BMJ Open

Paving the way for solutions improving access to kidney transplantation: a qualitative study from a multistakeholder perspective

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ABSTRACT

Objectives The aim of this study was to obtain an in-depth perspective from stakeholders involved in access to kidney transplantation to pave the way for solutions in improving access to kidney transplantation. This study qualitatively explored factors influencing optimal access to kidney transplantation from a broad stakeholder perspective.

Design A qualitative study was performed using semistructured interviews both in focus groups and with individual participants. All interviews were recorded, transcribed and coded according to the principles of grounded theory.

Setting Participants were healthcare providers (geographically spread), patients and (former living) kidney donors, policy-makers and insurers.

Participants Stakeholders (N=87) were interviewed regarding their perceptions, opinions and attitudes regarding access to kidney transplantation.

Results The problems identified by stakeholders within the domains—policy, medical, psychological, social and economic—were acknowledged by all respondents. According to respondents, more efforts should be made to make healthcare providers and patients aware of the clinical guideline for kidney transplantation. The same opinion applied to differences in medical inclusion criteria used in the different transplantation centres. Stakeholders saw room for improvement based on psychological and social themes, especially regarding the provision of information. Many stakeholders described the need to rethink the current economic model to improve access to kidney transplantation. This discussion led to a definition of the most urgent problems for which, according to the respondents, a solution must be sought to optimise access to kidney transplantation.

Conclusions Stakeholders indicated a high sense of urgency to solve barriers in patient access to kidney transplantation. Moreover, it appears that some barriers are quite straightforward to overcome; according to stakeholders, it is striking that this process has not yet been overcome. Stakeholders involved in kidney transplantation have provided directions for future solutions, and now it is possible to search for solutions with them.

STRENGTHS AND LIMITATIONS OF THIS STUDY

⇒ This large, qualitative study (N=87) involved not only patients and healthcare providers but also policymakers and insurers.
⇒ In contrast to other studies, this study examined barriers to kidney transplantation from a multistakeholder perspective.
⇒ Qualitative research presents the opportunity to obtain more in-depth stakeholder perspectives that can pave the way for clear solutions.
⇒ More interviews in focus groups would provide an even more in-depth perspective.
⇒ Data on the ‘non-responders’ in this second phase is unknown, which may be related to the outcome.

INTRODUCTION

Overview of the issue

The scientific literature regarding chronic kidney disease indicates that transplantation is the most suitable kidney replacement therapy for patients with end-stage renal disease and that pre-emptive transplantation is preferred.² Notably, a large group of kidney patients are not on a waiting list.² Many patients remain on dialysis even though transplantation is the preferred alternative.³ In many cases, a kidney from a living donor appears to be a better choice than a kidney from a postmortem donor.³ Kidneys from living kidney donors are often of better quality, which leads to survival benefits.³ Due to the extensive waiting lists for postmortem donors, a pre-emptive transplant is only possible for those patients with a living donor.³ The shortage of postmortem kidneys makes receiving a kidney from a living donor more urgent.³⁰ Previous research has shown that barriers can hamper the access to (pre-emptive) kidney transplantation.³⁰

Concern regarding equity of access to transplantation

There is a growing concern that access to kidney transplantation is consistent with neither the
clinical guidelines regarding preparation for a kidney transplantation nor the principle of equal access to healthcare.\textsuperscript{11,12} For example, elderly patients and patients with a migration background can be identified as potentially vulnerable groups regarding access to kidney transplantation, because of a language barrier to become fully informed.\textsuperscript{13,14} It also appears that a patient’s socioeconomic status also plays a role in access to kidney transplantation.\textsuperscript{15} These patients often fail to adhere to therapy, which means that a transplantation is often not an option. Patient-related factors can further influence the choice of a living donor. For example, it is known that feelings of guilt can play a role in prudent donor recruitment. In addition, a lack of social support can play a role in this.\textsuperscript{16}

