

# Factors Impacting Conversations with Friends and Family about Living Kidney Donation

## Abstract

### Introduction

Living donor kidney transplantation is the optimal modality of renal replacement therapy for advanced kidney disease. It is associated with superior recipient and graft survival, better quality of life and self-reported health status compared to dialysis. Living kidney donation occurs less frequently in members of Black, Asian and Minority Ethnic (BAME) communities in Western countries. This scoping review explores the factors affecting the ability of patients (and health professionals) to initiate conversations about living kidney donation with family and friends, with a focus on BAME population groups.

### Methods

208 published articles were identified from online databases using keywords: 'barriers', 'decision making', 'living donor', and 'kidney transplantation'. Studies limited to donors or involving paediatric recipients were excluded,

### Results

There were 25 studies that met the inclusion criteria. Of these, 21 studies included BAME communities. Participants of South Asian ethnicity were underrepresented. Key themes were; 1) lack of knowledge 2) risk perception 3) fear of financial burden on donors 4) guilt 5) religious and cultural influences and 6) mistrust of the medical establishment. There were noticeable differences by ethnicity, in level of knowledge, risk perception and fear of financial burden. Religious/cultural reservations and medical mistrust were only reported in people from BAME populations. Two studies explored health professionals' views.

### Discussion

This literature review has identified different barriers to the pursuit of living kidney donation, some of which are linked to ethnicity. This study informs the development of a patient decision aid to support people to have conversations with potential donors, with particular focus on South Asian groups, the second largest ethnic group in the UK.

### Key words:

Living kidney donation, chronic kidney disease, kidney failure, kidney transplant, ethnicity, Decision making.

**Ahmed Ahmed<sup>1,2</sup>, Anna Winterbottom<sup>1,2</sup>, John Stoves<sup>2,3</sup>, Shenaz Ahmed<sup>1,2</sup>, Sunil Daga<sup>1,2</sup>**

*1 Renal Department, St. James's University Hospital, Leeds UK; 2 Leeds Institute of Health Sciences, University of Leeds, Leeds UK; 3 Renal Department, St Luke's Hospital, Bradford UK*

[Ahmed.ahmed30@nhs.net](mailto:Ahmed.ahmed30@nhs.net)

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## Introduction

Living donor kidney transplantation (LDKT) is advocated as the optimal treatment for people with advanced kidney disease offering improved graft and patient survival<sup>(1)</sup>, patient reported quality of life and morbidity profile following transplantation<sup>(2,3)</sup>. Despite this, LDKT is only performed for 35% of people with advanced kidney disease in the United Kingdom with a notable ethnic disparity. Members of Black and minority ethnic (BAME) communities constitute approximately 14% of the general population in the United Kingdom but represent a third of people on the national kidney transplant waiting list<sup>(4,5)</sup>. Only 14% of people with advanced kidney disease (AKD) from the BAME communities are recipients of LDKT<sup>(4)</sup>. This may be in part due to increased prevalence of chronic illnesses such as diabetes mellitus and hypertension which predispose people to develop advanced kidney disease<sup>(6)</sup>.

Decision making about living kidney donation is a complex process; healthcare professionals convey information to people with kidney disease but to ensure there is no perception of coercion by the clinician, they rely on their patients discussing donation with their friends and family members.

Multiple factors are known to be associated with the uncertainty surrounding LDKT in the Western countries, where national deceased donor programs are established. A UK based multi-centre questionnaire study<sup>(7)</sup> found that older patients, those from a BAME background, and people of non-Christian religions demonstrated greater uncertainty about positive psychosocial statements related to LDKT. Similarly, certain patients' demographics including ethnicity, age, car and home ownership, marital status and education level were associated with the likelihood of having a living donor transplant<sup>(8)</sup>. Gender disparity in living kidney donation was observed in previous studies with females more likely to be donors than recipients<sup>(9)</sup>.

