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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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**Keywords**

health services accessibility, communication barriers, kidney disease, kidney transplantation, stakeholder participation

## 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

to a definition of the most urgent problems, for which, according to the respondents, a solution must be sought to optimize access to kidney transplantation.

## Conclusions

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

## Article summary

### Strengths and limitations of this study

- This large qualitative study (N=87) not only involves patients or healthcare providers, but also policymakers and insurers.
- Unlike other studies, this study examines barriers to kidney transplantation from a multi-stakeholder perspective.
- Qualitative research gives the opportunity to obtain more in-depth perspectives from stakeholders that pave the way for clear solutions.

## Word count

3998

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

## Method and analysis

### *Procedure*

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

### *Patient and public involvement*

Patients were not involved in the design of the study. Participating patients will be informed about the results of the study by e-mail.

### *Informants*

The interviews were initially conducted in homogeneous focus groups comprising patients, donors, social workers, nephrologists, surgeons, nurses, policy employees, and insurance representatives. Later, the focus group interviews were supplemented with one-to-one interviews to include informants with busy agendas.

The stakeholders were identified according to the selected sample method (24). Notably, healthcare providers were selected based on positions in academic and non-academic hospitals to understand the similarities and differences. Later, the participating stakeholders helped to search for other stakeholders – the snowball method (24). The kidney patients are adults 18 years of age or older. They have been pre-emptively and non-pre-emptively transplanted and were identified by the participating healthcare providers in this study. During the first phase of the study, new stakeholders were added until a point of saturation occurred, as is common in grounded theory (24). The subjects in the second phase also participated in our previous study (Table 1). All participants gave informed consent.

**Table 1.** Overview of respondents

| Respondents | Realized |
|---|---|
| Nephrologists | 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*

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

### *Language barriers*

In the previous study, respondents, especially health care providers, indicated that the available information about transplantation and donation is less effective for patients with language barriers or of non-Dutch origin. The current study reveals that most respondents, especially health care providers, recognize this problem. Care providers indicated that much is already being done, including the deployment of an interpreter. Moreover, the Kidney Team at Home (a tailored, home-based educational intervention program) was a frequently mentioned example where kidney patients receive information about kidney failure and kidney replacement therapy together with their family and other members of their social network in their home environment. Some respondents believed it is the patient's responsibility to learn the Dutch language. Nevertheless, respondents 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 to promoting a transplant; however, a donor's possible disappointment after transplantation can reduce new donors' enthusiasm to donate. Respondents reported that a group of kidney patients and donors indicated that the donors miss sufficient contact with the hospital after the transplant or aftercare. In the current study, care providers often do not recognize the lack of aftercare. Patients and donors recognize the lack of aftercare and are convinced that the care of donors needs 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 needing treatment. In addition, they suggested that donors who miss after care are “calling for appreciation,” and this is not a medical issue. All stakeholders agreed that aftercare must be well organized for donors, usually because of their special merit and motivation in donating a kidney and also because a perceived lack of after care can negatively influence the availability of future donors.

### *Economic*

#### *Differences in financial agreements and incentives*

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

## 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 believe that the medical criteria for acceptance for transplantation should be the same everywhere. However, previous research indicated that not all criteria are objective (e.g., the trade-off between the risk of transplantation and the gain in quality of life and survival of the patient in complex cases) (8). Our research emphasizes the need for more transparency in how various medical criteria are handled, for both healthcare professionals and patients.

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

Previous studies demonstrate the importance of involving patients' social networks when discussing treatment options for kidney failure (27). This current research shows that even though many improvements have already been made (e.g., a kidney team at home), the use of social media channels deserves more attention. Previous research showed that language barriers could lead to patients not being fully informed about the transplantation trajectory. The literature indicates that there are many initiatives on this subject, for example deploying an interpreter or the Kidney Team at Home where kidney patients received information about kidney failure and kidney replacement therapy together with their family and other members of their social network in the home environment (28, 29). A group of stakeholders was surprised that language problems still play a role because there are many (digital) possibilities to solve this (e.g., with a translation application). According to the stakeholders, efforts to bridge potential language barriers should continue to be explored, and existing interventions can be better utilized. It should be noted that translation by family will not always be the best solution because this translator does not always speak the language of medical science.

Due to the better organ quality of living donation and the shortage of post-mortem donors, it is important to optimize the motivation for living donation or to improve it even further. Some former donors indicated that their expectations of aftercare were only sometimes met. According to stakeholders expressions of disappointment by former donors could lead to reduced motivation for living kidney donation by future donors (23). In this current study, many stakeholders recognized the differences in donor aftercare between transplant centers. Donor motivation is also widely discussed in the literature, with long-term regret and psychological factors playing a role (28). All respondents agreed that donors should be given adequate attention and care and be able to look back on their donations with satisfaction, so they do not feel abandoned.

