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Stakeholders involved in kidney care giving direction for future policy: a qualitative study from a multi-stakeholders' perspective

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3 **Stakeholders involved in kidney care giving direction for future policy: a qualitative study from a**
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5
6 **multi-stakeholders' perspective**

7
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37 **Keywords**

38 health services accessibility, communication barriers, kidney disease, kidney transplantation,
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40 stakeholder participation
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Abstract

Objectives

The aim was to obtain more in-depth perspectives from stakeholders themselves involved in access to kidney transplantation, paving the way for clear solutions that improve access to kidney transplantation. Therefore, this study qualitatively explores the factors influencing optimal access to kidney transplantation from a broad stakeholder perspective.

Design

A qualitative study was performed using semi-structured interview. All interviews were recorded, transcribed and coded.

Setting

Participants are healthcare providers (geographical spread), patients and (former living) kidney donors, policy makers and insurers.

Participants

Stakeholders (N = 87), including nephrologists, patients, former living kidney donors, social workers, surgeons, nurses, policymakers, and insurance representatives, were interviewed about their perceptions, opinions, and attitudes regarding access to kidney transplantation.

Results

The problems identified by the different stakeholders within the defined domains – policy, medical, psychological, social and economic – were acknowledged by all respondents. The discussion has led

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3 to a definition of the most urgent problems, for which, according to the respondents, a solution must
4
5 be sought to optimize access to kidney transplantation.
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10 **Conclusions**

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12 More attention should be paid to make healthcare providers and patients aware of the clinical
13
14 guidelines for kidney transplantation. The same applies to familiarity with differences in medical
15
16 criteria. Stakeholders see room for improvement on psychological and social themes, especially
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18 regarding information. Many stakeholders see the need to rethink the current economic model to
19
20 improve access to kidney transplantation. Now that stakeholders involved in kidney transplantation
21
22 have given directions for future solutions, it is possible to try to find solutions with them.
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29 **Article summary**

30 **Strengths and limitations of this study**

- 31
32 • This large qualitative study (N=87) not only involves patients or healthcare providers, but also
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34 policymakers and insurers.
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- 37
38 • Unlike other studies, this study examines barriers to kidney transplantation from a multi-
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40 stakeholder perspective.
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- 43
44 • Qualitative research gives the opportunity to obtain more in-depth perspectives from
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46 stakeholders that pave the way for clear solutions.
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50 **Word count**

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52 3998
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Introduction

The scientific literature for kidney disease indicates that transplantation is the most suitable kidney replacement therapy for patients with end-stage kidney disease (ESRD) and that pre-emptive transplantation is preferred (1). Notably, a large group of kidney patients are not on a waiting list (2). Many patients remain on dialysis even though transplantations are the preferred alternative (3). In many cases, a kidney from a pre-emptive donor appears to be better than a kidney from a post-mortem donor (4). Kidneys from pre-emptive donors are often of better quality, which leads to survival benefits (5). Due to the long waiting lists for post-mortem donors, a pre-emptive transplant is only possible for those patients with a living donor (6-8). The shortage of post-mortem kidneys makes receiving a kidney from a living donor more urgent (9, 10). Previous research has shown that barriers can hamper the access to a (pre-emptive) kidney transplant (11). There is growing concern that access to transplantation is neither consistent with clinical guidelines nor with the principle of equal access to health care (12). Furthermore, elderly patients and patients with a migration background can be identified as potentially vulnerable groups regarding access to transplantation (13, 14). It appears that a patient's socioeconomic status plays a role in access to kidney transplantation (15). These patients often fail to adhere to the therapy, so a transplant is often not an option. In the Dutch setting, regional nephrology centers refer to seven academic hospitals. In most cases, a referral is made to the nearest hospital. This means they generally refer to one center, although they are free to refer to any academic center. Another factor that also influences a timely referral for transplant is comorbidity (16). Patient-related factors can also influence the choice of a living donor. For example, it is known that feelings of guilt can play a role in prudent donor recruitment. Furthermore, a lack of social support can also play a role (17).

All these issues lead to disparities in on-time access to kidney transplantation when considered from different perspectives (e.g., patients, healthcare providers, and policymakers). Reducing these disparities in access to transplantation has recently been expressed as a research priority (18). Several

1
2
3 studies emphasize the need to bring about policy change. In line with these recommendations, it is
4
5 argued that various factors that play a role in kidney transplantation should be examined from a broad
6
7 stakeholder perspective (19, 20). To solve this unmet medical need, we conducted a three-phase study
8
9 to explore potential barriers to transplant access with all stakeholders involved in kidney care.
10
11 Qualitative investigations can map complex policy issues where stakeholders have different opinions
12
13 and preferences (21). The results from the first phase revealed that several barriers are known to
14
15 negatively affect access to kidney transplantation and increase inequality. In this current study, we
16
17 describe the second phase in which we confronted separate stakeholder groups and explored how they
18
19 reacted to the different views of other stakeholders. This led to a reflection in which stakeholders
20
21 expressed their own opinion about the barriers identified by others and provide directions by
22
23 stakeholders themselves for future solutions. The following five domains were discussed: policy,
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25 medical, psychological, social and economic.
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33 **Method and analysis**

34 *Procedure*

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38 The theoretical basis for this qualitative study is grounded theory, which emphasizes the interviewer's
39
40 neutral position. In this respect, grounded theory is the opposite of the more familiar forms of
41
42 thematic approaches or thematic analysis, where the discussion between the interviewer and
43
44 informant is led by a predefined domain list (22). The themes found in our previous study were used
45
46 as discussion items in the current study (23). During in-depth interviews, respondents provided their
47
48 opinions on themes from other stakeholders involved in kidney transplantation. With these insights,
49
50 we aimed to develop an overview of differences and similarities from stakeholders' perspectives on
51
52 the most urgent themes for further investigation and follow-up. Identifying these urgent themes led to
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3 a conceptual model (see Figure 1). The protocol was approved by The Medical Ethical Committee of
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5 Erasmus MC Rotterdam, registered under MEC-2018–1473.
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10 *Patient and public involvement*

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12 Patients were not involved in the design of the study. Participating patients will be informed about the
13
14 results of the study by e-mail.
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18 *Informants*

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20 The interviews were initially conducted in homogeneous focus groups comprising patients, donors,
21
22 social workers, nephrologists, surgeons, nurses, policy employees, and insurance representatives.
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26 Later, the focus group interviews were supplemented with one-to-one interviews to include informants
27
28 with busy agendas.
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31 The stakeholders were identified according to the selected sample method (24). Notably,
32
33 healthcare providers were selected based on positions in academic and non-academic hospitals to
34
35 understand the similarities and differences. Later, the participating stakeholders helped to search for
36
37 other stakeholders – the snowball method (24). The kidney patients are adults 18 years of age or older.
38
39 They have been pre-emptively and non-pre-emptively transplanted and were identified by the
40
41 participating healthcare providers in this study. During the first phase of the study, new stakeholders
42
43 were added until a point of saturation occurred, as is common in grounded theory (24). The subjects in
44
45 the second phase also participated in our previous study (Table 1). All participants gave informed
46
47 consent.
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53

54 **Table 1.** Overview of respondents

56 Respondents	57 Realized
58 Nephrologists	59 18

Kidney patients	14
Donors	9
Social workers	17
Policymakers	15
Nurses	5
Surgeons	5
Insurance representatives	4
Total	N = 87

Data collection

The interviews were conducted based on the following domains: policy, medical, psychological, social and economic regarding access to kidney transplantation. Every domain contained two or three themes. In this study, we defined themes in each domain that hamper equal access to transplantation. For instance, under the policy domain, it was mentioned that the clinical guidelines were often unknown among professionals or that professionals disagreed with the content of the guidelines. Notably, different stakeholders hold different views on these matters. The first theme was that access to transplantation relies heavily on well-informed patients, (potential) kidney donors, and health professionals. Despite the existence of national clinical guidelines, participants reported that they are ambiguous. Another group of themes was that patient and donor decision-making is hampered by a lack of information about the different options, fears, and difficulties with the complex process that involves multiple stakeholders. Financial incentives can influence access as they are not always aimed at encouraging early referral to kidney transplantation. The ethics domain ethics was incorporated as a common thread through the other domains.

Data analysis

All interviews were recorded, transcribed verbatim, and all the textual data was coded using NVivo- software. Text elements, as spoken by the informants, were given codes representing their content. For example, if a health care provider expressed that “the economic incentives are a terrible fact,” this text was coded as “economic incentives, terrible fact.” Based on this inductive approach, a conceptual model was developed based on the codes (see Figure 1). Codes were grouped into themes in several steps to arrive at a final model. In the first coding phase, text elements were labeled and sorted into open codes. In the second phase of the coding process, the open codes were grouped if closely related or, if the 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 categorized into subthemes. The fourth and final phase of the coding process consisted of selective coding. This grouping of codes led to a code tree with branches where the material from the first three phases was classified into key themes that could be used for the final analysis (24).

All interviews were coded twice, by two coders, which led to two code trees. The decision to use a second coder eliminates any blind spots by the first coder; this increases the interrater reliability of the analysis (25). To further improve reliability, an input meeting was organized 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 were integrated into a final code tree from which the subthemes for each domain and a final conceptual model followed (see Figure 1). The conceptual model shows the domains and underlying subthemes (on the left) about which stakeholders were asked for their opinions. The complexity gap (in the middle) shows the priority stakeholders gave to a follow-up for these domains and subthemes in this current study.

Results

Of the 117 informants that had participated in the first phase, 87 were able and willing to participate in the second phase. The present 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. Stakeholders' responses follow each theme. The conceptual model that we deduced from the analysis is presented in Figure 1. The results are presented below 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 quote (see Appendix 1).

Policy-related

Use of different guidelines

In the previous study, it became apparent that having guidelines for 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 guidelines prior to discussing this domain. In all groups, respondents were convinced that these guidelines should be interpreted identically in all hospitals. Notably, even after presenting the guideline references, a group of care providers persisted in claiming that the guideline did not apply as the accepted guidelines for the field or that several conflicting guidelines exist. Most stakeholders suggested that the guidelines should also be easy to find for patients.

Lack of clarity about roles

In the previous study, it became apparent that some healthcare providers, especially nephrologists, surgeons, and social workers, find it difficult to identify their role in the complex decision-making process surrounding transplantation due to the many stakeholders involved. There is not always agreement about who is responsible for providing timely and sufficient information to the kidney patient and the donor. In addition, there is not always consensus about who undertakes the final weighting of the transplant criteria. In the current study, most respondents were surprised by the reported need for more clarity on the roles and responsibilities in the transplantation process. Notably, healthcare providers unanimously agreed that the roles and responsibilities must be clear but most of them argued that from their own perspectives, the roles are clear. Respondents agreed that lack of clarity leads to confusion about the process in general, and for patients specifically, which will most likely lead to suboptimal care.

3.2 Medical

Use of different criteria for transplantation

In the previous study, respondents reported that different transplant centers have different acceptance criteria regarding comorbidity (e.g., obesity and fragility) and age. This leads to different referrals and acceptance of patients for kidney transplantation. In the current study, some respondents reported that using different criteria is not necessarily a problem as long as the healthcare providers and the patients are informed and possibly redirected to other centers if more applicable. Another group of respondents stressed that criteria should be identical at all centers.

Psychological

Motivating factors for (extended) dialysis

In the previous study, respondents reported that a small group of patients experience positive social effects when undergoing dialysis through interaction between patients themselves and between patients and medical staff and as to their opinion is. This could possibly lead to an incentive to dialyze longer than necessary. In the current study, patients could often not imagine this motivation. Other respondents – caregivers and policymakers – believe a patient’s choice to continue dialysis for longer but believe that the effort should be aimed at discouraging dialysis. 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. A small group of respondents, mostly the group of policymakers and insurers, believe that it should not always be a choice to be able to continue dialysis for longer 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 about transplantation lead to a longer dialysis time. A small group of health care providers indicated that this barrier is difficult to remove. The results of the current study suggest that most respondents recognize the fear of transplantation in some patients. Some respondents, especially healthcare providers, attribute this to the fact that not every transplant goes well. These patients return to dialysis, which can increase the fear of a patient yet to be transplanted. Still, all respondents agree that the effort to eliminate fear must be maximized.