This review explores the different modifiable factors affecting patients' decision making in initiating conversations about living kidney donation with their potential donors. We aim to explore current literature from the perspectives of patients and their healthcare professionals. This review will guide the development of an intervention to improve patients' ability to initiate conversations around living kidney donation with families and friends with a focus on BAME communities.

## Methods

A survey of primary empirical research employing a rapid review method<sup>(10)</sup>. The keywords included in the search strategy were: "Kidney transplantation", "living donor", "Barriers", "Decision making" and "recipients", with reference to the review aims. Articles were identified from: electronic databases Medline and PubMed (01/01/1990-30/11/2020); hand-searching key journals; complete search of reference lists of all articles included in this and prior reviews; reference list of a relevant unpublished doctoral thesis; key authors contacted to request articles; author search in Google Scholar.

### *Inclusion and exclusion criteria*

Studies included people with AKD, those receiving dialysis, recipients of kidney transplants from deceased or living donors and studies targeting health professionals involved in decision making around LDKT including doctors, transplants co-ordinators and nurses. Studies were excluded if they targeted only living donors, paediatric recipients and abstracts for conference proposes. Two hundred and eight articles were identified and 25 met the inclusion criteria and were included in the review.

Relevant information extracted from the studies in this review included: Study location, year of publication, methods, sample size, characteristics of the participants and the themes included in each study identifying barriers to patients' decision making in initiating discussions about Living kidney donation. Data was recorded in an excel sheet to facilitate categorisation and analysis.

## Results

Frequently reported themes are summarised according to their prevalence among ethnic groups in Figure (1). Study characteristics are summarised in Tables 1,2,3 by data collection method.

Figure (1): Barriers to LDKT among ethnic groups

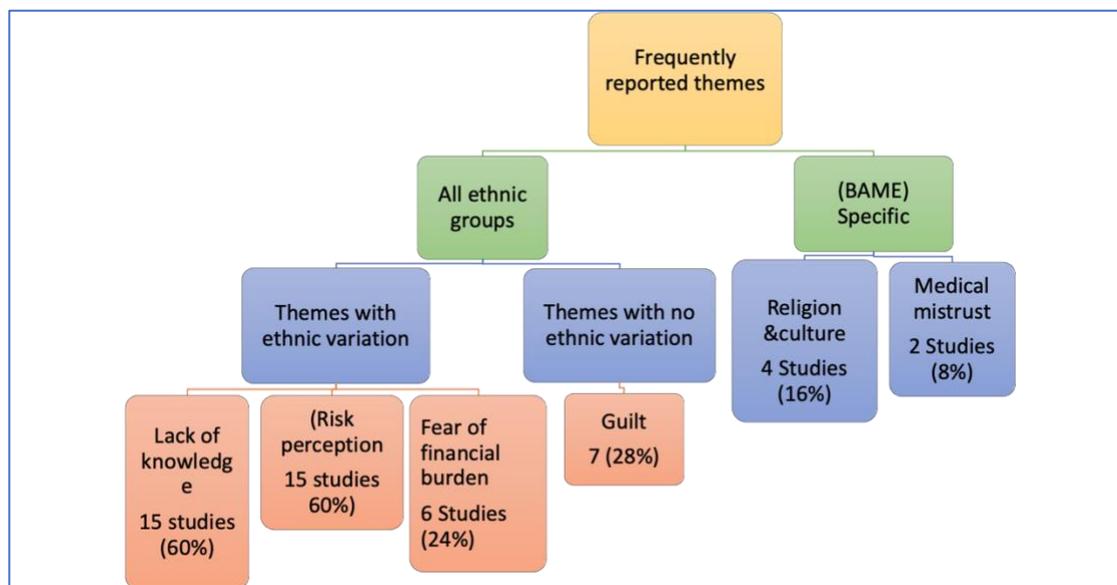


Table (1): Questionnaires/Surveys studies [Click link to view](#)