**Context of the Dutch transplantation system**

In the Netherlands, kidney transplantations are only performed in the seven academic hospitals. Although nephrology centres are free to refer to any academic centre, in most cases, a patient is referred by a regional nephrologist to the nearest academic hospital. The routine preparation for transplantation and criteria for acceptance of the transplant candidate and the timing of referral are described in the Dutch guidelines published on the websites of the Dutch Federation of Nephrology, the Dutch Transplant Association and Nefrovisie.\textsuperscript{12}

Living kidney donors usually report via the transplant candidate to the recipient’s transplant centre, where they are informed and possibly prepared for kidney donation in accordance with the applicable national guidelines. Incompatible couples (AB0 and/or HLA incompatible) are given the opportunity to participate in the Nationals Kidney Exchange Programme. Altruistic kidney donors are accepted for both directed and non-anonymous donation. Allocation of kidneys from deceased donors takes place in the Netherlands via Eurotransplant. Due to a shortage of kidney donors, there is a waiting list for kidney from deceased donors, with an average waiting time of 2.2 years after starting dialysis.\textsuperscript{17}

All these issues have led to disparities in on-time access to kidney transplantation when considered from different perspectives (eg, patients, healthcare providers and policy-makers). Reducing these disparities in access to transplantation has recently been expressed as a research priority.\textsuperscript{18} Several studies have emphasised the need to bring about policy change and in line with these recommendations, it has been argued that various factors that play a role in kidney transplantation should be examined from a broad stakeholder perspective.\textsuperscript{2,19}

To solve this unmet medical need, we are conducting a three-phase study to explore potential barriers to transplant access with all stakeholders involved in kidney care.\textsuperscript{20} In phase 1, we accessed meaningful experiences, using in-depth interviews, in which stakeholders from the kidney field mentioned barriers in access to kidney transplantation (see table 1). In phase 2, as presented in this current article, we shared the insights from the various stakeholders in the first phase with the same respondents from phase 1. This can lead to an integrated view in which stakeholders provide their own opinions regarding the barriers identified by others and directions can be given for possible solutions. In a following third phase, we will seek solutions with the same stakeholders as in phases 1 and 2 to establish a direction for future policy.

The results from the first phase revealed that several barriers are known to negatively affect access to kidney transplantation and increase inequality (see figure 1, first column).\textsuperscript{21} The following five domains emerged from this phase: policy, medical, psychological, social and economic. Within the policy domain, it was mentioned that healthcare providers experience a lack of clarity regarding clinical guidelines. The medical domain emerged in that there is no consensus regarding criteria for acceptance for transplantation, for example, age, body mass index or comorbidity. Within the psychological domain, it was mentioned that fear of transplantation or positive social interactions during dialysis can relate to delays in access to kidney transplantation. The social domain emerged because a lack of an effective social network or lack of skills to activate social support systems negatively influences access to kidney transplantation. In addition, a language barrier still hampers patient access to

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**Table 1** Overview of respondents

<table>
<thead>
<tr>
<th>Stakeholders</th>
<th>Total of participants included</th>
<th>Total of participants in focus groups</th>
<th>Total of participants in individual interviews</th>
<th>Participants from the academic</th>
<th>Participants from the non-academic</th>
</tr>
</thead>
<tbody>
<tr>
<td>Nephrologists</td>
<td>18</td>
<td>15</td>
<td>3</td>
<td>9</td>
<td>9</td>
</tr>
<tr>
<td>Social workers</td>
<td>17</td>
<td>14</td>
<td>3</td>
<td>5</td>
<td>12</td>
</tr>
<tr>
<td>Nurses</td>
<td>5</td>
<td>5</td>
<td>0</td>
<td>5</td>
<td>0</td>
</tr>
<tr>
<td>Surgeons</td>
<td>5</td>
<td>5</td>
<td>0</td>
<td>5</td>
<td>0</td>
</tr>
<tr>
<td>Policy-makers</td>
<td>15</td>
<td>14</td>
<td>1</td>
<td>n/a</td>
<td>n/a</td>
</tr>
<tr>
<td>Insurance representatives</td>
<td>4</td>
<td>3</td>
<td>1</td>
<td>n/a</td>
<td>n/a</td>
</tr>
<tr>
<td>Kidney patients</td>
<td>14</td>
<td>13</td>
<td>1</td>
<td>n/a</td>
<td>n/a</td>
</tr>
<tr>
<td>Donors</td>
<td>9</td>
<td>9</td>
<td>0</td>
<td>n/a</td>
<td>n/a</td>
</tr>
<tr>
<td>Total</td>
<td>N=87</td>
<td>78</td>
<td>9</td>
<td>24</td>
<td>21</td>
</tr>
</tbody>
</table>