Social

Limited social network

1
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3 In the previous study, it became apparent that many patients fail to find a living donor, usually because
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5 of limited social networks. The current study reveals that respondents, especially health care providers,
6
7 recognize this problem but simultaneously indicate significant development in supporting patients and
8
9 their social networks. However, most respondents agree that social support interventions still need
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11 further development.
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16 17 *Language barriers*

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19 In the previous study, respondents, especially health care providers, indicated that the available
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21 information about transplantation and donation is less effective for patients with language barriers or
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23 of non-Dutch origin. The current study reveals that most respondents, especially health care providers,
24
25 recognize this problem. Care providers indicated that much is already being done, including the
26
27 deployment of an interpreter. Moreover, the Kidney Team at Home (a tailored, home-based
28
29 educational intervention program) was a frequently mentioned example where kidney patients receive
30
31 information about kidney failure and kidney replacement therapy together with their family and other
32
33 members of their social network in their home environment. Some respondents believed it is the
34
35 patient's responsibility to learn the Dutch language. Nevertheless, respondents unanimously agreed
36
37 that the language barrier deserves more attention.
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45 *Differences in aftercare between patients and donors*

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47 In the previous study, respondents reported that aftercare for donors deserves attention. According to
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49 most respondents, donors are an indispensable link to promoting a transplant; however, a donor's
50
51 possible disappointment after transplantation can reduce new donors' enthusiasm to donate.
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53 Respondents reported that a group of kidney patients and donors indicated that the donors miss
54
55 sufficient contact with the hospital after the transplant or aftercare. In the current study, care providers
56
57 often do not recognize the lack of aftercare. Patients and donors recognize the lack of aftercare and are
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1
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3 convinced that the care of donors needs more attention. Some health care providers explained the
4
5 perceived lack of aftercare, stating that after a while, the donor is no longer seen as a patient needing
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7 treatment. In addition, they suggested that donors who miss after care are “calling for appreciation,”
8
9 and this is not a medical issue. All stakeholders agreed that aftercare must be well organized for
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11 donors, usually because of their special merit and motivation in donating a kidney and also because a
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13 perceived lack of after care can negatively influence the availability of future donors.
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19 *Economic*

20 21 22 23 24 *Differences in financial agreements and incentives*

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26 In the previous study, respondents reported that insurers do not always apply the same purchasing
27
28 prices for dialysis treatment and that, in some cases, financial arrangements include production
29
30 agreements. All respondents, except patients and donors (because of their lack of knowledge on this
31
32 subject), reported that kidney transplantation would be more cost-effective than dialysis treatment.
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34 Some policymakers and insurers were convinced that using different purchase prices could incentivize
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36 a preference for dialysis. In the current study, patients and donors expressed shock that economic
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38 factors can play a role in the kidney transplantation process. A group of caregivers, patients, and
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40 donors indicated that this is a difficult domain. They reported that their knowledge of the subject was
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42 insufficient. Healthcare providers agreed that optimal care should be prioritized in all cases. According
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44 to this group, economic motives are not desirable. Many health care providers claimed that economic
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46 factors do not play a role in the care they deliver. Conversely, a small group of healthcare providers
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48 and almost all policymakers and insurers believe financial incentives are likely to play a role. They
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50 suggested it is evident because of the healthcare market forces in the Netherlands, such as paying per
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52 treatment. Most stakeholders expressed their doubts about the contribution of a revenue model in favor
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54 of dialysis to optimal care.
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Discussion

The problems identified by the different stakeholders within the defined domains (policy, medical, psychological, social and economic) were acknowledged by all respondents. The discussion led to a definition of the most urgent problems for which, according to the stakeholders, a solution must be sought to optimize access to transplantation.

Similar to previous research, this study indicated that, despite the existence of guidelines, the intended target group is not always aware of them (23). The current research showed that most stakeholders are convinced that there should be no ambiguity among healthcare providers about the availability or findability of the current guidelines. Most stakeholders also suggested that the guidelines should be more accessible to patients. Although the guideline is translated for patients, our research demonstrates that its existence is often unknown and that findability needs more priority. It is remarkable that even though guidelines are available for healthcare providers and patients, they cannot be found. Awareness of guidelines is known to lead to uniform care (1). However, the quality of care deteriorates if there are no guidelines. For this reason, the urgency expressed by stakeholders to bring the awareness and findability of the guidelines to the attention of stakeholders is understandable.

Previous research found that the division of roles and responsibilities within the entire transplantation process is not always clear for healthcare providers (23). This current study shows that stakeholders agree that this lack of clarity leads to confusion and suboptimal care. It is also known that a clear division of roles improves job satisfaction and thus ensures less turnover in teams (2). It is, therefore, understandable that stakeholders argue for a clearer division of roles in a center.

The referring nephrologists and transplant centers do not always use the same medical criteria to deem a patient suitable for a kidney transplant (23). This current study demonstrates that opinions can be divided into two groups. Some stakeholders believe that medical criteria in the various centers can be different, provided they are transparent for care providers and patients. Other stakeholders

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2
3 believe that the medical criteria for acceptance for transplantation should be the same everywhere.

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6 However, previous research indicated that not all criteria are objective (e.g., the trade-off between the
7
8 risk of transplantation and the gain in quality of life and survival of the patient in complex cases) (8).

9
10 Our research emphasizes the need for more transparency in how various medical criteria are handled,
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12 for both healthcare professionals and patients.

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14
15 Fears for transplantation and social interaction and the structure offered on dialysis leads to a
16
17 more extended dialysis period than necessary for a group of patients, despite transplantation being
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19 possible (23, 26). Previous studies have also revealed an association between fear of transplantation
20
21 and a patient's choice to delay this treatment (23, 27). In this current study stakeholders unanimously
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23 agreed that everything must be done to remove barriers that block the possible option of
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25 transplantation. Furthermore, some stakeholders question the non-committal nature of this choice
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27 when a better and cheaper treatment, in this case, a kidney transplant, is available. This is remarkable
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29 because shared decision-making is increasingly used in healthcare, whereby the patient has an
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31 important voice in the desired treatment (4).

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38 Previous studies demonstrate the importance of involving patients' social networks when discussing
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40 treatment options for kidney failure (27). This current research shows that even though many
41
42 improvements have already been made (e.g., a kidney team at home), the use of social media channels
43
44 deserves more attention. Previous research showed that language barriers could lead to patients not
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46 being fully informed about the transplantation trajectory. The literature indicates that there are many
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48 initiatives on this subject, for example deploying an interpreter or the Kidney Team at Home where
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50 kidney patients received information about kidney failure and kidney replacement therapy together
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52 with their family and other members of their social network in the home environment (28, 29). A
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54 group of stakeholders was surprised that language problems still play a role because there are many
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56 (digital) possibilities to solve this (e.g., with a translation application). According to the stakeholders,
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3 efforts to bridge potential language barriers should continue to be explored, and existing interventions
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5 can be better utilized. It should be noted that translation by family will not always be the best solution
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7 because this translator does not always speak the language of medical science.
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12 Due to the better organ quality of living donation and the shortage of post-mortem donors, it is
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14 important to optimize the motivation for living donation or to improve it even further. Some former
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16 donors indicated that their expectations of aftercare were only sometimes met. According to
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18 stakeholders expressions of disappointment by former donors could lead to reduced motivation for
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20 living kidney donation by future donors (23). In this current study, many stakeholders recognized the
21
22 differences in donor aftercare between transplant centers. Donor motivation is also widely discussed in
23
24 the literature, with long-term regret and psychological factors playing a role (28). All respondents
25
26 agreed that donors should be given adequate attention and care and be able to look back on their
27
28 donations with satisfaction, so they do not feel abandoned.
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36 Regarding the economic theme this current study reveals that stakeholders were surprised by the
37
38 possible existence and influence of financial incentives for dialysis over transplantation. Most
39
40 stakeholders have differing views on the direction that current financial incentives could influence and
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42 argue for a different structure. Similarly, other studies show that there has been intense debate about
43
44 the benefits of complex financial incentives in healthcare (29, 30). In the Netherlands, in particular,
45
46 financial incentives have become more popular since 2006 due to the introduction of the free market
47
48 structure in health care (30). In other sectors, this may have been beneficial, but in the case of dialysis
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50 and transplantation, the incentives need to be in line with optimal patient care and could lead to higher
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52 costs for society.
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58 **Conclusions**

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3 The results indicate room for improvement to achieve equal access to transplantation. Transplant
4 stakeholders are convinced that there are still barriers to be removed in all domains addressed in this
5 study. More attention should be paid to make healthcare providers and patients aware of the clinical
6 guidelines for. The same applies to familiarity with differences in medical criteria. The stakeholders
7 also see room for improvement on psychological and social themes, especially regarding information.
8 The study shows that, despite many stakeholders being aware of economic perspectives on kidney
9 care, they see a need for a change in order to improve access to kidney transplantation.
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22 **Implications for further research**

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24 All these findings leave room for improvement by formulating policy changes to allow better access to
25 kidney transplantation. More research is needed to discover solutions for the barriers and develop
26 implementation strategies. Therefore, further research could look for solutions based on the above
27 themes with all stakeholders involved in this research. Research is needed to find ways to unite the
28 different interests in the economic field.
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38 **Practical implications**

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40 A solution-oriented approach to solving the economic barriers should provide a broader understanding
41 of how economic systems in health care function and how the systems can be broken without
42 interruption of care. As stated in the introduction, in the third phase of our study, we will stimulate the
43 stakeholders to arrive at suggestions that could accommodate the different points of view and achieve
44 a more productive “ecosystem” in kidney transplantation (31).
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Author contributions

RvM, JB, JvdW, SI contributed to the conceptualization, validation, methodology, writing, data curation, reviewing and editing, original draft preparation, visualization, and investigation. All authors have read and approved the final version of this manuscript.

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The authors declare neither financial nor non-financial competing interests

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Data sharing statement

The data underlying this article will be shared on reasonable request to the corresponding author.

Ethics approval statement

The protocol was approved by The Medical Ethical Committee of Erasmus MC Rotterdam, registered under MEC-2018-1473.

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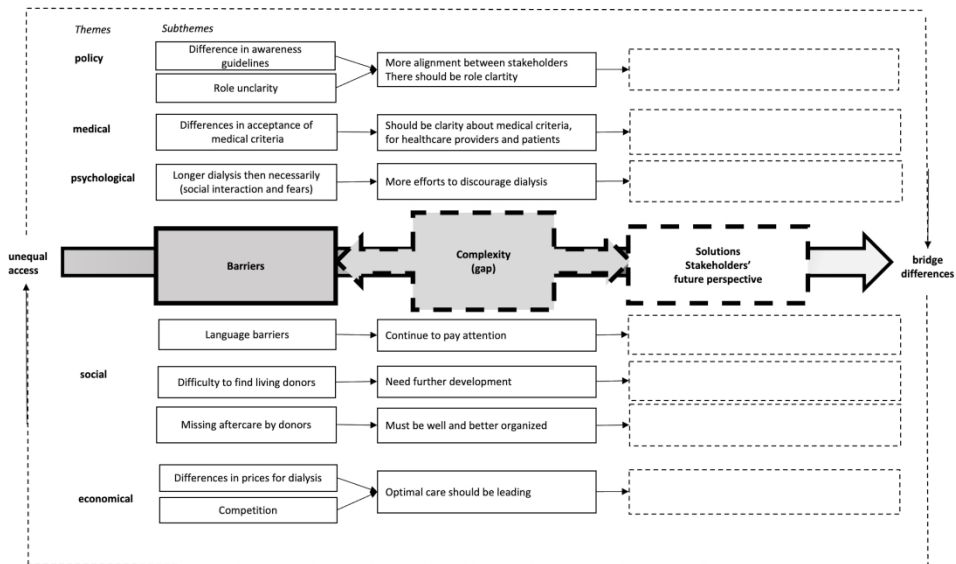