Regarding the economic theme this current study reveals that stakeholders were surprised by the possible existence and influence of financial incentives for dialysis over transplantation. Most stakeholders have differing views on the direction that current financial incentives could influence and argue for a different structure. Similarly, other studies show that there has been intense debate about the benefits of complex financial incentives in healthcare (29, 30). In the Netherlands, in particular, financial incentives have become more popular since 2006 due to the introduction of the free market structure in health care (30). In other sectors, this may have been beneficial, but in the case of dialysis and transplantation, the incentives need to be in line with optimal patient care and could lead to higher costs for society.

## Conclusions

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

## Implications for further research

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

## Practical implications

A solution-oriented approach to solving the economic barriers should provide a broader understanding of how economic systems in health care function and how the systems can be broken 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 the different points of view and achieve 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.

## 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 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.

## References

1. Liem YS, Weimar W. Early living-donor kidney transplantation: a review of the associated survival benefit. Transplantation. 2009;87(3):317-8.
2. Schold JD, Huml AM, Poggio ED, Sedor JR, Husain SA, King KL, et al. Patients with high priority for kidney transplant who are not given expedited placement on the transplant waiting list represent lost opportunities. Journal of the American Society of Nephrology. 2021;32(7):1733-46.
3. Asderakis A, Augustine T, Dyer P, Short C, Campbell B, Parrott NR, et al. Pre-emptive kidney transplantation: the attractive alternative. Nephrology, dialysis, transplantation: official

publication of the European Dialysis and Transplant Association-European Kidney Association. 1998;13(7):1799-803.

4. Medin C, Elinder CG, Hylander B, Blom B, Wilczek H. Survival of patients who have been on a waiting list for kidney transplantation. Nephrology Dialysis Transplantation. 2000;15(5):701-4.

5. Liem YS, Weimar W. Early living-donor kidney transplantation: a review of the associated survival benefit. Transplantation. 2009;87(3):317-8. DOI: 10.1097/TP.0b013e3181952710

6. Edwards EB, Bennett LE, Cecka JM. Effect of HLA matching on the relative risk of mortality for kidney recipients: a comparison of the mortality risk after transplant to the mortality risk of remaining on the waiting list. Transplantation. 1997;64(9):1274-7. DOI: 10.1097/00007890-199711150-00007

7. Wolfe RA, Ashby VB, Milford EL, Ojo AO, Ettenger RE, Agodoa LY, et al. Comparison of mortality in all patients on dialysis, patients on dialysis awaiting transplantation, and recipients of a first cadaveric transplant. N Engl J Med. 1999;341(23):1725-30. DOI: 10.1056/nejm199912023412303

8. Ogutmen B, Yildirim A, Sever MS, Bozfakioglu S, Ataman R, Erek E, et al. Health-related quality of life after kidney transplantation in comparison intermittent hemodialysis, peritoneal dialysis, and normal controls. Transplant Proc. 2006;38(2):419-21. DOI: 10.1016/j.transproceed.2006.01.016

9. Bastani B. The present and future of transplant organ shortage: some potential remedies. Journal of nephrology. 2020;33(2):277-88.

10. Waterman AD, Robbins ML, Peipert JD. Educating prospective kidney transplant recipients and living donors about living donation: practical and theoretical recommendations for increasing living donation rates. Current transplantation reports. 2016;3(1):1-9.

11. Vamos EP, Novak M, Mucsi I. Non-medical factors influencing access to kidney transplantation. Int Urol Nephrol. 2009;41(3):607-16. DOI: 10.1007/s11255-009-9553-x

12. Batabyal P, Chapman JR, Wong G, Craig JC, Tong A. Clinical practice guidelines on wait-listing for kidney transplantation: consistent and equitable? Transplantation. 2012;94(7):703-13. DOI: 10.1097/TP.0b013e3182637078

13. Roodnat JI, Laging M, Massey EK, Kho M, Kal-van Gestel JA, Ijzermans JN, et al. Accumulation of unfavorable clinical and socioeconomic factors precludes living donor kidney transplantation. Transplantation. 2012;93(5):518-23. DOI: 10.1097/TP.0b013e318243030f

14. Timmerman L, Ismail SY, Luchtenburg AE, Zuidema WC, IJzermans JN, Busschbach JJ, et al. Exploring knowledge about dialysis, transplantation, and living donation among patients and their living kidney donors. International journal of behavioral medicine. 2015;22(5):580-9. DOI: 10.1007/s12529-015-9461-7

15. Keith D, Ashby VB, Port FK, Leichtman AB. Insurance type and minority status associated with large disparities in prelisting dialysis among candidates for kidney transplantation. Clinical Journal of the American Society of Nephrology. 2008;3(2):463-70.