n/a, not available.
kidney transplantation. Furthermore, donor aftercare is not sufficient, which can lead a negative view regarding donation. Under the economic domain, it emerged that there are differences in purchasing agreements and reimbursements for dialysis and transplantation. These differences could produce economic incentives for choosing treatment paths.

**Aim of the study**

In this article, we describe the second phase of the study, in which we addressed separate stakeholder groups and explored how they reacted to the various opinions of other stakeholders. The aim of this research was to find directions for future solutions through reflection to gain more insight into what stakeholders consider as important to improve access to kidney transplantation. The following five domains, emerged from the previous research, were addressed: policy, medical, psychological, social and economic.21

**METHODS AND ANALYSIS**

**Procedure**

The theoretical basis for this qualitative study was grounded theory, which emphasises the neutral position of an interviewer.22 The themes found in our previous study were used as discussion items in the current study (see figure 1, first column).21 The interviews were conducted using a semistructured interview guide (see online supplemental appendix 1). During virtual (teams) in-depth interviews by RvM and Vincent Krijgsman (research employee), respondents provided opinions regarding themes from other stakeholders involved in kidney transplantation. These participants did not know the researcher, only from an earlier interview phase (phase 1). From these insights, we aimed to develop an overview of differences and similarities from stakeholder perspectives regarding the most urgent themes for further investigation and follow-up.

Identification of these urgent themes led to a conceptual model (see figure 1). The average interview time was 60 min. We have used COREQ criteria to report the qualitative research (see online supplemental appendix 2).23

**Patient and public involvement**

Patients were not involved in the design of the study. Participating patients will be informed regarding the results of the study by email.

**Interviewees**

The interviews were initially conducted in homogeneous focus groups with an average of three participants from the following groups: patients, donors, social workers, nephrologists, surgeons, nurses, policy employees and insurance representatives. Later, the focus group interviews were supplemented with one-on-one interviews to include informants with busy agendas.

The stakeholders were identified according to the selected sample method.24 Thus, respondents who were considered as representative for this study were selected. Participants were approached by RvM and Vincent Krijgsman. Notably, healthcare providers were selected based on their positions in academic and non-academic hospitals. Later, the

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![Figure 1](http://bmjopen.bmj.com/first-published-as-10.1136/bmjopen-2022-071483-on-1-june-2023-downloaded-from-bmjopen.bmj.com)
participating stakeholders helped to search for other stakeholders using the snowball method. Participants were also selected with respect to demographic spread. Kidney patients were adults 18 years of age or older. They had been preemptively and non-preemptively transplanted with kidneys from living kidney donors and had been identified by the participating healthcare providers in this study. During the first phase of the study, new stakeholders were added until a point of saturation occurred, as is common in grounded theory. Participants in the second phase had also participated in the first phase (table 1). In the first phase of the study, 117 participants were involved; in this second phase, 87 participants were involved. The lost to follow-up (26%) was mostly due to the full agendas of healthcare providers, often related to the COVID-19 pandemic. A number of other respondents decided to end participation in the study due to retirement or movement to a different job. All participants provided written informed consent. Participants were not asked to comment on the findings from this current study.

**Data collection**

Interviews were conducted (RvM) based on the following domains: policy, medical, psychological, social and economic. Every domain contained one or more subthemes (figure 1).

**Data analysis**

All textual data was coded using NVivo software. Text elements, as spoken by the interviewees, were given codes representing their content. Based on this inductive approach, a conceptual model was developed based on the codes (see figure 1). In the first coding phase, text elements were labelled and sorted into open codes. In the second phase of the coding process, open codes were grouped if closely related; if a code was not relevant, it was eliminated. Axial coding was applied in the third phase of the coding process. In this phase, open codes were categorised into subthemes. The fourth and final phase of the coding process consisted of selective coding. Grouping of codes led to a code tree with branches in which the material from the first three phases was classified into key themes that could be used for the final analysis.