Figure 1

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Appendix 1. Quotes

Themes and subthemes	Quotes
Policy <i>Use of different guidelines</i>	<i>Respondent, nephrologist: “But I think there is a need for a national guideline for more standardized criteria. I think that every regional center has pretty clear requirements it has to meet, if you can refer someone, so to speak.”</i>
<i>Lack of clarity about roles</i>	<i>Respondent, social worker: “[um] Well, I think that’s a shame [the lack of clarity about roles] because I notice that I find it confusing for myself, and I think it’s confusing for the patient too because they get a bit stuck.”</i>
Medical <i>Use of different criteria for transplantation</i>	<i>Respondent, policy officer: “In practice, this is not so bad because you know the patient or the donor in this case, don’t you? Then the patient or the donor speaks who [uh] you can explain well why you don’t do that in this case. And that you might [uh] indicate that there are other centers where there are better [uh] surgeons”</i>
Psychological <i>Motivating factors for (extended) dialysis</i> <i>Fear as a delaying or excluding factor for</i>	<i>Respondent 14, Policy maker: “... hm, so I- that-that is on the one hand, uh, but, yes, then again I see myself as, [uh], ordinary citizen in this society, [uh], yes, on the the moment you don’t give these kinds of things a place, [uh], yes, there may also be limits to what we all think is okay with regard to healthcare costs.”</i> <i>Respondent 1, Nephrologist: “Very understandable [fear of transplantation]. Look, a [um] a transplant [um] can go very wrong,</i>

<p><i>transplantation</i></p>	<p><i>and,[um] you have [um] [um] the medication, that's not just a thing.</i></p> <p><i>And [um] a transplant then is not the end of the kidney failure, is it? It only starts then."</i></p>
<p>Social</p> <p><i>Limited social network</i></p> <p><i>Language barriers</i></p> <p><i>Differences in aftercare between patients and donors</i></p>	<p><i>Respondent, patient: "So, I actually think that with thirty or twenty-five percent (kidney function), it should be asked, do you have a donor? [uh] Inform them otherwise or start looking. You know, like that. Yes, it's weird, but otherwise, you could be put forward sooner to get on a list."</i></p> <p><i>Respondent 13, social worker: "Then the language barrier, because I also find that very recognizable. We try very hard to make some kind of support plan for someone who doesn't speak the language themselves."</i></p> <p><i>Respondent 30 nephrologist: Yes, that [differences in aftercare], yes, that does not surprise me. Look, the difficult thing is, of course, that donors are not actually patients, fortunately."</i></p>
<p>Economic</p> <p><i>Differences in financial agreements and incentives</i></p>	<p><i>Respondent 2, nephrologist: "I recognize those price differences [on dialysis] that are there. Dialysis and and [uh] yes, that is a problem, I must say. [...] [uh] I work in a [uh] in a ZBC, an independent treatment center for dialysis. [uh] And if you look at the rate differences, say, for the dialysis DBC [dialysis treatment center] per week, what you get in a [uh] ZBC compared to what you get in a, what</i></p>

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	<p><i>you get in a hospital, that is a difference of two, three hundred euros per week DBC per patient.”</i></p>
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BMJ Open

Stakeholders involved in kidney care giving direction to providing guidance for future policy: A qualitative study from a multi-stakeholder perspective

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3 **Stakeholders involved in kidney care giving direction to providing guidance for future policy: A**
4 **qualitative study from a multi-stakeholder perspective**
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39 **Keywords**

40 Health policy, organization of health services, quality in health care, dialysis, renal transplantation
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Abstract

Objectives

The aim of this study was to obtain more in-depth perspectives from stakeholders involved in access to kidney transplantation to pave the way for clear solutions for 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 semi-structured 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 health care 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 the stakeholders within the defined domains – policy, medical, psychological, social, and economic – were acknowledged by all respondents. According to respondents, more attention should be paid to make health care providers and patients aware of the

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3 clinical guideline for kidney transplantation. The same opinion applied to familiarity with differences
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5 in medical criteria. Stakeholders saw room for improvement based on psychological and social
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7 themes, especially regarding the provision of information. Many stakeholders described the need to
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9 rethink the current economic model to improve access to kidney transplantation. This discussion led to
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11 a definition of the most urgent problems for which, according to the respondents, a solution must be
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13 sought to optimize access to kidney transplantation.
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19 **Conclusions**

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

36 **Strengths and limitations of this study**

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38 • This large, qualitative study (N = 87) involved not only patients and health care providers but
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40 also policymakers and insurers.
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42 • In contrast to other studies, this study examined barriers to kidney transplantation from a
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44 multi-stakeholder perspective.
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46 • Qualitative research presents the opportunity to obtain more in-depth stakeholder perspectives
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48 that can pave the way for clear solutions.
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55 **Word count**

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Introduction

Overview of the issue

The scientific literature regarding kidney disease indicates that transplantation is the most suitable kidney replacement therapy for patients with end-stage renal disease (ESRD) and that pre-emptive transplantation is preferred¹. Notably, a large group of kidney patients are not on a waiting list².

Many patients remain on dialysis even though transplantation is the preferred alternative³. In many cases, a kidney from a living donor appears to be a better choice than a kidney from a post-mortem donor⁴. Kidneys from living kidney donors are often of better quality, which leads to survival benefits

¹. Due to the extensive waiting lists for post-mortem donors, a pre-emptive transplant is only possible for those patients with a living donor⁵⁻⁷. The shortage of post-mortem kidneys makes receiving a kidney from a living donor more urgent^{8,9}. Previous research has shown that barriers can hamper the access to (pre-emptive) kidney transplantation¹⁰.

Concern regarding equity of access to transplantation

There is 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 health care^{11,12}. In the Dutch setting, the clinical guideline regarding preparation for a kidney transplantation prescribes, for example, when to recommend a pre-emptive kidney transplantation and what age or BMI is accepted as the standard for eligibility for a kidney transplantation¹². Furthermore, elderly patients and patients with a migration background can be identified as potentially vulnerable groups regarding access to transplantation^{13,14}. It appears that a patient's socioeconomic status also plays a role in access to kidney transplantation¹⁵. Patients with a lower socioeconomic status often fail to adhere to therapy, which means that a transplantation is often not an option. Another factor that influences timely referral for transplant is comorbidity¹⁶. Patient-related factors can further influence

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3 the choice of a living donor. For example, it is known that feelings of guilt can play a role in prudent
4 donor recruitment. In addition, a lack of social support can play a role ¹⁷. In the Dutch setting, regional
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6 (non-academic) nephrology centers refer kidney patients to one of the seven academic hospitals that
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8 perform kidney transplantation. In most cases, a referral is made to the nearest academic hospital.
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10 Therefore, although nephrology centers are free to refer to any academic center, but they generally
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12 refer to only one. Living kidney donors make themselves known to transplant center (academic hospital),
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14 usually via the transplant candidate. They donate their kidney to someone they know (for example a
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16 partner) or to someone they don't know. Due to a shortage of living and post-mortem donors, there is a
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18 waiting list for kidneys, with a waiting period of 2.2 years ¹⁸.
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24 All these issues have led to disparities in on-time access to kidney transplantation when
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26 considered from different perspectives (e.g., patients, health care providers, and policymakers).
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28 Reducing these disparities in access to transplantation has recently been expressed as a research
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30 priority ¹⁹. Several studies have emphasized the need to bring about policy change and in line with
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32 these recommendations, it has been argued that various factors that play a role in kidney
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34 transplantation should be examined from a broad stakeholder perspective ²⁰.
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38 To solve this unmet medical need, we are conducting a three-phase study to explore potential
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40 barriers to transplant access with all stakeholders involved in kidney care ²¹. In phase 1, we accessed
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42 meaningful experiences using in-depth interviews in which stakeholders from the kidney field
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44 mentioned barriers in access to kidney transplantation (see Table 1). In phase 2, as presented in this
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46 current article, we shared the insights from the various stakeholders in the first phase with the same
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48 respondents from phase 1. This can lead to an integrated view in which stakeholders provide their own
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50 opinions regarding the barriers identified by others and directions can be given for possible solutions.
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52 In third phase, we will seek solutions with the same stakeholders as in phases 1 and 2 to establish a
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54 direction for future policy.
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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)²². The following five domains emerged from this phase: policy, medical, psychological, social, and economic. Within the policy domain, it was mentioned that health care 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, BMI, 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 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. Qualitative investigations can map complex policy issues in which stakeholders have different opinions and preferences²³. This process led to a reflection in which stakeholders expressed their own opinion regarding the barriers identified by others and provided directions themselves for future solutions. The following five domains were discussed: policy, medical, psychological, social, and economic.

Methods and analysis

Procedure

The theoretical basis for this qualitative study was grounded theory, which emphasizes the neutral position of an interviewer²⁴. In this respect, grounded theory is the opposite of more familiar forms of thematic approaches or thematic analysis, in which the discussion between the interviewer and informant is led by a predefined domain list. The themes found in our previous study were used as discussion items in the current study (see Figure 1, first column)²². The interviews were conducted using a semi-structured interview guide (see 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 minutes. The protocol was approved by The Medical Ethical Committee of Erasmus MC Rotterdam and registered under MEC-2018–1473. We have used COREQ criteria to report the qualitative research (see Appendix 2)²⁵.

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 e-mail.

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 method²⁶. Thus, respondents who were considered as representative for this study were selected. Participants were approached by RvM and Vincent Krijgsman. Notably, health care providers were selected based on their positions in academic and non-academic hospitals. Later, the participating stakeholders helped to search for other stakeholders using the snowball method²⁶. Participants were also selected with respect to demographic spread. Kidney patients were adults 18 years of age or older. They had been pre-emptively and non-pre-emptively transplanted with kidneys from living kidney donors and had been identified by the participating health care 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 (24). 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 loss to follow-up (26%) was mostly due to the full agendas of health care 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.

Table 1. Overview of respondents

Stakeholders	Participants	Focus groups	Individuals	Academic	Non-academic
Nephrologists	18	4	3	9	9
Social workers	17	3	3	5	12
Nurses	5	1	0	5	0
Surgeons	5	2	0	5	0
Policymakers	15	3	1	n/a	n/a
Insurance representatives	4	1	1	n/a	n/a
Kidney patients	14	3	1	n/a	n/a

Donors	9	4	0	n/a	n/a
Total	<i>N</i> = 87	23	9	22	23

Data collection

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

Data analysis

All interviews were recorded and transcribed verbatim, and all textual data was coded using NVivo- software. Text elements, as spoken by the interviewees, were given codes representing their content²⁷. For example, if a health care provider expressed that “the economic incentives are a terrible fact,” this text was coded as “economic incentives, terrible fact.” 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 labeled and sorted into open codes. In the second phase of the coding process, the 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 categorized into subthemes. The fourth and final phase of the coding process consisted of selective coding. This 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 (24).

All interviews were coded twice, by two coders (RvM & Vincent Krijgsman), leading to two code trees. The decision to use a second coder eliminated any blind spots exhibited by the first coder and increased the interrater reliability of the analysis²⁸. To further improve reliability, an input meeting was organized with the research team and both coders to discuss and identify possible blind spots.

