion, participants agreed with the need to tackle the current barriers to donation and acknowledged the need for a video to be tailored to a specific community.

A focus group comprising transplant recipients and past donors was held to aid the design of the study. The focus group helped frame the research question and outcomes. Patients were not involved in the direct recruitment into the study. Results of the study will be shared with patient groups and via kidney patient charities.

RESULTS

Majority of participants were either working full time or part time, two identified themselves as disabled, English was the main language for the majority and all lived in East Midlands, characteristics of participants are shown in [table 1](#).

Religious issues

For both Muslim and Sikh participant groups it was important that organ donation and transplantation was commensurate with their religious beliefs.

**Table 1** Baseline demographics

Number of participants*	18
Gender	Male 10; female 8
Work status	Full time: 4 Part time: 9 Not working: 4 Student: 1
Identified themselves as disabled	Yes: 2 No: 16
Educational qualifications	Didn't complete secondary school: 0 Completed secondary school (high school): 1 GCSE/O level (high school diploma): 4 A-level (advanced level): 3 Diploma/certificate/skill qualification: 4 Under graduate degree: 3 Higher degree: 2 None of above: 0 Other: 0 Missing: 1
Age group	Under 16: 0 16–29: 2 30–39: 4 40–49: 2 50–59: 6 60–69: 3 70+: 1
Religion	Muslim: 12 Sikh: 4
Religiosity	Extremely: 5 Moderately: 8 Slightly: 1 Not very religious: 2 Not answered: 2
National identity	English: 3 Scottish: 0 Welsh: 0 Irish: 0 Northern Irish: 0 British: 8 Other: 5 Not answered: 2
Main language	English: 10 Other: 6 Not answered: 2
Place of birth	UK: 4 Non-UK: 12 Not answered: 2
Region of UK live in	East Midlands: 18
Ethnic group	White: 0 Mixed: 0 Asian/Asian British: 13 Black: 5 Other: 0
Donor	3
Recipient	10

Continued

Table 1 Continued

Focus group 1 Sikh recipients (54 min)	Participant SR1—male recipient Participant SR2—participant 1's wife Participant SR3—participant 4's wife Participant SR4—male recipient Participant SR5—male recipient
Focus group 2 Muslim recipients (1 hour 17 min)	Participant MR1—female recipient (related by marriage to participant 3) Participant MR2—female recipient Participant MR3—male recipient (related by marriage to participant 1) Participant MR4—male recipient Participant MR5—male recipient Participant MR6—participant 5's wife Participant MR7—female recipient
Focus group 3 Muslim live donors and recipients (1 hour)	Participant MD1—female, daughter of participant 2 Participant MD2—female donor Participant MD3—female, daughter of participant 2 Participant MD4—female, daughter of participant 2 Participant MD5—male donor, son of participant 6 Participant MD6—male recipient of kidney from son (participant 5) Participant MD7—male donor, father of participant 8 Participant MD8—male recipient of kidney from father (participant 7)
*Two participants did not complete demographic questionnaire.	

While both Muslim and Sikh participant groups appeared to want to understand that organ donation and transplantation fitted in with their religious views, this was much easier to achieve for the Sikh participants.

SR2: I don't think it was a factor—culture or religion didn't come into it. I can't think of any religious things [to prevent organ donation].

SR5: The culture doesn't bother me much. I have done the right thing at the right time.

For Muslim participants, the issue was much more complicated. Illness may be seen to be a test sent from God which should be endured until God presents a solution.

MR7: You're ill, mainly from an Islamic point of view, you know maybe we look at it as a test from God. You know, so we've got to go through this to the best of our abilities.

This led to the view that transplantation may be going against God's will and so LDKT in particular should not be considered. There was disagreement about this however as others believed that organ donation and transplantation was not problematic from a Muslim participant's perspective.

MR1: Islamically we believe that when it comes to your health, you do what you can within your means. It's not that it's [organ donation] not permissible.