Study number	Author	Title; DOI	Year published	Location	Study design	Participant's characteristics	Ethnicity	Sample size	Summary of findings
1	Burroughs et al	One organ donation, three perspectives: experiences of donors, recipients, and third parties with living kidney donation; DOI: 10.7182/prtr.13.2.71t8xj210l18mx25	2003	USA	Surveys	Donors (174) People with AKD (174) third-party family/friend (174)	95% white – 3% African American – 1 % Asian and 1% Hispanics	522	Recipients overestimated how difficult and painful the surgery and recovery were for donors  Themes: Risk perception
2	Kranenburg et al	Post-mortal or living related donor: preferences of kidney patients DOI: 10.1111/j.1432-2277.2005.00081.x	2005	Spain	Questionnaires & structured interviews	People with semi-AKD and on the waiting list. Ethnicity not	Unspecified	61	Main motivation to choose living kidney donation was the better quality of the living kidney. Main motivation for choosing post-mortal kidney was fear of burdening a loved one Themes: risk perception
3	Lunsford et al	Racial differences in coping with the need for kidney transplantation and willingness to ask for live organ donation DOI: 10.1053/j.ajkd.2005.10.018.	2006	USA	Questionnaires	People with AKD	61% African Americans	333	African Americans are more likely to have different perception of the need for Tx and maladaptive coping mechanisms Themes: Risk perception
4	Waterman et al	Why African- Americans are not pursuing living kidney donation. DOI:10.1097/00007890-2006607152-00649	2006	USA	Survey	People with AKD and on Dialysis	67% African Americans and on 33 % Caucasian Americans	479	African Americans had lower levels of knowledge, more concerns about the surgery, more fear of transplant failure and being rejected from potential donors if they refused than Caucasian Americans. African Americans believe rich/White patients are treated better by health services Themes: lack of knowledge, risk perception, guilt and medical mistrust
5	Zimmerman et al	The influence of socio-demographic factors, treatment perceptions and attitudes to living donation on willingness to consider living kidney donor among kidney transplant candidates DOI 10.1093/ndt/gfi218	2006	Canada	Survey	People with AKD and on the waiting list.	61% Caucasians, other ethnicities non-specified	146	Willingness to consider Living kidney donation was independently associated with a lower perceived risk of perioperative complications to the donor (adjusted OR 3.59, P1/40.02), the perception that the recipient would live longer following living donor transplantation Themes: risk perception, lack of knowledge
6	Rodrigue et al	Patients' willingness to talk to others about living kidney donation DOI: 10.7182/prtr.18.10jp08439772t722	2008	USA	Questionnaires	People with AKD and on the waiting list.	51% Caucasians and 49% African Americans	132	White race, more education, less concern about living donor kidney transplantation, and poorer perceived health are associated with greater willingness to talk to others about living kidney donation, Themes: risk perception, Lack of knowledge
7	Barnieh et al	Barriers to living kidney donation identified by eligible candidates with end-stage renal disease DOI: 10.1093/ndt/gfq388.	2011	Canada	Questionnaires	People with AKD who are not on RRT	Unspecified	145	Not knowing how to ask someone for their kidney was the most frequently reported barrier, identified by 71% of respondents. Those that stated that living donation did not pose significant long-term health risks to the donor were more likely to pursue living kidney donation Themes: Lack of Knowledge, risk perception, guilt
8	Ismail et al	Modifiable factors in access to living donor kidney transplantation among diverse populations	2013	Netherlands	Questionnaires	People with AKD for transplant	51 % of non-Western referred origin and 49% of Western	160	Western patients scored higher in Knowledge and were more willing to communicate to potential donors