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3 This process was repeated each time the 20 interviews were coded. After each input meeting, a
4
5 consensus meeting was held with the authors and the second coder. The consensus meeting led to the
6
7 identification of similarities and differences between the two coding trees. These coding trees were
8
9 integrated into a conceptual model (see Figure 1). The conceptual model showed the domains and
10
11 underlying subthemes (on the left) about which stakeholders had been asked for opinions. The
12
13 complexity gap (in the center) showed the priority stakeholders had placed on a follow-up for these
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15 domains and subthemes in the current study.
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22 **Results**

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24 Of the 117 informants that had participated in the first phase, 87 were able to participate in the second
25
26 phase. The present study included 14 patients, 9 donors, 17 social workers, 18 nephrologists, 5
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28 surgeons, 5 nurses, 15 policy employees, and 4 insurance representatives.
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33 The five domains and the discussion themes are presented below. Stakeholder responses follow each
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35 theme. The conceptual model that we deduced from the analysis is presented in Figure 1. The results
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37 are presented below, along with brief introductions of the discussion items found in the first phase of
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39 the study and the outcome of the current study. Each result is supported with a quotation (see
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41 Appendix 3).
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47 *Policy-related*

48 49 50 51 *Use of different guidelines*

52 The previous study showed that having guidelines for kidney transplantation, which include
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54 consideration of whether a patient is considered suitable for a kidney transplantation, does not always
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56 lead to a uniform way of thinking. For example, participants in the first phase claimed that guidelines
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3 were only for preparation, could not be found, or were not available, even though a national guideline
4 was available.
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8 In the current study, all healthcare providers and policymakers were made aware of the
9 existence of a Dutch national guideline prior to discussing this domain. In all groups, respondents
10 were convinced that guidelines should be interpreted identically in all hospitals. Most respondents
11 suggested that the guidelines should also be straightforward for patients to locate. A more remarkable
12 finding was that even after being presented with the existence of a Dutch national guideline, a group of
13 health care providers persisted in asserting that the guidelines does not exist or is not the accepted
14 guideline for the field.
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24 25 26 *Lack of clarity regarding roles* 27

28 In the previous study, it became apparent that some health care providers, especially nephrologists,
29 surgeons, and social workers, found it difficult to identify their role in the complex decision-making
30 process surrounding transplantation due to the many stakeholders involved. There was not always
31 agreement regarding who is responsible for providing timely and sufficient information to the kidney
32 patient and the donor. In addition, there was not always consensus regarding who should undertake the
33 final weighting of the transplant criteria.
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42 In the current study, most respondents were surprised by the reported need for more clarity
43 regarding roles and responsibilities in the transplantation process. It is a remarkable finding that not all
44 caregivers were aware of the differences in the division of roles. Notably, health care providers
45 unanimously agreed that the roles and responsibilities must be clear, but most of them argued that the
46 roles were clear from their own perspectives. Respondents agreed that lack of clarity can lead to
47 confusion about the process in general, and for patients specifically, most likely leading to suboptimal
48 care.
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3 *Medical*
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8 *Use of different criteria for transplantation*
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10 In the previous study, respondents reported that different transplant centers maintain different
11 acceptance criteria regarding comorbidity (e.g., obesity and fragility) and age. This variation leads to
12 different referrals and acceptance of patients for kidney transplantation.
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17 In the current study, some respondents, more often health care providers, reported that using
18 different criteria is not necessarily a problem as long as the health care providers and the patients are
19 informed and, if indicated, are referred to other centers in a timely way. Another group of respondents
20 stressed that criteria should be identical at all centers. It is remarkable that in many cases the
21 differences in medical criteria were not clear to most stakeholders, while they were aware that
22 awareness is important for healthcare providers and patients.
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33 *Psychological*
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38 *Motivating factors for (extended) dialysis*
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40 In the previous study, respondents reported that a small proportion of patients experience positive
41 social effects when undergoing dialysis through interactions among the patients themselves and
42 between patients and medical staff. This effect could possibly lead to an incentive to dialyze longer
43 than necessary. In the current study, patients often could not imagine this motivation. Other
44 respondents – in particular health care providers and policymakers – respected patients' choice to
45 continue dialysis for longer periods but believed that efforts should be made towards discouraging
46 dialysis if possible. Other stakeholders, such as policymakers and insurers, were less aware of this
47 issue. Most patients and donors could not imagine at all that patients would desire to undergo dialysis
48 for a longer period than necessary. Most respondents from all groups agreed unanimously that
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3 motivation for longer dialysis should not be based on acquiring social contacts and that solutions
4 should be sought for this concern. An unexpected finding was that a small group of respondents,
5
6 mostly the group of policymakers and insurers, believed that it should not always be a choice to be
7
8 able to continue dialysis for longer periods due to high costs.
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15 *Fear as a delaying or excluding factor for transplantation*

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17 In the previous study, respondents reported that some patients' fears and worries regarding
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19 transplantation had led to longer times on dialysis. A small group of health care providers indicated
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21 that this barrier is difficult to remove.
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24 The results of the current study suggest that most respondents recognized a fear of
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26 transplantation in some patients. Some respondents, especially healthcare providers, attributed this to
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28 the fact that not every transplant goes well. These patients return to dialysis, which can increase fear in
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30 a patient who is yet to be transplanted. Nevertheless, all respondents agreed that the effort to eliminate
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32 fear must be maximized.
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38 *Social*

39 40 41 42 *Limited social network*

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44 In the previous study, it became apparent that many patients fail to find a living donor, usually because
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46 of limited social networks.
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49 Respondents in the current study, especially health care providers, recognized this problem but
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51 simultaneously reported significant development in supporting patients and their social networks.
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53 However, as expected, most respondents agreed that social support interventions still require further
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55 development.
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Language barriers

Respondents in the previous study, especially health care 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 health care providers, recognized this problem as well. Health care 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 program) 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, health care providers often did not recognize a lack of aftercare. Most patients and donors recognized the lack of aftercare and were convinced that the care of donors requires more attention. Some health care 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

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3 medical issue. The results show that, according to most respondents in all stakeholders' groups, a lack
4 of aftercare can be seen as an important barrier for donors. All stakeholders agreed that aftercare must
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6 be well organized for donors, usually due to their special merit and motivation in donating a kidney
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8 and also because a perceived lack of aftercare can negatively influence the availability of future
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10 donors.
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17 *Economic*

21 *Differences in financial agreements and incentives*

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24 In the Dutch setting, hospitals receive payment per diagnosis–treatment combinations. Residents are
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26 insured for care and the health care provider declares the costs of a treatment directly to the healthcare
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28 insurer. Furthermore, academic hospitals can receive extra funding for specialized (transplant) care. In
29
30 the Netherlands, kidney transplants are only performed in academic centers. Thus, a peripheral center
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32 must refer to an academic center for kidney transplantations. In the previous study, respondents
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34 reported that insurers do not always apply the same purchasing prices for dialysis treatment and that in
35
36 some cases, financial arrangements include production agreements. All respondents other than patients
37
38 and donors (because of their lack of knowledge regarding this subject) reported that kidney
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40 transplantation would be more cost-effective than dialysis treatment. Some policymakers and insurers
41
42 were convinced that using different purchase prices could incentivize a preference for dialysis.
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47 Remarkably, in the current study, patients and donors expressed shock that economic factors
48
49 can play a role in the kidney transplantation process. A group of health care providers, patients, and
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51 donors indicated that this is a difficult domain and that their knowledge of the subject was insufficient.
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53 Health care providers agreed that optimal care should be prioritized in all cases; according to this
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55 group, economic motivations are not desirable. Many health care providers claimed that economic
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57 factors do not play a role in the care they deliver. Conversely, a small group of health care providers
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3 and nearly all policymakers and insurers stated that financial incentives are likely to play a role. They
4 suggested that this fact is evident because of healthcare market forces, such as paying per treatment, in
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6 the Netherlands. Most stakeholders expressed doubts regarding the contribution to optimal care by a
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8 revenue model in favor of dialysis.
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14 **Discussion**

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16 The problems identified by the different stakeholders within the defined domains (policy, medical,
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18 psychological, social, and economic) were acknowledged by all respondents. The discussion led to a
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20 definition of the most urgent problems for which, according to the stakeholders, a solution must be
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22 sought to optimize access to transplantation.
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26 Similar to previous research, this study has indicated that, despite the existence of a guideline,
27
28 the intended target group is not always aware of its availability²². The current findings show that most
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30 stakeholders are convinced that there should be no ambiguity among health care providers regarding
31
32 the availability or findability of the current guidelines. Most stakeholders also suggested that the
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34 guidelines should be more accessible to patients. Our research has demonstrated that their existence is
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36 often unknown by patients and that findability needs more priority; it is remarkable that even though
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38 guidelines are available for health care providers and patients, they cannot always be found.
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42 Awareness of guidelines has been assumed to lead to uniform care; however, the quality of care
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44 deteriorates if there are no guidelines²⁹. For this reason, the urgency expressed by stakeholders to bring
45
46 awareness and findability of guidelines to the attention of stakeholders is understandable.
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50 Previous research has found that the division of roles and responsibilities within the entire
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52 transplantation process is not always clear for health care providers²². The present findings indicate
53
54 that stakeholders agree that this lack of clarity leads to confusion and suboptimal care. It is also known
55
56 that a clear division of roles leads to better care for the patient³⁰. It is therefore understandable that
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58 stakeholders argued for a clearer division of roles in a center to optimize kidney care.
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3 The referring nephrologists and transplant centers do not always use the same medical criteria
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6 to deem a patient suitable for a kidney transplant ²². The current study has demonstrated that opinions
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8 can be divided into two groups. Some stakeholders stated that medical criteria in the various centers
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10 can be different, provided that they are transparent for health care providers and patients. Other
11
12 stakeholders indicated that the medical criteria for acceptance for transplantation should be the same
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14 everywhere. However, previous research has indicated that not all criteria are objective (e.g., the trade-
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16 off between the risk of transplantation and the gain in quality of life and survival of the patient in
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18 complex cases) ⁷. Our findings emphasize the need for increased transparency regarding how various
19
20 medical criteria are evaluated, for both healthcare professionals and patients.
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24 Fears of transplantation as well as social interactions and the structure offered by dialysis have
25
26 led to more extended dialysis periods than necessary for a group of patients, despite the possibility of
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28 transplantation ²². Previous studies have also revealed an association between fear of transplantation
29
30 and a patient's choice to delay this treatment ^{31 32}. In the current study, stakeholders unanimously
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32 agreed that everything possible must be done to remove barriers that block the option of
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34 transplantation. Furthermore, some stakeholders questioned the non-committal nature of the choice
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36 patients make to continue dialysis for longer when a better and cheaper treatment, in this case a kidney
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38 transplant, is available for them. This observation is remarkable because shared decision-making in
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40 which the patient has an important voice in the desired treatment is becoming increasingly used in
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42 healthcare ⁴.
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50 Previous studies have demonstrated the importance of involving patients' social networks when
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52 discussing treatment options for kidney failure ³³. Our current findings show that even though many
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54 improvements have already been made (e.g., the Kidney Team at Home), the use of social media
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56 channels deserves more attention. Previous research has shown that language barriers can lead to
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58 patients' not being fully informed regarding the transplantation trajectory. The literature indicates that
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3 many initiatives exist regarding this subject, for example the deployment of an interpreter or the
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5 Kidney Team at Home, through which kidney patients can receive information about kidney failure
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7 and kidney replacement therapy together with their family and other members of their social network
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9 in a home environment ^{34 35}. A group of stakeholders was surprised that language problems still play a
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11 role because there are many (digital) possibilities to solve this deficiency (e.g., use of a translation
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13 application). According to the stakeholders, efforts to bridge potential language barriers should
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15 continue to be explored, and existing interventions can be better utilized. It should be noted that
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17 translation by a family member is not always the ideal solution because the translator may not
18
19 understand the terminology of medical science.
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26 Due to the higher quality of organs from living donors and the shortage of post-mortem donors, it is
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28 important to optimize the motivation for living donation or to improve it even further. Some former
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30 donors indicated that their expectations of aftercare were only sometimes met. According to
31
32 stakeholders, expressions of disappointment by former donors could lead to reduced motivation for
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34 living kidney donation by future donors ²². In the current study, many stakeholders recognized
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36 differences in donor aftercare among transplant centers. Donor motivation has also been discussed
37
38 widely in the literature, with long-term regret and psychological factors specified as playing a role ³⁴.
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40 All respondents agreed that donors should be given adequate attention and care, so that they do not
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42 feel abandoned, and that they should be able to reflect on their donations with satisfaction.
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49 Regarding the economic theme, the current study found that stakeholders were surprised by the
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51 possible existence and influence of financial incentives for dialysis over transplantation. Most
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53 stakeholders expressed differing views regarding the direction that current financial incentives could
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55 influence and argued for a different structure. Similarly, other studies have recognized an intense
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57 debate regarding the benefits of complex financial incentives in healthcare ^{36 37}. In the Netherlands in
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3 particular, financial incentives have become more popular since 2006 due to the introduction of a free
4 market structure in health care ³⁶. This introduction may have been beneficial in other sectors, but in
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6 the case of dialysis and transplantation, the incentives must remain in line with optimal patient care
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8 and could lead to higher costs for society otherwise.
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15 A methodological limitation of this study is that not all respondents were able to participate in focus
16
17 groups due to the busy schedules of some stakeholders. Further focus group interviews could have
18
19 provided a more in-depth perspective of stakeholder recommendations for solutions.
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24 **Conclusions**

25 These results indicate room for improvement in achieving equal access to transplantation.

26 Stakeholders involved in kidney care recognize a high sense of urgency to solve barriers in access to
27
28 kidney transplantation based on different factors. Moreover, it appears that some barriers do not seem
29
30 excessively complicated to overcome, and familiarity with guidelines and medical criteria for health
31
32 care providers and patients are candidates to be solved in the short term. Furthermore, stakeholders
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34 also see room for improvement in psychological and social themes, especially regarding the provision
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36 of information. This study also found that many stakeholders are aware of economic influences on
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38 kidney care and acknowledge a need for a change to improve access to kidney transplantation.
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47 **Implications for further research**

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

A solution-oriented approach to solving the economic barriers should provide a broader understanding of the functioning of economic systems in health care 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 ³⁸.