MR7: They would have to have a statement quoted from the Quran. There is a statement in line with the social responsibility bit. It's your social responsibility to offer a kidney.

What was agreed on was that organ donation and transplantation should not be considered unless it was understood to be permissible within Islam.

MR3: Once the fatwas are passed, once there's clarity, then people will think [about organ donation]

It was agreed that there was a lack of clarity and information within the Muslim community and that that clarity needed to come from religious leaders and be documented in religious writings and teachings.

MD6: I think it should be wrote down, full information and for the mosque to provide it.

Given that these participants had been involved in the kidney transplantation process, it is not surprising that they reported being reassured by their local religious leaders. There was little doubt that Muslim participants felt the need for more reassurance and explicit permission to participate in organ transplantation than their Sikh counterparts and that for them, the fit between donation, transplantation and their religious beliefs was less straightforward than within the Sikh religion.

All participants agreed that it could be difficult to initiate discussions around the subject of transplantation with potential live donors, and this is not a new finding. There were however, religious influences which exacerbated the difficulties for these groups.

SR2: They think that if we discuss it, it's bringing bad luck. I think that's what they think. The people that I talked to were Sikhs and they were a bit 'don't talk about that'. It's taboo. If you talk about it, who knows what might happen. You're probably bring bad luck down.

In addition, while many participants had received a number of offers from potential live donors, it was deemed that many of these were not serious offers which would have been pursued to fruition.

MR7: How it is in the whole community, your friends and relatives come and see how you are. And they say, shall I give you a kidney? But they don't actually want to give you the kidney You know, the formal greeting, the formal offering. But it's not really So the patient says 'oh, how thoughtful of you. How kind of you. But no thank you'. It's just a formality as well.

For LDKT in particular, some participants had received negative comments from other community members. One participant who received a kidney from his son was discouraged by members of his community.

MD6: But before they confused me. They say why you doing this? You are an old man and his is a young man.

The daughters of a recipient who accepted a kidney from his wife also had a similar experience.

MD1: Why are you guys taking the risk? Is the risk worth it? It will affect two lives basically. It would leave us without any parents. Because it was my mum and dad as well, it was two parents who were going to die.

For some participants, this made them more reluctant to consider LDKT.

MD5: It took him some time because of all the negative thoughts really regarding the whole operation risk.

These negative comments and discouragement of LDKT did not appear to be part of the experiences of any of the Sikh participants in the study. Nevertheless, it was important for all participants to have some level of acceptance and validation by members of their community and when this was not forthcoming, it delayed their decision of when to pursue the transplantation route, or whether to do so at all.

There were cultural as well as religious issues at play for some members of these groups when considering who might be the most appropriate live kidney donor within the family.

MD7: We just felt that it wouldn't be fair on his wife to be's family to put to them 'would you agree to him donating a kidney to his brother' My other daughter was not married at the time Because of the, I wouldn't say 'stigma', because of common beliefs in our community, in our faith and in our community, we felt that if she did donate, eventually when the time came for her to marry, we would have to tell the other people that she is a kidney donor and maybe that might have made it awkward to find a suitor.

Participants were considering what the impact of donating a kidney might be for the donor in the long

term and whether they would be accepted within the community moving forward in life. This complicated the transplantation process and may have prevented some potential organ donors from being identified or being given permission by their family to consider becoming a live organ donor.

Lack of knowledge within the community

While some participants discussed hearing negative views regarding their participation in the transplantation process, this was largely seen to be due to a lack of knowledge and understanding of the transplantation process within the wider community.

MR3: They are very ignorant. They are quite ignorant when it comes to stuff like that. Some are not informed.

It was agreed that one of the main messages which the communities needed was the benefit of transplantation for the individual and the likelihood of success in order to allay the fears of community members which appeared to be mostly associated with the risks involved.

MR5: When I found out more and I would have done it because the success rate is very high anyway. But people are talking with no knowledge.

SR2: How life changing it is. From being unwell to overnight feeling so well and back to living a normal life.