All interviews were coded twice, by two coders (RvM and Vincent Krijsman), leading to two code trees. The decision to use a second coder eliminated any blind spots exhibited by the first coder and increased the inter-rater reliability of the analysis. To further improve reliability, an input meeting was organised with the research team and both coders to discuss and identify possible blind spots. This process was repeated each time 20 interviews were coded. After each input meeting, a consensus meeting was held with the authors and second coder. The consensus meeting led to the identification of similarities and differences between the two coding trees. These coding trees were integrated into a conceptual model (see figure 1). The conceptual model shows the domains and underlying subthemes (on the left) about which stakeholders had been asked for opinions. The complexity gap (in the centre) shows the priority stakeholders had placed on a follow-up for these domains and subthemes in the current study.

**RESULTS**

Of the 117 informants who had participated in the first phase, 87 were able to participate in the second phase. This study included 14 patients, 9 donors, 17 social workers, 18 nephrologists, 5 surgeons, 5 nurses, 15 policy employees and 4 insurance representatives.

The five domains and the discussion themes are presented below. The conceptual model that we deduced from the analysis is presented in figure 1. The results are presented below, along with brief introductions of the discussion items found in the first phase of the study and the outcome of the current study. Each result is supported with a quotation (see online supplemental appendix 3).

**Policy related**

**Use of different guidelines**

The previous study showed that having guidelines for kidney transplantation, which include consideration of whether a patient is considered suitable for a kidney transplantation, does not always lead to a uniform way of thinking. For example, participants in the first phase claimed that guidelines were only for preparation, could not be found, or were not available, even though a national guideline was available.

In the current study, all healthcare providers and policymakers were made aware of the existence of a Dutch national guideline prior to discussing this domain. In all groups, respondents were convinced that guidelines should be interpreted identically in all hospitals. Most respondents suggested that the guidelines should also be straightforward for patients to locate. A more remarkable finding was that even after being presented with the existence of a Dutch national guideline, a group of healthcare providers persisted in asserting that the guidelines do not exist or is not the accepted guideline for the field.

**Lack of clarity regarding roles**

In the current study, it became apparent that some healthcare providers, especially nephrologists, surgeons and social workers, found it difficult to identify their role in the complex decision-making process surrounding transplantation due to the many stakeholders involved. There was not always agreement regarding who is responsible for providing timely and sufficient information to the kidney patient and the donor. In addition, there was not always consensus regarding who should undertake the final weighting of the transplant criteria.

In the current study, most respondents were surprised by the reported need for more clarity regarding roles and responsibilities in the transplantation process. It is a remarkable finding that not all caregivers were aware of the differences in the division of roles. Notably, healthcare providers unanimously agreed that the roles and
Responsibilities must be clear, but most of them argued that the roles were clear from their own perspectives. Respondents agreed that lack of clarity can lead to confusion about the process in general, and for patients specifically, most likely leading to suboptimal care.

**Medical**

**Use of different criteria for transplantation**

In the previous study, respondents reported that different transplant centres maintain different acceptance criteria regarding comorbidity (e.g., obesity and fragility) and age. This variation leads to different referrals and acceptance of patients for kidney transplantation.

In the current study, some respondents, more often healthcare providers, reported that using different criteria is not necessarily a problem as long as the healthcare providers and the patients are informed and, if indicated, are referred to other centres in a timely way. Another group of respondents stressed that criteria should be identical at all centres. It is remarkable that in many cases the differences in medical criteria were not clear to most stakeholders, while they were aware that awareness is important for healthcare providers and patients.