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Author contributions

RvM, JB, JvdW, and SI contributed to conceptualization, validation, methodology, writing, data curation, reviewing and editing, original draft preparation, visualization, and investigation. All authors read and approved the final version of this manuscript.

Competing interests statement

The authors declare neither financial nor non-financial competing interests.

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Data-sharing statement

The data underlying this article will be shared upon reasonable request to the corresponding author.

Ethics approval statement

The protocol was approved by The Medical Ethical Committee of Erasmus MC Rotterdam, registered under MEC-2018–1473.

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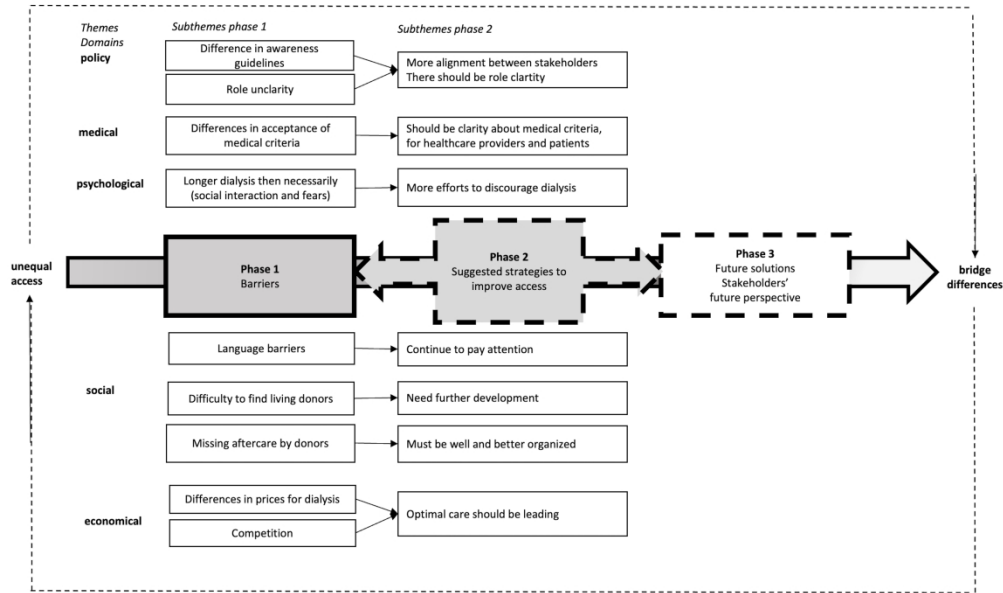


Figure 1

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7 Stakeholders involved in kidney care giving direction to providing guidance for future policy:
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12 Welcome to participants.(
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14 Summary of the grounded theory approach as used in this study.

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77 Do you want to come back to anything discussed in this interview?

78 Do you want to add something else that has not been discussed in this interview?

79 Are there any questions or comments?

80 Summary of the follow-up of the study.

COREQ (CONsolidated criteria for REporting Qualitative research) Checklist

A checklist of items that should be included in reports of qualitative research. You must report the page number in your manuscript where you consider each of the items listed in this checklist. If you have not included this information, either revise your manuscript accordingly before submitting or note N/A.

Topic	Item No.	Guide Questions/Description	Reported on Page No.
Domain 1: Research team and reflexivity			
<i>Personal characteristics</i>			
Interviewer/facilitator	1	Which author/s conducted the interview or focus group?	
Credentials	2	What were the researcher's credentials? E.g. PhD, MD	
Occupation	3	What was their occupation at the time of the study?	
Gender	4	Was the researcher male or female?	
Experience and training	5	What experience or training did the researcher have?	
<i>Relationship with participants</i>			
Relationship established	6	Was a relationship established prior to study commencement?	
Participant knowledge of the interviewer	7	What did the participants know about the researcher? e.g. personal goals, reasons for doing the research	
Interviewer characteristics	8	What characteristics were reported about the interviewer/facilitator? e.g. Bias, assumptions, reasons and interests in the research topic	
Domain 2: Study design			
<i>Theoretical framework</i>			
Methodological orientation and Theory	9	What methodological orientation was stated to underpin the study? e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis	
<i>Participant selection</i>			
Sampling	10	How were participants selected? e.g. purposive, convenience, consecutive, snowball	
Method of approach	11	How were participants approached? e.g. face-to-face, telephone, mail, email	
Sample size	12	How many participants were in the study?	
Non-participation	13	How many people refused to participate or dropped out? Reasons?	
<i>Setting</i>			
Setting of data collection	14	Where was the data collected? e.g. home, clinic, workplace	
Presence of non-participants	15	Was anyone else present besides the participants and researchers?	
Description of sample	16	What are the important characteristics of the sample? e.g. demographic data, date	
<i>Data collection</i>			
Interview guide	17	Were questions, prompts, guides provided by the authors? Was it pilot tested?	
Repeat interviews	18	Were repeat interviews carried out? If yes, how many?	
Audio/visual recording	19	Did the research use audio or visual recording to collect the data?	
Field notes	20	Were field notes made during and/or after the interview or focus group?	
Duration	21	What was the duration of the interviews or focus group?	
Data saturation	22	Was data saturation discussed?	
Transcripts returned	23	Were transcripts returned to participants for comment and/or	

Topic	Item No.	Guide Questions/Description	Reported on Page No.
		correction?	
Domain 3: analysis and findings			
<i>Data analysis</i>			
Number of data coders	24	How many data coders coded the data?	
Description of the coding tree	25	Did authors provide a description of the coding tree?	
Derivation of themes	26	Were themes identified in advance or derived from the data?	
Software	27	What software, if applicable, was used to manage the data?	
Participant checking	28	Did participants provide feedback on the findings?	
<i>Reporting</i>			
Quotations presented	29	Were participant quotations presented to illustrate the themes/findings? Was each quotation identified? e.g. participant number	
Data and findings consistent	30	Was there consistency between the data presented and the findings?	
Clarity of major themes	31	Were major themes clearly presented in the findings?	
Clarity of minor themes	32	Is there a description of diverse cases or discussion of minor themes?	

Developed from: Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *International Journal for Quality in Health Care*. 2007. Volume 19, Number 6: pp. 349 – 357

Once you have completed this checklist, please save a copy and upload it as part of your submission. DO NOT include this checklist as part of the main manuscript document. It must be uploaded as a separate file.

Appendix 3

Quotes

Themes and subthemes	Underlying quotes
<p>Policy</p> <p>Subtheme: Guidelines</p> <p>Subtheme: Role unclarity</p>	<p><i>Participant, social worker: "[Er] Yes, of course it would be nice if there were just [eh] the same guidelines for everyone."</i></p> <p><i>Participant, nephrologist: "Well, then I would say that it would be most convenient if agreements were made locally (eh) in that center about who has what tasks. Yes (eh) just work agreements in a (eh) in a center. Who does what? In any case, you do indeed have to (eh) in your own hospital (eh) as a transplant team, so to speak, if I'm talking about the university hospital, must be coordinated: who does what? A division of roles is required if you work in a team. That indeed seems (eh) quite self-evident to me, indeed, yes."</i></p>
<p>Medical</p> <p>Subtheme: Medical criteria</p>	<p><i>Participant, social worker: "I think that, yes you can [eh] transparency in any case, that the patient is entitled to that, to be able to see to which hospital [eh] let's say, in terms of age a transplant is allowed or not. [eh] And then, and then [eh] choose yourself [eh] where you want to go for the, for the transplant that is not only based on age or BMI, but on all other criteria [eh] [the patient] keep a little bit of control in your hand."</i></p>
<p>Psychological</p> <p>Subtheme: Dialysis for longer than necessary</p> <p>Subtheme: Fears for kidney transplantation</p>	<p><i>Participant, nurse: "Yes, I think for a patient it has also just [eh] naturally become a piece of [eh] network, and so stopping with that feels like a kind of emptiness. I think the patients there [eh]--. If you have signs that the patient is in danger of becoming isolated in some way, that you already start zooming in on what could be a safety net there, eh. Maybe a buddy system, or with guidance, or [eh] there are hobbies [eh] that they didn't have before, [eh] they can give substance to that again. So, and also fellow sufferers."</i></p> <p><i>Participant, surgeon: "Some patients hear stories of patients on dialysis who have had complications and who may have come to the hospital in a very long process with multiple operations. So I understand that too (fear of transplant) and it stands or falls with good information."</i></p>

<p>Social</p> <p>Subtheme: Language barrier</p> <p>Subtheme: Finding living donor</p> <p>Subtheme: Missing aftercare</p>	<p><i>Participant, nephrologist: "Eh, in itself something in which there are already many initiatives (language barrier). I think in particular in our region, where there are of course many multicultural differences. And well, kidney team at home, that is of course by definition a kind of initiative to make care more accessible to non-Western backgrounds and to overcome the language barriers. So I think that those kinds of initiatives are good and can be rolled out nationally where possible."</i></p> <p><i>Participant, patient: "No, okay, I think you could use a little guidance with that [use someone else's social media]. That is, of course, a very cheeky question."</i></p> <p><i>Participant, social worker: "I can imagine that [eh] that more attention could be paid to that. Look, [eh] people (kidney patients) who are eligible for a kidney transplant, they have of course been under care [eh] of the hospital. And such a donor, yes, the donor pops up a few times in the whole process. And [eh] I can imagine, [eh] maybe a little more attention [eh] can be spent on the donor [eh]."</i></p>
<p>Economic</p> <p>Subtheme: Market forces</p>	<p><i>Participant, nephrologist: "I assume that we just have that throughout the country, is that everyone is of course so keen that we all aim for a transplant (eh). But (eh) it's true that if you do it right, and therefore transplant a lot of patients as a ZBC (an independent treatment centre), you will actually be, say (eh) financially (eh) punished for it. And that is of course not true. You provided very good care, but because you provide very good care, then your earning (eh) model, in terms of your production, is declining. And so, as a (eh) independent treatment center, you also lose out. No, what you say, [name of other participant], a (eh) good treatment should also reward you well."</i></p>

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Paving the way for solutions improving access to kidney transplantation: a qualitative study from a multi-stakeholder perspective.

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3 **Paving the way for solutions improving access to kidney transplantation: a qualitative study from a**
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40 **Keywords**

41 Health policy, organization of health services, quality in health care, dialysis, renal transplantation
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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 semi-structured 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 health care 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 health care providers and patients aware of the clinical guideline for kidney

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3 transplantation. The same opinion applied to differences in medical inclusion criteria used in the
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5 different transplantation centers. Stakeholders saw room for improvement based on psychological and
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7 social themes, especially regarding the provision of information. Many stakeholders described the
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9 need to rethink the current economic model to improve access to kidney transplantation. This
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11 discussion led to a definition of the most urgent problems for which, according to the respondents, a
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13 solution must be sought to optimize access to kidney transplantation.
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19 **Conclusions**

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

37 **Strengths and limitations of this study**

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39 • This large, qualitative study (N = 87) involved not only patients and health care providers but
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41 also policymakers and insurers.
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45 • In contrast to other studies, this study examined barriers to kidney transplantation from a
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47 multi-stakeholder perspective.
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51 • Qualitative research presents the opportunity to obtain more in-depth stakeholder perspectives
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53 that can pave the way for clear solutions.
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57 • More interviews in focus groups would provide an even more in-depth perspective.
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61 • Data on the 'non responders' in this second phase is unknown, which may be related to the
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63 outcome.