Many recipients and donors felt it was their duty to raise awareness of transplantation and the benefits it had brought to them individually and widely publicised their kidney transplant within the community.

SR2: We made a point of telling everyone.

While participants felt that there was a lack of knowledge, understanding and experience around transplantation within the ethnic minority community, a large number of participants identified family or community members they knew of who had had renal failure or a kidney transplant. This knowledge did not appear to translate into a community-wide understanding of transplantation, however. It was identified that things were changing within the community as a number of participants felt that younger community members understood and accepted transplantation more easily than the older generation.

MR6: In a few year's time with the new generation, it will change ... Because they mix. They are Westernised.

MR7: The younger generation, they are able to understand the Quran, the hadith in a much better way.

Therefore, although it was identified that there was ignorance within the communities with regard to organ donation, there were also signs that some attitudes were changing and that these were influencing not only the

younger community members, but the perceptions and behaviours of the older generation too.

Time

The issue of time played an important role within the transplantation process for many participants. This was manifest in a variety of ways.

It took time for both donor and recipient to make the decision to be involved in the transplantation process. Irrespective of level of knowledge or input from health professionals, many individuals needed time to come to terms with how they felt about either donating or accepting a kidney. Many recipients felt very ambivalent about accepting a kidney from a live donor due to worry about how it might affect the donor.

SR5: My daughter offered me, but I said no. I told her 'you've got a long life to live. Don't worry about me She offered but then my conscience didn't let me.

MD1: I think it took him a few years to sit down and say look, this [kidney transplantation] is an option for me.

MR3: I said no to 2 or 3 transplant offers from the transplant list. I refused it twice because I didn't have confidence.

Donors equally needed time to consider whether they were committed to donating, and the decision was usually reached when they could see their relative or friend's condition deteriorating. Them becoming unwell appeared to act as the catalyst for their decision.

MD1: I think it got to a point obviously we could see him feeling unwell and I think my mum decided, you know I may not be a match, but we should just try.

SR2: I think XXX felt so wretched by then that his health at that point superseded [his reservations about transplantation].

While a deteriorating condition of health may have encouraged both donors and recipients to consider LDKT, conversely, being on the national waiting list appeared to inhibit consideration of the live donor option.

MD1: Because once you're on the register obviously you have hope that you are actually going to get a kidney so that hope kind of slows you down. After a few years you think I'm not getting anywhere. I'll just do the live donor.

Sometimes healthcare professionals reinforced the idea that being on the national transplant waiting list would result in a transplant and validated participants decisions to hold off pursuing LDKT.

MR7: The nurses are really kind. They say within 6 months you're most probably going to get your kidney.

While comments such as these may be aimed at being reassuring, health professionals may not have anticipated

that they might result in patients delaying decisions about LDKT. Conversely, other comments by health professionals encouraged participants to seriously consider LDKT as a treatment option.

SR2: I think initially we were quite apprehensive about having a kidney transplant But the GP was a bit more helpful and he pushed it and said you haven't really got a choice. It's a chance you have to take.

For many, the information about transplantation was variable and did not appear to give out a clear message that in terms of long-term health, transplantation was a superior option, although with associated risks. Understanding the difficulties for ethnic minority group patients receiving a kidney from the national waiting list and that they were likely to wait longer than their Caucasian counterparts was a crucial piece of information. Once participants understood about the benefits of transplantation and the likelihood of a prolonged waiting time on the deceased organ donor list, this appeared to assist with their decision-making.

MR5: So we knew that he would have to wait a long time before he could get a kidney so we thought that you know, if someone can donate, that would probably be the better option and the quickest and easiest option.

Patients themselves sometimes acted as gatekeepers of information for their families when they were unsure whether they wanted to pursue transplantation as a treatment option.

MD5: I think for us because my dad, he of course knew a lot more than us, he sort of kept us in the dark because he didn't want we would talk about it, but he wouldn't give us a lot of information.