Table (2): Interviews studies

Study number	Author	Title	Year published	Location	Study design	Participants' characteristics	Ethnicity	Sample size	Important findings
14	E J Gordon	"They don't have to suffer for me": why dialysis patients refuse offers of living donor kidneys DOI: 10.1525/maq.2001.15.2.245	2001	USA	Interviews	People with AKD and on dialysis	African Americans 64%. European Americans 30%. Other 6%	79	Patients turn offers due to fear about donor's wellbeing and compromising relations with donors  Themes: Risk perception
15	Ismail et al	Psychological barriers for living kidney donation: how to inform the potential donors DOI:10.1097/01.jp.0000284981.83557.dc	2007	Netherlands	Interviews	People with AKD and on the waiting list who didn't pursue living kidney donation (91) and their potential donors (53) and a control group of those identified a living donor and started assessments for living donor transplantation (53) and their donors (51)		248	Volunteering was perceived as a condition for proceeding with the donor-recipient relationship, sense of guilt if complications happen to the donor following transplantation  Themes: Guilt
16	Boulware et al	Identifying and addressing barriers to African American and non-African American families' discussions about pre-emptive living related kidney transplantation. DOI: 10.7182/prfr.21.2.2001j18x785u10hg	2011	USA	Group interviews	People with AKD and their families	2 African American groups and 2 Non-African American groups 0% African Americans	16	Both groups of patients were concerned about how to initiate discussions, worried about burdening family members and inducing guilt.  Themes: lack of Knowledge, guilt
17	Ismail et al	Religious attitudes towards living donation among Dutch renal patients DOI: 10.1007/s11019-011-9326-z	2011	Netherlands	Interviews/focus groups	People with AKD and on the waiting list with no living donors	Non-European ethnic groups in Netherlands: Turkish, Moroccan, Surinamese, Dutch Antillean and Cape Verdean	50	Religion was not recognised as an obstacle for living donation however there are uncertainties and a lack of awareness about the position of religion regarding living organ donation within communities  Theme: Religion
18	Davies et al	Inter- and Intrapersonal Barriers to Living Donor Kidney Transplant among Black Recipients and Donors DOI: 10.1007/s40615-016-0270-8	2016	USA	Interviews	Donors and recipients	Black African Americans	20	Avoidance of severity of End stage kidney disease and desire to maintain health privacy Themes: Risk perception. "Culture of salience"
19	M A Jones, Cornwall	"It's hard to ask": examining the factors influencing decision-making among end-stage renal disease patients considering approaching family and friends for a kidney PMID: 29723174	2018	New Zealand	Interviews	People with AKD and on the waiting list with no living donors and those with living donors undergoing work up.	Six participants identified as Māori, three identified as Māori/New Zealand European, five identified as New Zealand European, and one identified as Other European	15	Reciprocity, inability to accept responsibility, worries about donor's health. Health literacy  Themes: Culture, lack of knowledge, Risk perception
20	Sandal et al	Health Professional-Identified Barriers to Living Donor Kidney Transplantation: A Qualitative Study DOI: 10.1177/2054358119828389	2019	Canada	Interviews	Transplant coordinators, dialysis nurses, and general nephrologists	Un-specified	16	Health care professionals reported better ability to convince younger patients to resort to living donation and that patients fear approaching potential donors and don't know how to formulate their donation request Themes: lack of knowledge