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Word count

4918

For peer review only

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 (ESRD) and that pre-emptive transplantation is preferred¹. Notably, a large group of kidney patients are not on a waiting list². Many patients remain on dialysis even though transplantation is the preferred alternative³. In many cases, a kidney from a living donor appears to be a better choice than a kidney from a post-mortem donor⁴. Kidneys from living kidney donors are often of better quality, which leads to survival benefits¹. Due to the extensive waiting lists for post-mortem donors, a pre-emptive transplant is only possible for those patients with a living donor⁵⁻⁷. The shortage of post-mortem kidneys makes receiving a kidney from a living donor more urgent^{8,9}. Previous research has shown that barriers can hamper the access to (pre-emptive) kidney transplantation¹⁰.

Concern regarding equity of access to transplantation

There is 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 health care^{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^{13,14}. It also appears that a patient's socioeconomic status also plays a role in access to kidney transplantation¹⁵. 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 this¹⁶.

Context of the Dutch transplantation system

In the Netherlands, kidney transplantations are only performed in the seven academic hospitals. Although nephrology centers are free to refer to any academic center, 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 Nefrovisie¹².

Living kidney donors usually report via the transplant candidate to the recipient's transplant center, where they are informed and possibly prepared for kidney donation in accordance with the applicable national guidelines. Incompatible couple (ABO and/or HLA incompatible) are given the opportunity to participate in the Nationals Kidney Exchange Program. Altruistic kidney donors are accepted for both directed and non-directed 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 dialysis¹⁷.

All these issues have led to disparities in on-time access to kidney transplantation when considered from different perspectives (e.g., patients, health care providers, and policymakers). Reducing these disparities in access to transplantation has recently been expressed as a research priority¹⁸. Several studies have emphasized 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^{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 care²⁰. In phase 1, we accessed meaningful experiences, using in-depth interviews, in which stakeholders from the kidney field

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3 mentioned barriers in access to kidney transplantation (see Table 1). In phase 2, as presented in this
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5 current article, we shared the insights from the various stakeholders in the first phase with the same
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7 respondents from phase 1. This can lead to an integrated view in which stakeholders provide their own
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9 opinions regarding the barriers identified by others and directions can be given for possible solutions.
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11 In a following third phase, we will seek solutions with the same stakeholders as in phases 1 and 2 to
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13 establish a direction for future policy.
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17 The results from the first phase revealed that several barriers are known to negatively affect
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19 access to kidney transplantation and increase inequality (see Figure 1, first column)²¹. The following
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21 five domains emerged from this phase: policy, medical, psychological, social, and economic. Within
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23 the policy domain, it was mentioned that health care providers experience a lack of clarity regarding
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25 clinical guidelines. The medical domain emerged in that there is no consensus regarding criteria for
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27 acceptance for transplantation, for example age, BMI, or comorbidity. Within the psychological
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29 domain, it was mentioned that fear of transplantation or positive social interactions during dialysis can
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31 relate to delays in access to kidney transplantation. The social domain emerged because a lack of an
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33 effective social network or lack of skills to activate social support systems negatively influences
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35 access to kidney transplantation. In addition, a language barrier still hampers patient access to kidney
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37 transplantation. Furthermore, donor aftercare is not sufficient, which can lead a negative view
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39 regarding donation. Under the economic domain, it emerged that there are differences in purchasing
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41 agreements and reimbursements for dialysis and transplantation. These differences could produce
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43 economic incentives for choosing treatment paths.
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51 *Aim of the study*

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53 In this article, we describe the second phase of the study, in which we addressed separate stakeholder
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55 groups and explored how they reacted to the various opinions of other stakeholders. The aim of this
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57 research was to find directions for future solutions through reflection to gain more insight into what
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3 stakeholders consider as important to improve access to kidney transplantation. The following five
4 domains, emerged from the previous research were addressed: policy, medical, psychological, social,
5 and economic²¹.
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10 11 12 **Methods and analysis**

13 14 15 16 17 *Procedure*

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19 The theoretical basis for this qualitative study was grounded theory, which emphasizes the neutral
20 position of an interviewer²². The themes found in our previous study were used as discussion items in
21 the current study (see Figure 1, first column)²¹. The interviews were conducted using a semi-
22 structured interview guide (see Appendix 1). During virtual (Teams) in-depth interviews by RvM and
23 Vincent Krijgsman (research employee), respondents provided opinions regarding themes from other
24 stakeholders involved in kidney transplantation. These participants did not know the researcher, only
25 from an earlier interview phase (phase 1). From these insights, we aimed to develop an overview of
26 differences and similarities from stakeholder perspectives regarding the most urgent themes for further
27 investigation and follow-up. Identification of these urgent themes led to a conceptual model (see
28 Figure 1). The average interview time was 60 minutes. The protocol was approved by The Medical
29 Ethical Committee of Erasmus MC Rotterdam and registered under MEC-2018-1473. We have used
30 COREQ criteria to report the qualitative research (see Appendix 2)²³.
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50 51 *Patient and public involvement*

52 Patients were not involved in the design of the study. Participating patients will be informed regarding
53 the results of the study by e-mail.
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58 59 *Interviewees*

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3 The interviews were initially conducted in homogeneous focus groups with an average of three
4 participants from the following groups: patients, donors, social workers, nephrologists, surgeons,
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6 nurses, policy employees, and insurance representatives. Later, the focus group interviews were
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8 supplemented with one-on-one interviews to include informants with busy agendas.
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12 The stakeholders were identified according to the selected sample method ²⁴. Thus,
13 respondents who were considered as representative for this study were selected. Participants were
14 approached by RvM and Vincent Krijgsman. Notably, health care providers were selected based on
15 their positions in academic and non-academic hospitals. Later, the participating stakeholders helped to
16 search for other stakeholders using the snowball method ²⁴. Participants were also selected with
17 respect to demographic spread. Kidney patients were adults 18 years of age or older. They had been
18 pre-emptively and non-pre-emptively transplanted with kidneys from living kidney donors and had
19 been identified by the participating health care providers in this study. During the first phase of the
20 study, new stakeholders were added until a point of saturation occurred, as is common in grounded
21 theory ²². Participants in the second phase had also participated in the first phase (Table 1). In the first
22 phase of the study, 117 participants were involved; in this second phase, 87 participants were
23 involved. The loss to follow-up (26%) was mostly due to the full agendas of health care providers,
24 often related to the COVID-19 pandemic. A number of other respondents decided to end participation
25 in the study due to retirement or movement to a different job. All participants provided written
26 informed consent. Participants were not asked to comment on the findings from this current study.
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57 **Table 1.** Overview of respondents
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Stakeholders	Total of	Total of	Total of	Participants	Participants

	participants included	participants in focus groups	participants in individual interviews	from the academic	from the non-academic
Nephrologists	18	15	3	9	9
Social workers	17	14	3	5	12
Nurses	5	5	0	5	0
Surgeons	5	5	0	5	0
Policymakers	15	14	1	n/a	n/a
Insurance representatives	4	3	1	n/a	n/a
Kidney patients	14	13	1	n/a	n/a
Donors	9	9	0	n/a	n/a
Total	<i>N</i> = 87	78	9	24	21

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 interviews were recorded and transcribed verbatim, and all textual data was coded using NVivo software. Text elements, as spoken by the interviewees, were given codes representing their content²⁵. 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 labeled 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 categorized into subthemes. The fourth and final phase of the coding process consisted of selective coding. This 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 (24).

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3 All interviews were coded twice, by two coders (RvM & Vincent Krijgsman), leading to two code
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5 trees. The decision to use a second coder eliminated any blind spots exhibited by the first coder and
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7 increased the interrater reliability of the analysis²⁶. To further improve reliability, an input meeting
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9 was organized with the research team and both coders to discuss and identify possible blind spots.
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11 This process was repeated each time 20 interviews were coded. After each input meeting, a consensus
12
13 meeting was held with the authors and second coder. The consensus meeting led to the identification
14
15 of similarities and differences between the two coding trees. These coding trees were integrated into a
16
17 conceptual model (see Figure 1). The conceptual model shows the domains and underlying subthemes
18
19 (on the left) about which stakeholders had been asked for opinions. The complexity gap (in the center)
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21 shows the priority stakeholders had placed on a follow-up for these domains and subthemes in the
22
23 current study.
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31 **Results**

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33 Of the 117 informants that had participated in the first phase, 87 were able to participate in the second
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35 phase. The present study included 14 patients, 9 donors, 17 social workers, 18 nephrologists, 5
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37 surgeons, 5 nurses, 15 policy employees, and 4 insurance representatives.
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42 The five domains and the discussion themes are presented below. The conceptual model that we
43
44 deduced from the analysis is presented in Figure 1. The results are presented below, along with brief
45
46 introductions of the discussion items found in the first phase of the study and the outcome of the
47
48 current study. Each result is supported with a quotation (see Appendix 3).
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52 *Policy-related*

53 *Use of different guidelines*

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3 The previous study showed that having guidelines for kidney transplantation, which include
4
5 consideration of whether a patient is considered suitable for a kidney transplantation, does not always
6
7 lead to a uniform way of thinking. For example, participants in the first phase claimed that guidelines
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9 were only for preparation, could not be found, or were not available, even though a national guideline
10
11 was available.
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15 In the current study, all healthcare providers and policymakers were made aware of the
16
17 existence of a Dutch national guideline prior to discussing this domain. In all groups, respondents
18
19 were convinced that guidelines should be interpreted identically in all hospitals. Most respondents
20
21 suggested that the guidelines should also be straightforward for patients to locate. A more remarkable
22
23 finding was that even after being presented with the existence of a Dutch national guideline, a group of
24
25 health care providers persisted in asserting that the guidelines does not exist or is not the accepted
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27 guideline for the field.
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32 33 *Lack of clarity regarding roles* 34

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36 In the previous study, it became apparent that some health care providers, especially nephrologists,
37
38 surgeons, and social workers, found it difficult to identify their role in the complex decision-making
39
40 process surrounding transplantation due to the many stakeholders involved. There was not always
41
42 agreement regarding who is responsible for providing timely and sufficient information to the kidney
43
44 patient and the donor. In addition, there was not always consensus regarding who should undertake the
45
46 final weighting of the transplant criteria.
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49
50 In the current study, most respondents were surprised by the reported need for more clarity
51
52 regarding roles and responsibilities in the transplantation process. It is a remarkable finding that not all
53
54 caregivers were aware of the differences in the division of roles. Notably, health care providers
55
56 unanimously agreed that the roles and responsibilities must be clear, but most of them argued that the
57
58 roles were clear from their own perspectives. Respondents agreed that lack of clarity can lead to
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3 confusion about the process in general, and for patients specifically, most likely leading to suboptimal
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5 care.
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10 *Medical*

11 12 13 14 15 *Use of different criteria for transplantation*

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17 In the previous study, respondents reported that different transplant centers maintain different
18 acceptance criteria regarding comorbidity (e.g., obesity and fragility) and age. This variation leads to
19 different referrals and acceptance of patients for kidney transplantation.
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23
24 In the current study, some respondents, more often health care providers, reported that using
25 different criteria is not necessarily a problem as long as the health care providers and the patients are
26 informed and, if indicated, are referred to other centers in a timely way. Another group of respondents
27 stressed that criteria should be identical at all centers. It is remarkable that in many cases the
28 differences in medical criteria were not clear to most stakeholders, while they were aware that
29 awareness is important for healthcare providers and patients.
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40 *Psychological*