**Psychological**

**Motivating factors for (extended) dialysis**

In the previous study, respondents reported that a small proportion of patients experience positive social effects when undergoing dialysis through interactions among the patients themselves and between patients and medical staff. This effect could possibly lead to an incentive to dialyse longer than necessary. In the current study, patients often could not imagine this motivation. Other respondents—in particular healthcare providers and policy-makers—stressed patients’ choice to continue dialysis for longer periods but believed that efforts should be made towards discouraging dialysis if possible. Other stakeholders, such as policy-makers and insurers, were less aware of this issue. Most patients and donors could not imagine at all that patients would desire to undergo dialysis for a longer period than necessary. Most respondents from all groups agreed unanimously that motivation for longer dialysis should not be based on acquiring social contacts and that solutions should be sought for this concern. An unexpected finding was that a small group of respondents, mostly the group of policy-makers and insurers, believed that it should not always be a choice to be able to continue dialysis for longer periods due to high costs.

**Fear as a delaying or excluding factor for transplantation**

In the previous study, respondents reported that some patients’ fears and worries regarding transplantation had led to longer times on dialysis. A small group of healthcare providers indicated that this barrier is difficult to remove.

The results of the current study suggest that most respondents recognised a fear of transplantation in some patients. Some respondents, especially healthcare providers, attributed this to the fact that not every transplant goes well. These patients return to dialysis, which can increase fear in a patient who is yet to be transplanted. Nevertheless, all respondents agreed that the effort to eliminate fear must be maximised.

**Social**

**Limited social network**

In the previous study, it became apparent that many patients fail to find a living donor, usually because of limited social networks.

Respondents in the current study, especially healthcare providers, recognised this problem but simultaneously reported significant development in supporting patients and their social networks. However, as expected, most respondents agreed that social support interventions still require further development.

**Language barriers**

Respondents in the previous study, especially healthcare providers, indicated that the available information regarding transplantation and donation is less effective for patients who have language barriers or are of non-Dutch origin.

Most respondents in the current study, especially healthcare providers, recognised this problem as well. Healthcare providers indicated that much is already being done, including the deployment of interpreters. Moreover, the Kidney Team at Home (a tailored, home-based educational intervention programme) was a frequently mentioned example by which kidney patients can receive information regarding kidney failure and kidney replacement therapy together with their family and other members of their social network, in their home environment. A more remarkable finding was that some respondents stated that it is the patient’s responsibility to learn the Dutch language. Nevertheless, most respondents in all stakeholder groups unanimously agreed that the language barrier deserves more attention.

**Differences in aftercare between patients and donors**

In the previous study, respondents reported that aftercare for donors deserves attention. According to most respondents, donors are an indispensable link in promoting a transplant; however, a donor’s possible disappointment after transplantation can reduce the enthusiasm of new donors to donate. Among the respondents, a group of kidney patients and donors indicated that the donors experienced insufficient contact with the hospital after the transplantation or during aftercare.

In the current study, healthcare providers often did not recognise a lack of aftercare. Most patients and donors recognised the lack of aftercare and were convinced that the care of donors requires more attention. Some healthcare providers explained the perceived lack of aftercare, stating that after a while, the donor is no longer seen as a patient who needs treatment. In addition, they suggested
that donors who miss aftercare are ‘calling for appreciation’ and that this is not only a medical issue. The results show that, according to most respondents in all stakeholders’ groups, a lack of aftercare can be seen as an important barrier for donors. All stakeholders agreed that aftercare must be well organised for donors, usually due to their special merit and motivation in donating a kidney and also because a perceived lack of aftercare can negatively influence the availability of future donors.

Economic
Differences in financial agreements and incentives
In the Dutch setting, hospitals receive payment per diagnosis–treatment combinations. Residents are insured for care and the healthcare provider declares the costs of a treatment directly to the healthcare insurer. Furthermore, academic hospitals can receive extra funding for specialised (transplant) care. In the Netherlands, kidney transplants are only performed in academic centres. Thus, a peripheral centre must refer to an academic centre for kidney transplantations. In the previous study, respondents reported that insurers do not always apply the same purchasing prices for dialysis treatment and that in some cases, financial arrangements include production agreements. All respondents other than patients and donors (because of their lack of knowledge regarding this subject) reported that kidney transplantation would be more cost-effective than dialysis treatment. Some policymakers and insurers were convinced that using different purchase prices could incentivise a preference for dialysis.