Table (3): Focus groups studies

Study number	Author	Title/ DOI	Year published	Location	Study design	Participants' characteristics	Ethnicity	Sample size	Important findings
21	Shilling et al	Healthcare professionals' perceptions of the barriers to living donor kidney transplantation among African Americans DOI: <a href="https://doi.org/10.1177/2054358119828389">10.1177/2054358119828389</a>	2006	USA	Focus groups	Physicians, transplant coordinators, pharmacists and a data coordinator	Health professional's ethnicity unspecified, Study targeted African Americans	18	Main barriers identified were pre-existing medical conditions, financial concerns, reluctance to ask family members and/or friends, distrust of the medical community, fear of surgery, and lack of awareness about living donor kidney transplantation Themes; Lack of Knowledge, medical mistrust, fear of financial burden, Risk perception
22	Waterman et al	Living Donation Decision Making: Recipients' Concerns and Educational Needs DOI: <a href="https://doi.org/10.1177/152692480601600105">10.1177/152692480601600105</a>	2006	USA	Focus groups	Recipients (33), donors (4) and their families (3)	Caucasians 73% African Americans 24%	40	Recipient might not pursue living kidney donation because they might feel guilty /indebted to the donor / causing harm  Themes: Risk perception, guilt
23	Alvaro et al	Living kidney donation among Hispanics: a qualitative examination of barriers and opportunities. DOI: <a href="https://doi.org/10.1177/152692480801800405">10.1177/152692480801800405</a>	2008	USA	Focus groups	All participants were aged Hispanics 16 or above	Hispanics	52	Lack of information was identified as the main barrier Themes: Lack of Knowledge
24	E J Gordon et al	Hispanic/Latino concerns about living kidney donation: a focus group study DOI: 10.7182/pit2014946	2014	USA	Focus groups	kidney transplant recipients, living kidney donors, AKD, and the general Hispanic public.	Participants were from Hispanic origin and classified to Mexican, Puerto Rican, Central or South American Other Latino	76	Knowledge deficits about LDKT and expectations of shorter life expectancy of donors following transplantation, fear of becoming unable to work, losing one's job, or being unable to pay household bills while recovering concerns with immigrant logistics  Themes: Lack of knowledge, fear of financial burden, risk perception
25	Seigel et al	Barriers to living donation among low-resource Hispanics DOI: <a href="https://doi.org/10.1177/1049732314546869">10.1177/1049732314546869</a>	2014	USA	Focus groups	Hispanic patients with chronic kidney disease	Hispanics	28	Lack of knowledge about LDKT process, fear that donors won't be able to support their families after transplantation and lack of social support because of illness Themes: Lack of knowledge, fear of financial burden

## Barriers from patients' perspective

A number of barriers were identified in these studies and described below along with corresponding study number (SN) with link in the Tables 1,2,3.

### *Lack of Knowledge*

Various aspects of knowledge are highlighted as playing a role in recipients' decision making including knowledge about renal disease, LDKT process and how and when to initiate the discussions with potential donors (SN 4,5,6,7,8,9,11,12,16,19,20,21,23,24,25). Ethnic variability was reported in the degree of knowledge as people from some BAME backgrounds were found to score lower in knowledge about the living donation process, donor eligibility and financial consequences following donation. This lack of knowledge was associated with a lower likelihood of engaging in the LDKT process and identifying a living donor (SN 4,8).

### *Risk perception*

The recipient's perception about their own health and donor's risks during and after the transplantation process has been linked to the levels of communication and willingness to introduce the concept of LDKT to potential donors across all ethnic groups (SN 1,2,3,4,5,6,7,10,11,14,18,19,21,22,24). African Americans on dialysis compared to Non-African Americans are more likely to deny the need for transplant, perceive benefits of staying on dialysis (SN 6) and have more concerns about the surgery (SN 4).

### *Religion and culture*

Despite the fact that no religion appears to explicitly forbid living or deceased organ donation<sup>(10)</sup>, recipients from non-Christian religions were found to have a lower likelihood for pursuing LDKT<sup>(7)</sup>. Ismail et al (SN 17) explored different religious attitudes towards living kidney donation in patients on the transplant waiting list with participants identifying themselves as Muslims, Christians, Buddhists and Atheists (38%, 50%, 8% and 6% respectively). Religion was not reported as a barrier to living kidney donation and the majority of the study participants had a positive attitude towards LDKT, motivated by their religious values to help others. Some people from Muslim communities had concerns around body preservation and disfigurement resulting from organ donation and transplantation. The study also highlighted uncertainties about the opinion of their own religion towards kidney donation with possible religious misinterpretations linked to community culture. Wong et al (SN 13) also reported

that religion was not perceived as a barrier to living donation, however some participants who identified as Black and Christian reported that their potential donors refrained from donation as their religion wouldn't allow them. None of those patients reported sharing the same belief as their donors. None of the studies explored views and possible reservations about living kidney donation from people within other major religious groups (eg Hinduism or Sikhism).