16. Tong A, Hanson CS, Chapman JR, Halleck F, Budde K, Papachristou C, et al. The preferences and perspectives of nephrologists on patients' access to kidney transplantation: a systematic review. Transplantation. 2014;98(7):682-91. DOI: 10.1097/tp.0000000000000336

17. Hanson CS, Chadban SJ, Chapman JR, Craig JC, Wong G, Tong A. Nephrologists' Perspectives on Recipient Eligibility and Access to Living Kidney Donor Transplantation. Transplantation. 2016;100(4):943-53. DOI: 10.1097/tp.0000000000000921

18. Tong A, Sautenet B, Chapman JR, Harper C, MacDonald P, Shackel N, et al. Research priority setting in organ transplantation: a systematic review. Transpl Int. 2017;30(4):327-43. DOI: 10.1111/tri.12924

19. Organization DT. Nederlandse Transplantatiestichting. 2018.

20. Schold JD, Mohan S, Huml A, Buccini LD, Sedor JR, Augustine JJ, et al. Failure to Advance Access to Kidney Transplantation over Two Decades in the United States. Journal of the American Society of Nephrology. 2021;32(4):913-26. DOI: 10.1681/ASN.2020060888

21. Tong A, Chapman J, Israni A, Gordon E, Craig J. Qualitative research in organ transplantation: recent contributions to clinical care and policy. American Journal of Transplantation. 2013;13(6):1390-9. DOI: 10.1111/ajt.12239

22. Mittendorff K. Leren reflecteren. Het onzekere voor het zekere: Kwetsbaarheid als kracht in loopbaandialogen. 2014:37-60.

23. van Merweland R, Luchtenburg A, van Busschbach J, van de Wetering J, Sohal Ismail D. 340.5: Factors Influencing Access to Kidney Transplantation (FIAT): An Integrative Multiphasic Stakeholders' Perspective. Transplantation. 2022;106(9S):S310.

24. Baarda DB, de Goede MPM, Teunissen J. Basisboek kwalitatief onderzoek: praktische handleiding voor het opzetten en uitvoeren van kwalitatief onderzoek: Stenfert Kroese; 2001.

25. Tracy SJ. Qualitative quality: Eight "big-tent" criteria for excellent qualitative research. Qualitative inquiry. 2010;16(10):837-51. DOI: 10.1177/1077800410383121

26. Steyaert S, Holvoet E, Nagler E, Malfait S, Van Biesen W. Reporting of "dialysis adequacy" as an outcome in randomised trials conducted in adults on haemodialysis. PloS one. 2019;14(2):e0207045.

27. Wuerth D, Finkelstein SH, Finkelstein FO. Psychosocial assessment of the patient on chronic peritoneal dialysis: an overview. Advances in chronic kidney disease. 2007;14(4):353-7.

28. Ismail SY, Luchtenburg AE, Kal VGJA, Zuidema WC, Weimar W, Busschbach JJ, et al. Modifiable factors in access to living-donor kidney transplantation among diverse populations. Transplantation. 2013;96(6):586-90. DOI: 10.1097/TP.0b013e31829b754c

29. Ismail SY, Luchtenburg AE, Timman R, Zuidema WC, Boonstra C, Weimar W, et al. Home-based family intervention increases knowledge, communication and living donation rates: a randomized controlled trial. Am J Transplant. 2014;14(8):1862-9. DOI: 10.1111/ajt.12751