41 42 43 44 45 *Motivating factors for (extended) dialysis*

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47 In the previous study, respondents reported that a small proportion of patients experience positive
48 social effects when undergoing dialysis through interactions among the patients themselves and
49 between patients and medical staff. This effect could possibly lead to an incentive to dialyze longer
50 than necessary. In the current study, patients often could not imagine this motivation. Other
51 respondents – in particular health care providers and policymakers – respected patients' choice to
52 continue dialysis for longer periods but believed that efforts should be made towards discouraging
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3 dialysis if possible. Other stakeholders, such as policymakers and insurers, were less aware of this
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5 issue. Most patients and donors could not imagine at all that patients would desire to undergo dialysis
6
7 for a longer period than necessary. Most respondents from all groups agreed unanimously that
8
9 motivation for longer dialysis should not be based on acquiring social contacts and that solutions
10
11 should be sought for this concern. An unexpected finding was that a small group of respondents,
12
13 mostly the group of policymakers and insurers, believed that it should not always be a choice to be
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15 able to continue dialysis for longer periods due to high costs.
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22 *Fear as a delaying or excluding factor for transplantation*

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24 In the previous study, respondents reported that some patients' fears and worries regarding
25
26 transplantation had led to longer times on dialysis. A small group of health care providers indicated
27
28 that this barrier is difficult to remove.
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31 The results of the current study suggest that most respondents recognized a fear of
32
33 transplantation in some patients. Some respondents, especially healthcare providers, attributed this to
34
35 the fact that not every transplant goes well. These patients return to dialysis, which can increase fear in
36
37 a patient who is yet to be transplanted. Nevertheless, all respondents agreed that the effort to eliminate
38
39 fear must be maximized.
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45 *Social*

46 47 48 49 *Limited social network*

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51 In the previous study, it became apparent that many patients fail to find a living donor, usually because
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53 of limited social networks.
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56 Respondents in the current study, especially health care providers, recognized this problem but
57
58 simultaneously reported significant development in supporting patients and their social networks.
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3 However, as expected, most respondents agreed that social support interventions still require further
4 development.
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10 *Language barriers*

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12 Respondents in the previous study, especially health care providers, indicated that the available
13 information regarding transplantation and donation is less effective for patients who have language
14 barriers or are of non-Dutch origin.
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19 Most respondents in the current study, especially health care providers, recognized this
20 problem as well. Health care providers indicated that much is already being done, including the
21 deployment of interpreters. Moreover, the Kidney Team at Home (a tailored, home-based educational
22 intervention program) was a frequently mentioned example by which kidney patients can receive
23 information regarding kidney failure and kidney replacement therapy together with their family and
24 other members of their social network, in their home environment. A more remarkable finding was
25 that some respondents stated that it is the patient's responsibility to learn the Dutch language.
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36 Nevertheless, most respondents in all stakeholder groups unanimously agreed that the language barrier
37 deserves more attention.
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43 *Differences in aftercare between patients and donors*

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45 In the previous study, respondents reported that aftercare for donors deserves attention. According to
46 most respondents, donors are an indispensable link in promoting a transplant; however, a donor's
47 possible disappointment after transplantation can reduce the enthusiasm of new donors to donate.
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52 Among the respondents, a group of kidney patients and donors indicated that the donors experienced
53 insufficient contact with the hospital after the transplantation or during aftercare.
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56 In the current study, health care providers often did not recognize a lack of aftercare. Most
57 patients and donors recognized the lack of aftercare and were convinced that the care of donors
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3 requires more attention. Some health care providers explained the perceived lack of aftercare, stating
4 that after a while, the donor is no longer seen as a patient who needs treatment. In addition, they
5 suggested that donors who miss aftercare are “calling for appreciation” and that this is not only a
6 medical issue. The results show that, according to most respondents in all stakeholders’ groups, a lack
7 of aftercare can be seen as an important barrier for donors. All stakeholders agreed that aftercare must
8 be well organized for donors, usually due to their special merit and motivation in donating a kidney
9 and also because a perceived lack of aftercare can negatively influence the availability of future
10 donors.
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24 *Economic*

25 26 27 28 *Differences in financial agreements and incentives*

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30 In the Dutch setting, hospitals receive payment per diagnosis–treatment combinations. Residents are
31 insured for care and the health care provider declares the costs of a treatment directly to the healthcare
32 insurer. Furthermore, academic hospitals can receive extra funding for specialized (transplant) care. In
33 the Netherlands, kidney transplants are only performed in academic centers. Thus, a peripheral center
34 must refer to an academic center for kidney transplantations. In the previous study, respondents
35 reported that insurers do not always apply the same purchasing prices for dialysis treatment and that in
36 some cases, financial arrangements include production agreements. All respondents other than patients
37 and donors (because of their lack of knowledge regarding this subject) reported that kidney
38 transplantation would be more cost-effective than dialysis treatment. Some policymakers and insurers
39 were convinced that using different purchase prices could incentivize a preference for dialysis.
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54 Remarkably, in the current study, patients and donors expressed shock that economic factors
55 can play a role in the kidney transplantation process. A group of health care providers, patients, and
56 donors indicated that this is a difficult domain and that their knowledge of the subject was insufficient.
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3 Health care providers agreed that optimal care should be prioritized in all cases; according to this
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5 group, economic motivations are not desirable. Many health care providers claimed that economic
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7 factors do not play a role in the care they deliver. Conversely, a small group of health care providers
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9 and nearly all policymakers and insurers stated that financial incentives are likely to play a role. They
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11 suggested that this fact is evident because of healthcare market forces, such as paying per treatment, in
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13 the Netherlands. Most stakeholders expressed doubts regarding the contribution to optimal care by a
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15 revenue model in favor of dialysis.
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21 Discussion

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23 The problems identified by the different stakeholders within the defined domains (policy, medical,
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25 psychological, social, and economic) were acknowledged by all respondents. The discussion led to a
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27 definition of the most urgent problems for which, according to the stakeholders, a solution must be
28
29 sought to optimize access to kidney transplantation.
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33 Similar to previous research, this study has indicated that, despite the existence of a guideline,
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35 the intended target group is not always aware of its availability²¹. The current findings show that most
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37 stakeholders are convinced that there should be no ambiguity among health care providers regarding
38
39 the availability or findability of the current guidelines. Most stakeholders also suggested that the
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41 guidelines should be more accessible to patients. Our research has demonstrated that their existence is
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43 often unknown by patients and that findability needs more priority; it is remarkable that even though
44
45 guidelines are available for health care providers and patients, they cannot always be found.
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49 Awareness of guidelines has been assumed to lead to uniform care; however, the quality of care
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51 deteriorates if there are no guidelines²⁷. For this reason, the urgency expressed by stakeholders to bring
52
53 awareness and findability of guidelines to the attention of stakeholders is understandable.
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56 Previous research has found that the division of roles and responsibilities within the entire
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58 transplantation process is not always clear for health care providers²¹. The present findings indicate
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3 that stakeholders agree that this lack of clarity leads to confusion and suboptimal care. It is also known
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5 that a clear division of roles leads to better care for the patient²⁸. It is therefore understandable that
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7 stakeholders argued for a clearer division of roles in a center to optimize kidney care.
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10 The referring nephrologists and transplant centers do not always use the same medical criteria
11
12 to deem a patient suitable for a kidney transplant ²¹. The current study has demonstrated that opinions
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14 can be divided into two groups. Some stakeholders stated that medical criteria in the various centers
15
16 can be different, provided that they are transparent for health care providers and patients. Other
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18 stakeholders indicated that the medical criteria for acceptance for transplantation should be the same
19
20 everywhere. However, previous research has indicated that not all criteria are objective (e.g., the trade-
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22 off between the risk of transplantation and the gain in quality of life and survival of the patient in
23
24 complex cases) ⁷. Our findings emphasize need for increased transparency regarding how various
25
26 medical criteria are evaluated, for both healthcare professionals and patients.
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31 Fears of transplantation as well as social interactions and the structure offered by dialysis have
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33 led to more extended dialysis periods than necessary for a group of patients, despite the possibility of
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35 transplantation ²¹. Previous studies have also revealed an association between fear of transplantation
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37 and a patient's choice to delay this treatment ^{29 30}. In the current study, stakeholders unanimously
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39 agreed that everything possible must be done to remove barriers that block the option of
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41 transplantation. Furthermore, some stakeholders questioned the non-committal nature of the choice
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43 patients make to continue dialysis for longer when a better and cheaper treatment, in this case a kidney
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45 transplant, is available for them. This observation is remarkable because shared decision-making in
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47 which the patient has an important voice in the desired treatment is becoming increasingly used in
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49 healthcare ⁴.
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56 Previous studies have demonstrated the importance of involving patients' social networks when
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58 discussing treatment options for kidney failure ³¹. Our current findings show that even though many
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3 improvements have already been made (e.g., the Kidney Team at Home), the use of social media
4 channels deserves more attention. Previous research has shown that language barriers can lead to
5 patients' not being fully informed regarding the transplantation trajectory. The literature indicates that
6 many initiatives exist regarding this subject, for example the deployment of an interpreter or the
7 Kidney Team at Home, through which kidney patients can receive information about kidney failure
8 and kidney replacement therapy together with their family and other members of their social network
9 in a home environment ^{32 33}. A group of stakeholders was surprised that language problems still play a
10 role because there are many (digital) possibilities to solve this deficiency (e.g., use of a translation
11 application). According to the stakeholders, efforts to bridge potential language barriers should
12 continue to be explored, and existing interventions can be better utilized. It should be noted that
13 translation by a family member is not always the ideal solution because the translator may not
14 understand the terminology of medical science.

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33 Due to the higher quality of organs from living donors and the shortage of post-mortem donors, it is
34 important to optimize the motivation for living donation or to improve it even further. Some former
35 donors indicated that their expectations of aftercare were only sometimes met. According to
36 stakeholders, expressions of disappointment by former donors could lead to reduced motivation for
37 living kidney donation by future donors ²¹. In the current study, many stakeholders recognized
38 differences in donor aftercare among transplant centers. Donor motivation has also been discussed
39 widely in the literature, with long-term regret and psychological factors specified as playing a role ³².
40 All respondents agreed that donors should be given adequate attention and care, so that they do not
41 feel abandoned, and that they should be able to reflect on their donations with satisfaction.

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56 Regarding the economic theme, the current study found that stakeholders were surprised by the
57 possible existence and influence of financial incentives for dialysis over transplantation. Most
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3 stakeholders expressed differing views regarding the direction that current financial incentives could
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5 influence and argued for a different structure. Similarly, other studies have recognized an intense
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7 debate regarding the benefits of complex financial incentives in healthcare ^{34 35}. In the Netherlands in
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9 particular, financial incentives have become more popular since 2006 due to the introduction of a free
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11 market structure in health care ³⁴. This introduction may have been beneficial in other sectors, but in
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13 the case of dialysis and transplantation, the incentives must remain in line with optimal patient care
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15 and could lead to higher costs for society otherwise.
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22 *Strength and limitations*

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24 This multi-stakeholder qualitative research has contributed to gaining a more common perspective on
25
26 what stakeholders involved in kidney care consider as important to improve access to kidney
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28 transplantation. As a limitation it can be argued that more interviews in focus groups would provide an
29
30 even more in-depth perspective. However, the number of responders in this study is already large for a
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32 qualitative investigation, and it is the largest study of its kind in kidney transplantation. Another
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34 limitation could be that we have not been able to assure that all perspectives are indeed represented, as
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36 unwilling 'non-responders' may well represent a relevant perspective and because responders closer to
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38 our own network are more likely to participate. Finally, perhaps a mixed stakeholder focus group
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40 could have shed more light on the dynamics of the discussion and hence guided the results towards
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42 more integration.
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50 **Conclusions**

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52 The results indicate room for improvement in achieving equal access to kidney transplantation.
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54 Stakeholders involved in kidney care recognize a high sense of urgency to solve barriers in access to
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56 kidney transplantation based on different factors. Moreover, it appears that some barriers do not seem
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58 excessively complicated to overcome, and familiarity with guidelines and medical criteria for health
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3 care providers and patients are candidates to be solved in the short term. Furthermore, stakeholders
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5 also see room for improvement in psychological and social themes, especially regarding the provision
6
7 of information. This study also found that many stakeholders are aware of economic influences on
8
9 kidney care and acknowledge a need for a change to improve access to kidney transplantation.
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15 **Implications for further research**