Various cultural behaviours were identified as potential barriers to LKD decision making. A "culture of silence" about renal disease was reported in families from (BAME) communities in the United Kingdom, restricting the patient's access to the large pool of potential donors (SN 13). The culture of reciprocity is prevalent in the Maori and Pacific communities and was reported to play a role in the decision making in LDKT: some patients refrained from asking for a kidney from a family member or loved one as it was considered too big as gift that couldn't be paid back (SN 19). No similar cultural attitudes were reported in patients from White ethnic background.

### *Guilt*

Guilt associated with requiring and asking for a kidney, has been reported as discouraging people from engaging in transplant discussions with their potential donors. Furthermore, recipients might feel guilty and indebted to the donor and refrain from accepting a kidney offer due to a concern that a family member may need the organ in future (SN 4,7,10,15,16,22).

### *Fear of financial burden*

People with AKD including those from a BAME background may have concerns about influencing financial hardship on potential donors by causing someone to lose their job and jeopardising their ability to look after their families (SN 10,12,13,21,24,25). However, those concerns are difficult to compare as health care services and social benefits are funded differently between countries. People from BAME communities in the United Kingdom are more likely than to express financial concerns preventing family members from accessing kidney donation compared to people from a white ethnicity (SN 13).

### *Medical mistrust*

Medical mistrust is an important factor affecting African Americans engagement with health services<sup>(12)</sup>. African American patients with advanced kidney disease were reported to believe that the health system treats rich people from a White ethnic background in a better way compared to others (SN 4,21).

## Health Professionals' Perspective

Only two studies explored health professionals' experiences in decision making around LKDT. Health professional views about barriers to African Americans seeking LKDT included: knowledge about LDKT, higher risk perception about the surgery, financial concerns and reluctance to engage in discussions about donation with potential donors and medical mistrust (SN 21).

Health professionals from Canada reported a greater confidence in their ability to convince younger patients to choose living donation, a finding that supports previous studies exploring factors associated with pursuing LDKT<sup>(7)</sup>. They also reported that patients fear approaching potential donors as they may not know how to formulate their donation request (SN 20).

## Discussion and conclusion

Decision making about living kidney donation is a complex process, and health professionals rely on people with AKD to initiate conversations with potential donors. This review has summarised some of the key barriers that people face when discussing potential LKDT with their family and friends. Most of the themes identified in this review were seen across all ethnic groups, however some variation was noted in the domains of knowledge, risk perception and fear of imposing a financial burden. Religious and cultural reservations as well as mistrust of the medical establishment were only identified in people from BAME communities in the Western countries.

Some of these barriers are modifiable and can be improved by targeted interventions, for example, improving knowledge and framing risk information in ways that are known to improve understanding. There was little focus on the views of individuals from diverse ethnic/religious groups in the UK particularly those from certain Muslims, Hindus and Sikhs. Despite kidney health professionals playing a key role in initiating conversations about LKD, few studies have explored their views on encouraging people to discuss donation with their friends and families.

Patient decision aids are interventions to help people make informed healthcare decisions. Unlike patient information leaflets which are aimed at improving knowledge about diseases and treatment options, patient decision aids provide evidence-based information about different aspects of each treatment option and their consequences without bias, and take into account people's values and preferences, encouraging people to make trade-offs about what is

important to them in order to reach a decision (13,14,15,16,17)

### Limitations

A scoping review method is not as comprehensive as a systematic review, may be more prone to bias and the inadvertent omission of key pieces of evidence. However adopting this method provides a screening measure to inform future research. And in this case was devised to assist in the development of a culturally sensitive multi-dimensional patient decision aid that utilises the best available evidence to facilitate conversations between the patients with kidney disease and their potential donors with particular focus on the South Asian community which constitutes the largest ethnic minority in the UK<sup>(7)</sup>.

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#### Conflict of interest

The authors have no conflict of interest to declare. The corresponding author declares that this is an original work which is not submitted/ accepted/ being considered by another journal/ publisher at the current time