30. Enthoven AC. Market forces and health care costs. JAMA. 1991;266(19):2751-2.

31. Moore JF. Business ecosystems and the view from the firm. The antitrust bulletin. 2006;51(1):31-75.

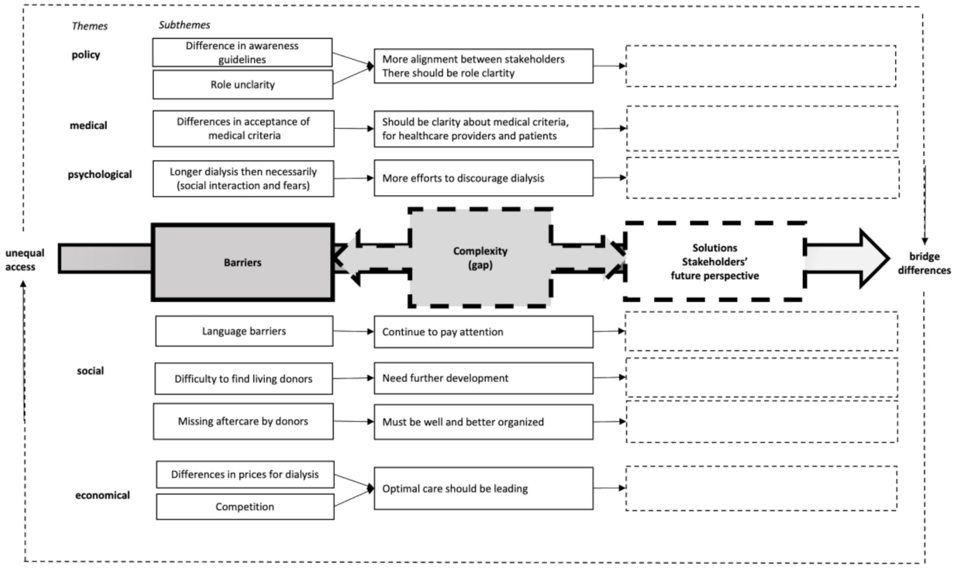

Figure 1

457x268mm (300 x 300 DPI)

**Appendix 1.** Quotes

| **Themes and subthemes** | **Quotes** |
|---|---|
| **Policy**<br>*Use of different guidelines* | *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."* |
| *Lack of clarity about roles* | *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."* |
| **Medical**<br>*Use of different criteria for transplantation* | *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"* |
| **Psychological**<br>*Motivating factors for (extended) dialysis* | *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."* |
| *Fear as a delaying or excluding factor for* | *Respondent 1, Nephrologist: "Very understandable [fear of transplantation]. Look, a [um] a transplant [um] can go very wrong,* |

| | |
|---|---|
| *transplantation* | *and,[um] you have [um] [um] the medication, that's not just a thing. And [um] a transplant then is not the end of the kidney failure, is it? It only starts then."* |
| **Social** | |
| *Limited social network* | *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."* |
| *Language barrieres* | *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.* |
| *Differences in aftercare between patients and donors* | *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."* |
| **Economic** | |
| *Differences in financial agreements and incentives* | *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* |

| | |
|---|---|
| | *you get in a hospital, that is a difference of two, three hundred euros per week DBC per patient."* |

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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| | |

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

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

**Conclusions**

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

## Article summary

### Strengths and limitations of this study

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

### Word count

4766

## 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 preferred[1] . Notably, a large group of kidney patients are not on a waiting list [2]. Many patients remain on dialysis even though transplantation is the preferred alternative [3]. In many cases, a kidney from a living donor appears to be a better choice than a kidney from a post-mortem donor [4]. 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 donor [5-7]. 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 transplantation [10].

### *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 transplantation[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 also plays a role in access to kidney transplantation [15]. 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 comorbidity [16]. 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 [17]. In the Dutch setting, regional (non-academic) nephrology centers refer kidney patients to one of the seven academic hospitals that perform kidney transplantation. In most cases, a referral is made to the nearest academic hospital. Therefore, although nephrology centers are free to refer to any academic center, but they generally refer to only one. Living kidney donors make themself known to transplant center (academic hospital), usually via the transplant candidate. They donate their kidney to someone they know (for example a partner) or to someone they don't know. Due to a shortage of living and post-mortem donors, there is a waiting list for kidneys, with a waiting period of 2.2 years [18].

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 priority [19]. 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 20].

To solve this unmet medical need, we are conducting a three-phase study to explore potential barriers to transplant access with all stakeholders involved in kidney care [21]. In phase 1, we accessed meaningful experiences using in-depth interviews in which stakeholders from the kidney field mentioned barriers in access to kidney transplantation (see Table 1). In phase 2, as presented in this current article, we shared the insights from the various stakeholders in the first phase with the same respondents from phase 1. This can lead to an integrated view in which stakeholders provide their own opinions regarding the barriers identified by others and directions can be given for possible solutions. In third phase, we will seek solutions with the same stakeholders as in phases 1 and 2 to establish a direction for future policy.

The results from the first phase revealed that several barriers are known to negatively affect access to kidney transplantation and increase inequality (see Figure 1, first column)[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 preferences [23]. 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 interviewer [24]. In this respect, grounded theory is the opposite of more familiar forms of thematical approaches or thematical 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 method [26]. 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 method [26]. 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 | $N = 87$ | 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 content [27]. 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 analysis [28]. 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 the 20 interviews were coded. After each input meeting, a consensus meeting was held with the authors and the second coder. The consensus meeting led to the identification of similarities and differences between the two coding trees. These coding trees were integrated into a conceptual model (see Figure 1). The conceptual model showed the domains and underlying subthemes (on the left) about which stakeholders had been asked for opinions. The complexity gap (in the center) showed the priority stakeholders had placed on a follow-up for these domains and subthemes in the current study.

**Results**

Of the 117 informants that had participated in the first phase, 87 were able 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. Stakeholder responses follow each theme. The conceptual model that we deduced from the analysis is presented in Figure 1. The results are presented below, along with brief introductions of the discussion items found in the first phase of the study and the outcome of the current study. Each result is supported with a quotation (see Appendix 3).