Remarkably, in the current study, patients and donors expressed shock that economic factors can play a role in the kidney transplantation process. A group of healthcare providers, patients and donors indicated that this is a difficult domain and that their knowledge of the subject was insufficient. Healthcare providers agreed that optimal care should be prioritised in all cases; according to this group, economic motivations are not desirable. Many healthcare providers claimed that economic factors do not play a role in the care they deliver. Conversely, a small group of healthcare providers and nearly all policymakers and insurers stated that financial incentives are likely to play a role. They suggested that this fact is evident because of healthcare market forces, such as paying per treatment, in the Netherlands. Most stakeholders expressed doubts regarding the contribution to optimal care by a revenue model in favour of dialysis.

Similar to previous research, this study has indicated that, despite the existence of a guideline, the intended target group is not always aware of its availability.21 The current findings show that most stakeholders are convinced that there should be no ambiguity among healthcare providers regarding the availability or findability of the current guidelines. Most stakeholders also suggested that the guidelines should be more accessible to patients. Our research has demonstrated that their existence is often unknown by patients and that findability needs more priority; it is remarkable that even though guidelines are available for healthcare providers and patients, they cannot always be found. Awareness of guidelines has been assumed to lead to uniform care; however, the quality of care deteriorates if there are no guidelines.27 For this reason, the urgency expressed by stakeholders to bring awareness and findability of guidelines to the attention of stakeholders is understandable.

Previous research has found that the division of roles and responsibilities within the entire transplantation process is not always clear for healthcare providers.24 The present findings indicate that stakeholders agree that this lack of clarity leads to confusion and suboptimal care. It is also known that a clear division of roles leads to better care for the patient.28 It is, therefore, understandable that stakeholders argued for a clearer division of roles in a centre to optimise kidney care.

The referring nephrologists and transplant centres do not always use the same medical criteria to deem a patient suitable for a kidney transplant.21 The current study has demonstrated that opinions can be divided into two groups. Some stakeholders stated that medical criteria in the various centres can be different, provided that they are transparent for healthcare providers and patients. Other stakeholders indicated that the medical criteria for acceptance for transplantation should be the same everywhere. However, previous research has indicated that not all criteria are objective (eg, the trade-off between the risk of transplantation and the gain in quality of life and survival of the patient in complex cases).7 Our findings emphasise need for increased transparency regarding how various medical criteria are evaluated, for both healthcare professionals and patients.

Fears of transplantation as well as social interactions and the structure offered by dialysis have led to more extended dialysis periods than necessary for a group of patients, despite the possibility of transplantation.21 Previous studies have also revealed an association between fear of transplantation and a patient’s choice to delay this treatment.29 30 In the current study, stakeholders unanimously agreed that everything possible must be done to remove barriers that block the option of transplantation. Furthermore, some stakeholders questioned the non-commital nature of the choice patients make to continue dialysis for longer when a better and cheaper treatment, in this case a kidney transplant, is available for them. This observation is remarkable because shared decision-making in
which the patient has an important voice in the desired treatment is becoming increasingly used in healthcare. Previous studies have demonstrated the importance of involving patients’ social networks when discussing treatment options for kidney failure. Our current findings show that even though many improvements have already been made (eg, the Kidney Team at Home), the use of social media channels deserves more attention. Previous research has shown that language barriers can lead to patients’ not being fully informed regarding the transplantation trajectory. The literature indicates that many initiatives exist regarding this subject, for example, the deployment of an interpreter or the Kidney Team at Home, through which kidney patients can receive information about kidney failure and kidney replacement therapy together with their family and other members of their social network in a home environment. A group of stakeholders was surprised that language problems still play a role because there are many (digital) possibilities to solve this deficiency (eg, use of a translation application). According to the stakeholders, efforts to bridge potential language barriers should continue to be explored, and existing interventions can be better used. It should be noted that translation by a family member is not always the ideal solution because the translator may not understand the terminology of medical science.

