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.

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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\(^1\), patient reported quality of life and morbidity profile following transplantation\(^2,3\). 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\(^4,5\). Only 14% of people with advanced kidney disease (AKD) from the BAME communities are recipients of LDKT\(^4\). 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\(^6\).

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\(^7\) 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\(^8\). Gender disparity in living kidney donation was observed in previous studies with females more likely to be donors than recipients\(^9\).

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\(^10\). 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>
<thead>
<tr>
<th>Table (1): Questionnaires/Surveys studies Click link to view</th>
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<tbody>
<tr>
<td>Study number</td>
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<td>8</td>
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</table>
### Table (2): Interviews studies

<table>
<thead>
<tr>
<th>Study number</th>
<th>Author</th>
<th>Title</th>
<th>Description</th>
<th>Location</th>
<th>Study design</th>
<th>Participants’ characteristics</th>
<th>Ethnicity</th>
<th>Sample size</th>
<th>Important findings</th>
</tr>
</thead>
<tbody>
<tr>
<td>14</td>
<td>Li, C.</td>
<td>“You Don’t Know in order to not want them” 2001 patients refuse organ donation in China</td>
<td>USA</td>
<td>Interviews</td>
<td>People with AIDS and their doctors</td>
<td>African Americans: 69%, European: 31%</td>
<td>79</td>
<td>Patients’ view that fear of brain damage and physical discomfort could delay donation.</td>
<td>Threat: Risk perception</td>
</tr>
<tr>
<td>15</td>
<td>Ismail et al.</td>
<td>Psychological barriers for living kidney donation: how to inform the potential donor</td>
<td>Netherlands</td>
<td>Interviews</td>
<td>People with AIDS and those on the waiting list, but who did not give living kidney donation (IV) and those potential donors (V) and the control group (I) identified a living donor and medical assessments for living donor transplantation (S) and their donors (S)</td>
<td>241</td>
<td>Willingness was perceived as a condition for proceeding with the transplantation relationship, sense of guilt if complications happen to the donor following transplantation</td>
<td>Threat: Guilt</td>
<td></td>
</tr>
<tr>
<td>16</td>
<td>Boulware et al.</td>
<td>Identifying and addressing barriers to African American 2011 waiting list patients in the potential donor</td>
<td>USA</td>
<td>Group interview</td>
<td>People with AIDS and their family members</td>
<td>African Americans group: 16%, African Americans: 69%, Other 9%</td>
<td>2 African American groups and 2 Non-Black African American groups</td>
<td>Risk perceptions of patients were concerned about how to initiate discussions, worried about confusing family members and taking a risk.</td>
<td>Threats: Lack of knowledge, guilt</td>
</tr>
<tr>
<td>17</td>
<td>Ismail et al.</td>
<td>Religious attitudes towards living kidney donation: 2011 Netherlands</td>
<td>Netherlands</td>
<td>Interviews</td>
<td>People with AIDS and those on the waiting list, but who did not give living kidney donation (IV) and those potential donors (V) and the control group (I) identified a living donor and medical assessments for living donor transplantation (S) and their donors (S)</td>
<td>Non-European ethnic groups: 17% African Americans: 69%, Brazilian, Mexican, Barbadian, Dutch Antillean and Cape Verdians</td>
<td>Religion was not recognized 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.</td>
<td>Threat: Religion</td>
<td></td>
</tr>
<tr>
<td>18</td>
<td>Owens et al.</td>
<td>Inter- and Intrapersonal Barriers to Living in 2016 Donor Kidney Transplant: Among Black Recipients and Donors</td>
<td>USA</td>
<td>Interviews</td>
<td>Donors and recipients</td>
<td>Black African Americans: 20%</td>
<td>Avoidance of severity of end-stage kidney disease and desire to maintain health privacy.</td>
<td>Threat: Religion</td>
<td></td>
</tr>
<tr>
<td>19</td>
<td>M. A. Brown and Cornwell</td>
<td>“It’s hard to ask” the leaving of the Donor: A qualitative study of kidney donation among end-stage renal disease patients considering approaching family to donate a kidney</td>
<td>New Zealand</td>
<td>Interviews</td>
<td>People with AIDS and those on the waiting list, but who did not give living kidney donation (IV) and those potential donors (V) and the control group (I) identified a living donor and medical assessments for living donor transplantation (S) and their donors (S)</td>
<td>Non-European ethnic groups: 17% African Americans: 69%, Brazilian, Mexican, Barbadian, Dutch Antillean and Cape Verdians</td>
<td>Recipient inability to accept responsibility, worried about donor’s well-being and death.</td>
<td>Threats: Culture, lack of knowledge, Risk perception</td>
<td></td>
</tr>
<tr>
<td>20</td>
<td>Sandell et al.</td>
<td>Health Professional’s Identified Barriers to Living in 2013 Donor Kidney Transplant: A Qualitative Study</td>
<td>Canada</td>
<td>Interviews</td>
<td>Transplant coordinators, donors, recipients, and general nephrologists</td>
<td>Unspecified</td>
<td>16</td>
<td>Patients lack of professional expertise regarding donor selection and decision-making (including risk and no information about living donor transplantation.</td>
<td>Threats: Lack of knowledge</td>
</tr>
</tbody>
</table>