*Policy-related*

*Use of different guidelines*

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

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

### *Lack of clarity regarding roles*

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

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

*Medical*

*Use of different criteria for transplantation*

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

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

*Psychological*

*Motivating factors for (extended) dialysis*

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

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

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

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

### *Social*

### *Limited social network*

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

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

*Language barriers*

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

### *Economic*

#### *Differences in financial agreements and incentives*

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

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

## 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 has indicated that, despite the existence of a guideline, the intended target group is not always aware of its availability [22]. The current findings show that most stakeholders are convinced that there should be no ambiguity among health care providers regarding the availability or findability of the current guidelines. Most stakeholders also suggested that the guidelines should be more accessible to patients. Our research has demonstrated that their existence is often unknown by patients and that findability needs more priority; it is remarkable that even though guidelines are available for health care providers and patients, they cannot always be found. Awareness of guidelines has been assumed to lead to uniform care; however, the quality of care deteriorates if there are no guidelines[29]. For this reason, the urgency expressed by stakeholders to bring awareness and findability of guidelines to the attention of stakeholders is understandable.

Previous research has found that the division of roles and responsibilities within the entire transplantation process is not always clear for health care providers [22]. The present findings indicate that stakeholders agree that this lack of clarity leads to confusion and suboptimal care. It is also known that a clear division of roles leads to better care for the patient[30]. It is therefore understandable that stakeholders argued for a clearer division of roles in a center to optimize kidney care.

The referring nephrologists and transplant centers do not always use the same medical criteria to deem a patient suitable for a kidney transplant [22]. The current study has demonstrated that opinions can be divided into two groups. Some stakeholders stated that medical criteria in the various centers can be different, provided that they are transparent for health care providers and patients. Other stakeholders indicated that the medical criteria for acceptance for transplantation should be the same everywhere. However, previous research has indicated that not all criteria are objective (e.g., the trade-off between the risk of transplantation and the gain in quality of life and survival of the patient in complex cases) [7]. Our findings emphasize the need for increased transparency regarding how various medical criteria are evaluated, for both healthcare professionals and patients.

Fears of transplantation as well as social interactions and the structure offered by dialysis have led to more extended dialysis periods than necessary for a group of patients, despite the possibility of transplantation [22]. Previous studies have also revealed an association between fear of transplantation and a patient’s choice to delay this treatment [31] [32]. In the current study, stakeholders unanimously agreed that everything possible must be done to remove barriers that block the option of transplantation. Furthermore, some stakeholders questioned the non-committal nature of the choice patients make to continue dialysis for longer when a better and cheaper treatment, in this case a kidney transplant, is available for them. This observation is remarkable because shared decision-making in which the patient has an important voice in the desired treatment is becoming increasingly used in healthcare [4].

Previous studies have demonstrated the importance of involving patients’ social networks when discussing treatment options for kidney failure [33]. Our current findings show that even though many improvements have already been made (e.g., the Kidney Team at Home), the use of social media channels deserves more attention. Previous research has shown that language barriers can lead to patients’ not being fully informed regarding the transplantation trajectory. The literature indicates that many initiatives exist regarding this subject, for example the deployment of an interpreter or the Kidney Team at Home, through which kidney patients can receive information about kidney failure and kidney replacement therapy together with their family and other members of their social network in a home environment [34 35]. A group of stakeholders was surprised that language problems still play a role because there are many (digital) possibilities to solve this deficiency (e.g., use of a translation application). According to the stakeholders, efforts to bridge potential language barriers should continue to be explored, and existing interventions can be better utilized. It should be noted that translation by a family member is not always the ideal solution because the translator may not understand the terminology of medical science.

Due to the higher quality of organs from living donors and the shortage of post-mortem donors, it is important to optimize the motivation for living donation or to improve it even further. Some former donors indicated that their expectations of aftercare were only sometimes met. According to stakeholders, expressions of disappointment by former donors could lead to reduced motivation for living kidney donation by future donors [22]. In the current study, many stakeholders recognized differences in donor aftercare among transplant centers. Donor motivation has also been discussed widely in the literature, with long-term regret and psychological factors specified as playing a role [34]. All respondents agreed that donors should be given adequate attention and care, so that they do not feel abandoned, and that they should be able to reflect on their donations with satisfaction.

Regarding the economic theme, the current study found that stakeholders were surprised by the possible existence and influence of financial incentives for dialysis over transplantation. Most stakeholders expressed differing views regarding the direction that current financial incentives could influence and argued for a different structure. Similarly, other studies have recognized an intense debate regarding the benefits of complex financial incentives in healthcare [36 37]. In the Netherlands in particular, financial incentives have become more popular since 2006 due to the introduction of a free market structure in health care [36]. This introduction may have been beneficial in other sectors, but in the case of dialysis and transplantation, the incentives must remain in line with optimal patient care and could lead to higher costs for society otherwise.