Due to the higher quality of organs from living donors and the shortage of postmortem donors, it is important to optimise the motivation for living donation or to improve it even further. Some former donors indicated that their expectations of aftercare were only sometimes met. According to stakeholders, expressions of disappointment by former donors could lead to reduced motivation for living kidney donation by future donors. In the current study, many stakeholders recognised differences in donor aftercare among transplant centres. Donor motivation has also been discussed widely in the literature, with long-term regret and psychological factors specified as playing a role. All respondents agreed that donors should be given adequate attention and care, so that they do not feel abandoned, and that they should be able to reflect on their donations with satisfaction.

Regarding the economic theme, the current study found that stakeholders were surprised by the possible existence and influence of financial incentives for dialysis over transplantation. Most stakeholders expressed differing views regarding the direction that current financial incentives could influence and argued for a different structure. Similarly, other studies have recognised an intense debate regarding the benefits of complex financial incentives in healthcare. In the Netherlands in particular, financial incentives have become more popular since 2006 due to the introduction of a free market structure in healthcare. This introduction may have been beneficial in other sectors, but in the case of dialysis and transplantation, the incentives must remain in line with optimal patient care and could lead to higher costs for society otherwise.

**Strength and limitations**

This multistakeholder qualitative research has contributed to gaining a more common perspective on what stakeholders involved in kidney care consider as important to improve access to kidney transplantation. As a limitation it can be argued that more interviews in focus groups would provide an even more in-depth perspective. However, the number of responders in this study is already large for a qualitative investigation, and it is the largest study of its kind in kidney transplantation. Another limitation could be that we have not been able to assure that all perspectives are indeed represented, as unwilling ‘non-responders’ may well represent a relevant perspective and because responders closer to our own network are more likely to participate. Finally, perhaps a mixed stakeholder focus group could have shed more light on the dynamics of the discussion and hence guided the results towards more integration.

**CONCLUSIONS**

The results indicate room for improvement in achieving equal access to kidney transplantation. Stakeholders involved in kidney care recognise a high sense of urgency to solve barriers in access to kidney transplantation based on different factors. Moreover, it appears that some barriers do not seem excessively complicated to overcome, and familiarity with guidelines and medical criteria for healthcare providers and patients are candidates to be solved in the short term. Furthermore, stakeholders also see room for improvement in psychological and social themes, especially regarding the provision of information. This study also found that many stakeholders are aware of economic influences on kidney care and acknowledge a need for a change to improve access to kidney transplantation.

**Implications for further research**

These findings indicate room for improvement by formulating policy changes to allow better access to kidney transplantation. Further research is needed to discover solutions for the barriers and to develop implementation strategies. Therefore, further research could seek solutions based on the above themes identified by the stakeholder groups involved in this study. More research is also necessary to find ways to unite the different interests in the economic field.

**Practical implications**

A solution-oriented approach to solving the economic barriers should provide a broader understanding of the functioning of economic systems in healthcare and how these systems can be adjusted without interruption of care. As stated in the introduction, in the third phase of our study, we will stimulate the stakeholders to arrive at suggestions that could accommodate different points of view and achieve a more productive ‘business ecosystem’ in kidney transplantation.
Acknowledgements We would like to thank all the participants who were involved in this study, including policy-makers, insurers, nephrologists, surgeons, nurses, social workers, patients, donors and the advisory board.

Contributors RVm, JvWB, JvWdW and SI contributed to conceptualisation, validation, methodology, writing, data curation, reviewing and editing, original draft preparation, visualisation and investigation. All authors read and approved the final version of this manuscript.

Funding This work was supported by the Kidney Foundation, with grant number 17SWO1. 2022.

Competing interests None declared.

Patient and public involvement Patients and/or the public were not involved in the design, or conduct, or reporting, or dissemination plans of this research.

Patient consent for publication Not applicable.

Ethics approval This study involves human participants and this study was approved by the Medical Ethical Committee of Erasmus MC, Rotterdam, Netherlands, and registered under MEC-2018-1473. Participants gave informed consent to participate in the study before taking part.

Provenance and peer review Not commissioned; externally peer reviewed.

Data availability statement Data are available on reasonable request.

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