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

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33 A solution-oriented approach to solving the economic barriers should provide a broader understanding
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35 of the functioning of economic systems in health care and how these systems can be adjusted without
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37 interruption of care. As stated in the introduction, in the third phase of our study, we will stimulate the
38
39 stakeholders to arrive at suggestions that could accommodate different points of view and achieve a
40
41 more productive “business ecosystem” in kidney transplantation ³⁶.
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47 **Acknowledgements**

48
49 We would like to thank all the participants who were involved in this study, including policy makers,
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51 insurers, nephrologists, surgeons, nurses, social workers, patients, donors, and the advisory board.
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56 **Author contributions**

1
2
3 RvM, JB, JvdW, and SI contributed to conceptualization, validation, methodology, writing, data
4
5 curation, reviewing and editing, original draft preparation, visualization, and investigation. All authors
6
7 read and approved the final version of this manuscript.
8
9

10 11 12 **Competing interests statement**

13
14
15 The authors declare neither financial nor non-financial competing interests.
16
17

18 19 20 **Funding statement**

21
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23
24

25 26 27 **Data-sharing statement**

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29 The data underlying this article will be shared upon reasonable request to the corresponding author.
30
31

32 33 34 **Ethics approval statement**

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36 The protocol was approved by The Medical Ethical Committee of Erasmus MC Rotterdam, registered
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38 under MEC-2018-1473.
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41 42 43 **References**

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Figure legend:

Figure 1 – Conceptual model

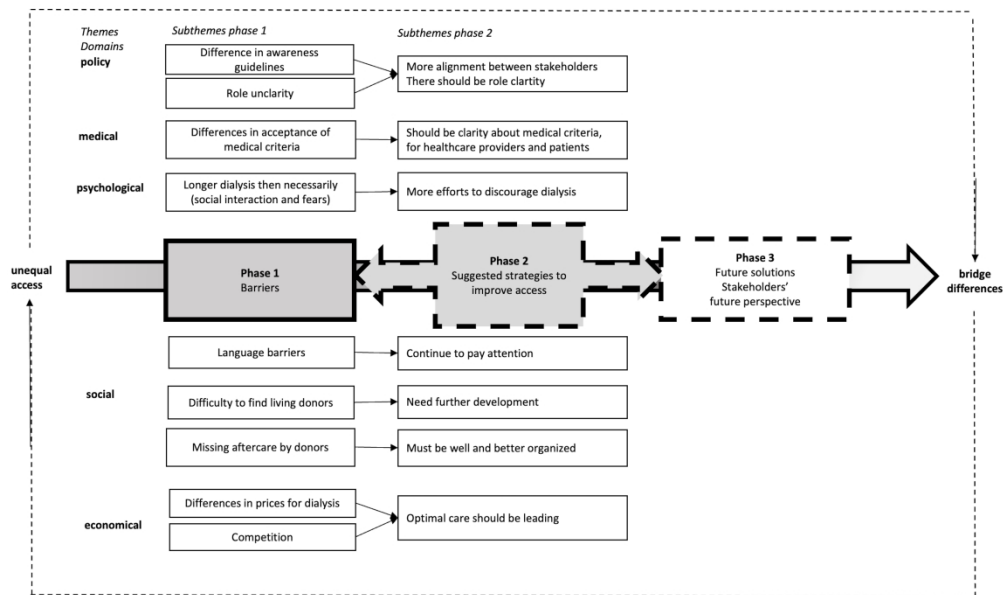


Figure 1

399x241mm (400 x 400 DPI)

Appendix 1

Interview Guide

Stakeholders involved in kidney care giving direction to providing guidance for future policy:
A qualitative study from a multi-stakeholder perspective.

Introduction

Welcome to participants.

Summary of the grounded theory approach as used in this study.

Domain(s)	Subtopic	Main question
1. Policy	An introduction to the following subtopics: a. Difference in awareness guidelines. b. Role unclarity.	What is your reaction on these subtopics?
2. Medical	An introduction to the following subtopic: a. Difference in acceptance of medical criteria.	What is your reaction on these subtopics?
3. Psychological	An introduction to the following subtopics: a. Longer dialysis the necessarily. b. Fears for transplantation.	What is your reaction on these subtopics?
4. Social	An introduction to the following subtopics: a. Language barrier. b. Difficulty to find a living donor. c. Missing aftercare by donors.	What is your reaction on these subtopics?
5. Economical	An introduction to the following subtopics: a. Differences in prices for dialysis. b. Competition.	What is your reaction on these subtopics?

End of the interview

Do you want to come back to anything discussed in this interview?

Do you want to add something else that has not been discussed in this interview?

Are there any questions or comments?

Summary of the follow-up of the study.

COREQ (CONsolidated criteria for REporting Qualitative research) Checklist

A checklist of items that should be included in reports of qualitative research. You must report the page number in your manuscript where you consider each of the items listed in this checklist. If you have not included this information, either revise your manuscript accordingly before submitting or note N/A.

Topic	Item No.	Guide Questions/Description	Reported on Page No.
Domain 1: Research team and reflexivity			
<i>Personal characteristics</i>			
Interviewer/facilitator	1	Which author/s conducted the interview or focus group?	
Credentials	2	What were the researcher's credentials? E.g. PhD, MD	
Occupation	3	What was their occupation at the time of the study?	
Gender	4	Was the researcher male or female?	
Experience and training	5	What experience or training did the researcher have?	
<i>Relationship with participants</i>			
Relationship established	6	Was a relationship established prior to study commencement?	
Participant knowledge of the interviewer	7	What did the participants know about the researcher? e.g. personal goals, reasons for doing the research	
Interviewer characteristics	8	What characteristics were reported about the interviewer/facilitator? e.g. Bias, assumptions, reasons and interests in the research topic	
Domain 2: Study design			
<i>Theoretical framework</i>			
Methodological orientation and Theory	9	What methodological orientation was stated to underpin the study? e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis	
<i>Participant selection</i>			
Sampling	10	How were participants selected? e.g. purposive, convenience, consecutive, snowball	
Method of approach	11	How were participants approached? e.g. face-to-face, telephone, mail, email	
Sample size	12	How many participants were in the study?	
Non-participation	13	How many people refused to participate or dropped out? Reasons?	
<i>Setting</i>			
Setting of data collection	14	Where was the data collected? e.g. home, clinic, workplace	
Presence of non-participants	15	Was anyone else present besides the participants and researchers?	
Description of sample	16	What are the important characteristics of the sample? e.g. demographic data, date	
<i>Data collection</i>			
Interview guide	17	Were questions, prompts, guides provided by the authors? Was it pilot tested?	
Repeat interviews	18	Were repeat interviews carried out? If yes, how many?	
Audio/visual recording	19	Did the research use audio or visual recording to collect the data?	
Field notes	20	Were field notes made during and/or after the interview or focus group?	
Duration	21	What was the duration of the interviews or focus group?	
Data saturation	22	Was data saturation discussed?	
Transcripts returned	23	Were transcripts returned to participants for comment and/or	

Topic	Item No.	Guide Questions/Description	Reported on Page No.
		correction?	
Domain 3: analysis and findings			
<i>Data analysis</i>			
Number of data coders	24	How many data coders coded the data?	
Description of the coding tree	25	Did authors provide a description of the coding tree?	
Derivation of themes	26	Were themes identified in advance or derived from the data?	
Software	27	What software, if applicable, was used to manage the data?	
Participant checking	28	Did participants provide feedback on the findings?	
<i>Reporting</i>			
Quotations presented	29	Were participant quotations presented to illustrate the themes/findings? Was each quotation identified? e.g. participant number	
Data and findings consistent	30	Was there consistency between the data presented and the findings?	
Clarity of major themes	31	Were major themes clearly presented in the findings?	
Clarity of minor themes	32	Is there a description of diverse cases or discussion of minor themes?	

Developed from: Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *International Journal for Quality in Health Care*. 2007. Volume 19, Number 6: pp. 349 – 357

Once you have completed this checklist, please save a copy and upload it as part of your submission. DO NOT include this checklist as part of the main manuscript document. It must be uploaded as a separate file.

Appendix 3

Quotes

Themes and subthemes	Underlying quotes
<p>Policy</p> <p>Subtheme: Guidelines</p> <p>Subtheme: Role unclarity</p>	<p><i>Participant, social worker: "[Er] Yes, of course it would be nice if there were just [eh] the same guidelines for everyone."</i></p> <p><i>Participant, nephrologist: "Well, then I would say that it would be most convenient if agreements were made locally (eh) in that center about who has what tasks. Yes (eh) just work agreements in a (eh) in a center. Who does what? In any case, you do indeed have to (eh) in your own hospital (eh) as a transplant team, so to speak, if I'm talking about the university hospital, must be coordinated: who does what? A division of roles is required if you work in a team. That indeed seems (eh) quite self-evident to me, indeed, yes."</i></p>
<p>Medical</p> <p>Subtheme: Medical criteria</p>	<p><i>Participant, social worker: "I think that, yes you can [eh] transparency in any case, that the patient is entitled to that, to be able to see to which hospital [eh] let's say, in terms of age a transplant is allowed or not. [eh] And then, and then [eh] choose yourself [eh] where you want to go for the, for the transplant that is not only based on age or BMI, but on all other criteria [eh] [the patient] keep a little bit of control in your hand."</i></p>
<p>Psychological</p> <p>Subtheme: Dialysis for longer than necessary</p> <p>Subtheme: Fears for kidney transplantation</p>	<p><i>Participant, nurse: "Yes, I think for a patient it has also just [eh] naturally become a piece of [eh] network, and so stopping with that feels like a kind of emptiness. I think the patients there [eh]--. If you have signs that the patient is in danger of becoming isolated in some way, that you already start zooming in on what could be a safety net there, eh. Maybe a buddy system, or with guidance, or [eh] there are hobbies [eh] that they didn't have before, [eh] they can give substance to that again. So, and also fellow sufferers."</i></p> <p><i>Participant, surgeon: "Some patients hear stories of patients on dialysis who have had complications and who may have come to the hospital in a very long process with multiple operations. So I understand that too (fear of transplant) and it stands or falls with good information."</i></p>

<p>Social</p> <p>Subtheme: Language barrier</p> <p>Subtheme: Finding living donor</p> <p>Subtheme: Missing aftercare</p>	<p><i>Participant, nephrologist: "Eh, in itself something in which there are already many initiatives (language barrier). I think in particular in our region, where there are of course many multicultural differences. And well, kidney team at home, that is of course by definition a kind of initiative to make care more accessible to non-Western backgrounds and to overcome the language barriers. So I think that those kinds of initiatives are good and can be rolled out nationally where possible."</i></p> <p><i>Participant, patient: "No, okay, I think you could use a little guidance with that [use someone else's social media]. That is, of course, a very cheeky question."</i></p> <p><i>Participant, social worker: "I can imagine that [eh] that more attention could be paid to that. Look, [eh] people (kidney patients) who are eligible for a kidney transplant, they have of course been under care [eh] of the hospital. And such a donor, yes, the donor pops up a few times in the whole process. And [eh] I can imagine, [eh] maybe a little more attention [eh] can be spent on the donor [eh]."</i></p>
<p>Economic</p> <p>Subtheme: Market forces</p>	<p><i>Participant, nephrologist: "I assume that we just have that throughout the country, is that everyone is of course so keen that we all aim for a transplant (eh). But (eh) it's true that if you do it right, and therefore transplant a lot of patients as a ZBC (an independent treatment centre), you will actually be, say (eh) financially (eh) punished for it. And that is of course not true. You provided very good care, but because you provide very good care, then your earning (eh) model, in terms of your production, is declining. And so, as a (eh) independent treatment center, you also lose out. No, what you say, [name of other participant], a (eh) good treatment should also reward you well."</i></p>