A methodological limitation of this study is that not all respondents were able to participate in focus groups due to the busy schedules of some stakeholders. Further focus group interviews could have provided a more in-depth perspective of stakeholder recommendations for solutions.

## Conclusions

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

## Implications for further research

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

### Practical implications

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

## References

1. Liem YS, Weimar W. Early living-donor kidney transplantation: a review of the associated survival benefit. *Transplantation* 2009;87(3):317-8. doi: 10.1097/TP.0b013e3181952710 [published Online First: 2009/02/10]
2. Schold JD, Mohan S, Huml A, et al. Failure to Advance Access to Kidney Transplantation over Two Decades in the United States. *Journal of the American Society of Nephrology* 2021;32(4):913-26. doi: 10.1681/ASN.2020060888
3. Asderakis A, Augustine T, Dyer P, et al. Pre-emptive kidney transplantation: the attractive alternative. *Nephrol Dial Transplant* 1998;13(7):1799-803. doi: 10.1093/ndt/13.7.1799 [published Online First: 1998/07/29]
4. Medin C, Elinder CG, Hylander B, et al. Survival of patients who have been on a waiting list for renal transplantation. *Nephrology Dialysis Transplantation* 2000;15(5):701-04.
5. Edwards EB, Bennett LE, Cecka JM. Effect of HLA matching on the relative risk of mortality for kidney recipients: a comparison of the mortality risk after transplant to the mortality risk of remaining on the waiting list. *Transplantation* 1997;64(9):1274-7. doi: 10.1097/00007890-199711150-00007 [published Online First: 1997/11/26]
6. Wolfe RA, Ashby VB, Milford EL, et al. Comparison of mortality in all patients on dialysis, patients on dialysis awaiting transplantation, and recipients of a first cadaveric transplant. *N Engl J Med* 1999;341(23):1725-30. doi: 10.1056/nejm199912023412303 [published Online First: 1999/12/02]
7. Ogutmen B, Yildirim A, Sever MS, et al. Health-related quality of life after kidney transplantation in comparison intermittent hemodialysis, peritoneal dialysis, and normal controls. *Transplant Proc* 2006;38(2):419-21. doi: 10.1016/j.transproceed.2006.01.016 [published Online First: 2006/03/22]
8. Bastani B. The present and future of transplant organ shortage: some potential remedies. *Journal of nephrology* 2020;33(2):277-88.
9. Waterman AD, Robbins ML, Peipert JD. Educating prospective kidney transplant recipients and living donors about living donation: practical and theoretical recommendations for increasing living donation rates. *Current transplantation reports* 2016;3(1):1-9.
10. Vamos EP, Novak M, Mucsi I. Non-medical factors influencing access to renal transplantation. *Int Urol Nephrol* 2009;41(3):607-16. doi: 10.1007/s11255-009-9553-x [published Online First: 2009/04/08]
11. Batabyal P, Chapman JR, Wong G, et al. Clinical practice guidelines on wait-listing for kidney transplantation: consistent and equitable? *Transplantation* 2012;94(7):703-13. doi: 10.1097/TP.0b013e3182637078 [published Online First: 2012/09/06]
12. Richtlijnendatabase.nl. Moment screening transplantatie bij eindstadium nierfalen 2020 [Available from: https://richtlijnendatabase.nl/richtlijn/zorg_bij_eindstadium_nierfalen/timing_bij_eind

stadium_nierfalen/moment_screening_voor_transplantatie_bij_eindstadium_nierfalen.html accessed 21 oktober 2021.