### Table (3): Focus groups studies

<table>
<thead>
<tr>
<th>Study number</th>
<th>Author</th>
<th>Title</th>
<th>Description</th>
<th>Location</th>
<th>Study design</th>
<th>Participants’ characteristics</th>
<th>Ethnicity</th>
<th>Sample size</th>
<th>Important findings</th>
</tr>
</thead>
<tbody>
<tr>
<td>11</td>
<td>Shilling et al.</td>
<td>Healthcare professionals’ 2006 perceptions of the barriers to living donor kidney transplantation among African Americans</td>
<td>USA</td>
<td>Focus groups</td>
<td>Physicians, transplant coordinators, health-care professionals’ 68%</td>
<td>Ethnicity unspecified, and a detailed study targeted African Americans</td>
<td>68</td>
<td>Leap barriers identified were pre-existing medical conditions, financial concerns, reluctance to ask family members and friends, distrust of the medical community, fear of surgery, and lack of awareness about living donor kidney transplantation.</td>
<td>Themes: Lack of knowledge, medical mistrust, fear of financial burden, Risk perception</td>
</tr>
<tr>
<td>12</td>
<td>Waterman et al.</td>
<td>Making: Recipients’ Concerns and Educational Needs</td>
<td>USA</td>
<td>Focus groups</td>
<td>Recipients (33), donors/Caucasians 75%, African 40</td>
<td>(4) and their families (1); Americans 24%</td>
<td>35</td>
<td>Recipient might not pursue living kidney donation because they might feel guilty for depleting the donor causal harm</td>
<td>Themes: Risk perception, guilt</td>
</tr>
<tr>
<td>13</td>
<td>Akoare et al.</td>
<td>Living kidney donation among 2008 Hispanics</td>
<td>USA</td>
<td>Focus groups</td>
<td>All participants were Hispanics aged 16 or above</td>
<td>52</td>
<td>Lack of information was identified as the main barrier</td>
<td>Themes: Lack of knowledge</td>
<td></td>
</tr>
<tr>
<td>14</td>
<td>E.J. Gordon et al.</td>
<td>Latinos concerns about 2014 living kidney donation: a focus group study</td>
<td>USA</td>
<td>Focus groups</td>
<td>Kidney transplant; Participants were from 76 recipients, living kidney, Hispanic origin and donors, People classified as Mexican, Mexican-American, and the general Puerto Rican, Central or Hispanic public groups</td>
<td>South American Other Latino</td>
<td>Knowledge deficits about LDLT 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 immigration logistics.</td>
<td>Themes: Lack of knowledge, fear of financial burden, Risk perception</td>
<td></td>
</tr>
<tr>
<td>15</td>
<td>Segal et al.</td>
<td>Barriers to living donation among low-resource Hispanics</td>
<td>USA</td>
<td>Focus groups</td>
<td>Hispanic patients with/without long-term kidney disease</td>
<td>28</td>
<td>Lack of knowledge about LDLT process, fear that donors won’t be able to support their families after transplantation and lack of social support because of illness</td>
<td>Themes: Lack of knowledge, fear of financial burden</td>
<td></td>
</tr>
</tbody>
</table>
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 level 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 (7), recipients from non-Christian religions were found to have a lower likelihood for pursuing LDKT (7). 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 (12). 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(7). 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 (7).

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References:

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/beings considered by another journal/publisher at the current time.