This withholding of information by the patient may have prevented potential live donors from considering this option in a timely manner, thereby prolonging the decision-making and transplantation process.

Cultural identification with transplantation

Participants highlighted that they needed to be able to identify with transplantation as an option for their cultural (and religious?) groups specifically. They identified that there was little culturally specific information available.

MR7: This idea of donating organs—there needs to be a greater awareness For our community—general Asian I'm talking general ethnic minority. All ethnic minorities.

MD6: But we need the message through the community; the channel of the community. They need to understand how we feel so everybody can know it will be ok.

Information introduced by religious leaders within community settings was felt to be a good way to spread the message about transplantation.



MR3: You would need the Imam who's basically leading the sermon to introduce. So to make people aware. So we have this situation [lack of organ donors]; maybe it's at crisis stage.

Having other members of the community who had gone through transplantation and were willing to share their stories was seen to be another way to reassure others who were considering entering into the process.

MR3: I think it would be better if it was someone in the community because that way they are able to relate to it so if anyone in their family was to have something like that happen to them, they would be able to say, this person, we're the same so it would work out for us.

In addition, having information freely available and offered in languages other than English would be beneficial.

MD6: I think most people can understand English, but the main problem is to have information about their own kind, mother tongue.

MD6: Written information in their language is very important. In the mosque for the whole community.

The person presenting information and their standing within the local community was crucial. It was suggested that religious leaders initially introducing information would be most easily received, but following that, healthcare professionals, or other members of the community who had successfully been through the process would be best placed to present the reality of organ donation.

MR3: So you would need the Imam who's basically leading the sermon to introduce ... we have a speaker from the hospital who's part of the transplant team He'll better explain it to you.

MD3: People who have experienced it because they know actually how it happened.

It was felt that a more nuanced approach to information giving which met the specific needs of particular groups would be most effective.

DISCUSSION

This study has highlighted the complexity of information giving and decision-making regarding LDKT. This complexity is amplified within some communities as specific cultural and religious norms result in decision-making being more challenging.

Healthcare providers often see the task of information giving to lie with them and the wider healthcare team. While it is crucial that all patients and their carers are given accurate and up to date information, the findings of this study suggest a broader approach to communication and information provision is adopted. For some cultural and religious groups, involvement of the wider community and endorsement from credible cultural and

religious leaders, are crucial to their decision-making, in addition, their individual decision-making needed to be compatible with religious scriptures. In these cases, the vehicle via which the information is provided is equally as important as the information itself. There is a case to be made for stronger partnerships between healthcare providers and cultural and religious leaders in order for information to be accurate, but also delivered in a culturally sensitive way. This may improve uptake of knowledge and increase the possibility that it will be assimilated and acted on.

As well as the delivery of the information being culturally specific, information delivered in the first language of the community using vocabulary which is easily understood is likely to enhance uptake. This is in addition to ensuring that the congruence of information with prevalent cultural and religious views. For some groups, this alignment of health advice with religious views and endorsement is best placed with respected religious leaders. Having publicised agreement by national religious groups can also promote acceptance within specific cultures. A lack of consistency of message may be a contributing factor to the misinformation and misunderstanding which appears to be prevalent in some ethnic minority groups. Good quality, clear and culturally specific information delivered in an appropriate manner by a credible source may address the problems of lack of understanding of transplantation in some groups and promote a support of all types of transplantation as an acceptable and beneficial treatment for renal disease.

It can be difficult to know what information would be the most effective when counselling for patients for transplantation, but for the groups studied here, communicating clearly the benefits of early transplantation over dialysis as a treatment for renal failure is crucial. In addition to this, the potential benefits of LKDT over and above what can be offered by deceased donor transplantation should be emphasised. Openness about the issues ethnic minority patients face in terms of the deceased donor waiting list are also key pieces of information which are relevant specifically to this population and should be highlighted in order for patients, and potential donors, to make a fully informed choice about their treatment options. Being overly optimistic about the chances of a potential deceased donor may delay discussions about LKDT and also reduce the number of individuals who seriously consider becoming a live donor, or joining the organ donation register from within these cultural groups. These are messages which it is crucial that the community as a whole hear and understand, if increased organ donation in these groups is to become a reality.