13. Roodnat JI, Laging M, Massey EK, et al. Accumulation of unfavorable clinical and socioeconomic factors precludes living donor kidney transplantation. *Transplantation* 2012;93(5):518-23. doi: 10.1097/TP.0b013e318243030f [published Online First: 2012/02/03]
14. Timmerman L, Ismail SY, Luchtenburg AE, et al. Exploring knowledge about dialysis, transplantation, and living donation among patients and their living kidney donors. *International journal of behavioral medicine* 2015;22(5):580-89. doi: 10.1007/s12529-015-9461-7
15. Keith D, Ashby VB, Port FK, et al. Insurance type and minority status associated with large disparities in prelisting dialysis among candidates for kidney transplantation. *Clinical Journal of the American Society of Nephrology* 2008;3(2):463-70.
16. Tong A, Hanson CS, Chapman JR, et al. The preferences and perspectives of nephrologists on patients' access to kidney transplantation: a systematic review. *Transplantation* 2014;98(7):682-91. doi: 10.1097/tp.0000000000000336 [published Online First: 2014/08/15]
17. Hanson CS, Chadban SJ, Chapman JR, et al. Nephrologists' Perspectives on Recipient Eligibility and Access to Living Kidney Donor Transplantation. *Transplantation* 2016;100(4):943-53. doi: 10.1097/tp.0000000000000921 [published Online First: 2015/10/02]
18. Nierstichting. Feiten en cijfers [Webpage]. 2022 [Available from: https://nierstichting.nl/leven-met-een-nierziekte/feiten-en-cijfers/ accessed January 10 2022.
19. Tong A, Sautenet B, Chapman JR, et al. Research priority setting in organ transplantation: a systematic review. *Transpl Int* 2017;30(4):327-43. doi: 10.1111/tri.12924 [published Online First: 2017/01/26]
20. Organization DT. Nederlandse Transplantatiestichting. 2018
21. Mittendorff K. Leren reflecteren. *Het onzekere voor het zekere: Kwetsbaarheid als kracht in loopbaandialogen* 2014:37-60.
22. Factors Influencing Access to Kidney Transplantation (FIAT): An Integrative Multiphasic Stakeholders' Perspective. AMERICAN JOURNAL OF TRANSPLANTATION; 2022. WILEY 111 RIVER ST, HOBOKEN 07030-5774, NJ USA.
23. Tong A, Chapman J, Israni A, et al. Qualitative research in organ transplantation: recent contributions to clinical care and policy. *American Journal of Transplantation* 2013;13(6):1390-99. doi: 10.1111/ajt.12239
24. Corbin J, Strauss A. Basics of qualitative research: Techniques and procedures for developing grounded theory: Sage publications 2014.
25. 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;19(6):349-57.
26. Brewerton PM, Millward LJ. Organizational research methods: A guide for students and researchers: Sage 2001.
27. Strauss A, Corbin JM. Grounded theory in practice: Sage 1997.
28. Tracy SJ. Qualitative quality: Eight “big-tent” criteria for excellent qualitative research. *Qualitative inquiry* 2010;16(10):837-51. doi: 10.1177/1077800410383121
29. Feder G, Eccles M, Grol R, et al. Using clinical guidelines. *Bmj* 1999;318(7185):728-30.
30. Bittner CA. The importance of role clarity for development of interprofessional teams. *The Journal of Continuing Education in Nursing* 2018;49(8):345-47.

31. Steyaert S, Holvoet E, Nagler E, et al. Reporting of “dialysis adequacy” as an outcome in randomised trials conducted in adults on haemodialysis. *PloS one* 2019;14(2):e0207045.
32. Vamos EP, Csepanyi G, Zambo M, et al. Sociodemographic factors and patient perceptions are associated with attitudes to kidney transplantation among haemodialysis patients. *Nephrology Dialysis Transplantation* 2009;24(2):653-60.
33. Wuerth D, Finkelstein SH, Finkelstein FO. Psychosocial assessment of the patient on chronic peritoneal dialysis: an overview. *Advances in chronic kidney disease* 2007;14(4):353-57.
34. Ismail SY, Luchtenburg AE, Kal VGJA, et al. Modifiable factors in access to living-donor kidney transplantation among diverse populations. *Transplantation* 2013;96(6):586-90. doi: 10.1097/TP.0b013e31829b754c [published Online First: 2013/06/27]
35. Ismail SY, Luchtenburg AE, Timman R, et al. Home-based family intervention increases knowledge, communication and living donation rates: a randomized controlled trial. *Am J Transplant* 2014;14(8):1862-9. doi: 10.1111/ajt.12751 [published Online First: 2014/06/18]
36. Enthoven AC. Market forces and health care costs. *JAMA* 1991;266(19):2751-52.
37. Redeker S, Massey EK, van Merweland RG, et al. Induced demand in kidney replacement therapy. *Health Policy* 2022
38. Moore JF. Business ecosystems and the view from the firm. *The antitrust bulletin* 2006;51(1):31-75.