Specific cultural and religious groups face many of the challenges in making an informed choice about transplantation which any individual would face, but their decision-making processes may be made even more problematic by specific cultural or religious issues.

With the issue of time, this can be viewed as a barrier or a facilitator depending on individual circumstances,

donors and recipient pairs felt they need time to weigh up options, the decision-making process includes waiting on the wait list for a deceased donor organ to come up, in this case while time could be viewed on as a barrier in fact time on the wait list can be a facilitator because patients accrue morbidity and mortality while on the wait list with associated poor quality of life and therefore, if a donor were available recipients would very likely pursue LDKT and avoid further waiting on the wait list.

Attitudes and perceptions to organ donation and transplantation have previously been studied in the Sikh community, however, these have tended not to specifically focus on LDKT, in contrast, in our study the focus has been to understand the barriers to LDKT which can be a life-saving option for many on the waiting list.^{8 24} Within the Muslim community, attitudes and beliefs are influenced by their sect, interplay of cultural factors, interpretation of messaging from religious elders, therefore, the barriers identified from studies done in other parts of the world in the Muslim community cannot necessarily be generalised and it is vital to explore barriers among the target population. The findings from this study will inform the development of a digital intervention specific to the target population, appropriate, culturally sensitive messaging is crucial to the uptake of LDKT within these communities. A study done in Brunei by Teo *et al* found no difference among Muslims and non-Muslims in their attitude towards donation,²⁵ whereas, in a study done in the UK involving ethnic minorities found Muslim members to be less likely than Hindus or Sikhs to agree with organ donation or be registered on the organ donation register.²⁶

There were some limitations of this study. Those taking part were primarily those who had engaged with the kidney transplantation process in some way and therefore were largely advocates of this as an effective treatment. Views of those who chose not to pursue transplantation may differ and be less positive about the transplantation process. The focus groups were nominally held in English, but some participants whose English was limited, brought family members with them to translate. This will have impact on the ability to directly transcribe individual's responses and use them as data. Male and female participants attended focus groups together, as did those of different ages. This may have limited the input of some participants as previous research has highlighted cultural issues in some groups which result in younger or less senior members of the community fully expressing their views in the presence of other community members.²⁷ The recognition of any gender differences may also have been limited as there have been shown to be gendered views regarding organ donation in previous research which may not have been expressed in this study due to mixed gender groupings.²⁸ Participant numbers were limited and represented only two religious and cultural groups, there were no Sikh donors. Obtaining data saturation was not the aim of this study. Moreover, data saturation is unlikely to have been achieved and therefore

the results should be viewed with this in mind. There is no reason to suspect that the perspectives shown in this study are not reflective of other members of the Sikh and Muslim communities, however. Finally, while the research team was diverse, the main facilitator of the focus groups was a white British female—her ability to engage with the communities in question may have been limited to her ethnic background and gender.

Other studies have highlighted similar barriers in ethnic minority communities,^{8 29–31} however, to date no successful intervention to overcome these barriers have been studied methodically to evaluate their outcomes. In addition to identifying barriers, our study is designing an intervention the impact of which will be studied in the later phases.

Conclusion

This study has highlighted that members of these ethnic communities can make informed choices about LDKT which have good health outcomes. Those who do this are often then advocates for this treatment choice within their own communities. Taking a more inclusive approach to transplantation counselling which involves health-care professionals, religious and/or cultural leaders and community members with experience of transplantation may go some way towards breaking down barriers and ensuring that all patients receive information which is appropriate and relevant to their specific needs, delivered in a culturally appropriate way. One size does not fit all, and understanding differing perceptions is vital if we are to address the questions and use the advocates of ethnic groups with regard to kidney transplantation.

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