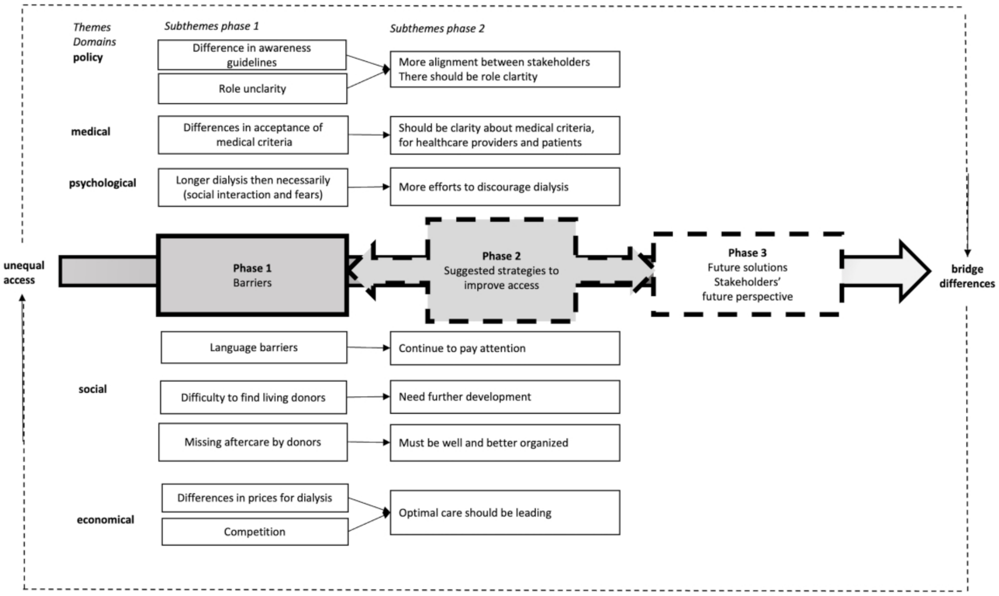

Figure 1

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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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Welcome to participants.(
Summary of the grounded theory approach as used in this study.

| **3 1 4 5&$678(** | **9 0 : +1"&2(** | **; 5&$(<0#7+&1$(** |
|---|---|---|
| **)=(>1?&2@(** | An introduction to the following subtopics:<br>a. Difference in awareness guidelines.<br>b. Role unclarity. | What is your reaction on these subtopics?( |
| **A=( ; #%&25?((** | An introduction to the following subtopic:<br>a. Difference in acceptance of medical criteria. | What is your reaction on these subtopics?<br>(<br>(<br>( |
| **B=(>7@2C1?1D&25?(** | An introduction to the following subtopics:<br>a. Longer dialysis the necessarily.<br>b. Fears for transplantation. | What is your reaction on these subtopics?<br>(<br>(<br>(<br>( |
| **E=(912&5?(** | An introduction to the following subtopics:<br>a. Language barrier.<br>b. Difficulty to find a living donor.<br>c. Missing aftercare by donors. | What is your reaction on these subtopics? |
| **F=(G21$1 4 &25?(** | An introduction to the following subtopics:<br>a. Differences in prices for dialysis.<br>b. Competition. | What is your reaction on these subtopics?<br>(<br>( |

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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** | | | |
| *Personal characteristics* | | | |
| 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? | |
| *Relationship with participants* | | | |
| 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 inter viewer/facilitator? e.g. Bias, assumptions, reasons and interests in the research topic | |
| **Domain 2: Study design** | | | |
| *Theoretical framework* | | | |
| Methodological orientation and Theory | 9 | What methodological orientation was stated to underpin the study? e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis | |
| *Participant selection* | | | |
| 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? | |
| *Setting* | | | |
| 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 | |
| *Data collection* | | | |
| Interview guide | 17 | Were questions, prompts, guides provided by the authors? Was it pilot tested? | |
| Repeat interviews | 18 | Were repeat inter views 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 inter view or focus group? | |
| Duration | 21 | What was the duration of the inter views 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** | | | |
| *Data analysis* | | | |
| 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? | |
| *Reporting* | | | |
| 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 |
|---|---|
| **Policy** | |
| Subtheme: Guidelines | *Participant, social worker: "[Er] Yes, of course it would be nice if there were just [eh] the same guidelines for everyone."* |
| Subtheme: Role unclarity | *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."* |
| **Medical** | |
| Subtheme: Medical criteria | *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."* |
| **Psychological** | |
| Subtheme: Dialysis for longer than necessary | *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."* |
| Subtheme: Fears for kidney transplantation | *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."* |

| | |
|---|---|
| **Social** | |
| Subtheme: Language barrier | *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."* |
| Subtheme: Finding living donor | *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."* |
| Subtheme: Missing aftercare | *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]."* |
| **Economic** | |
| Subtheme: Market forces | *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."* |

BMJ Open

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

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|---|---|
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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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Keywords

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

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

**Conclusions**

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

## Article summary

### Strengths and limitations of this study

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

## Word count

4918

## 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 preferred[1]. Notably, a large group of kidney patients are not on a waiting list [2]. Many patients remain on dialysis even though transplantation is the preferred alternative [3]. In many cases, a kidney from a living donor appears to be a better choice than a kidney from a post-mortem donor [4]. 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 donor [5-7]. 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 transplantation [10].

### *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 transplantation [15]. These patients often fail to adhere to therapy, which means that a transplantation is often not an option. Patient-related factors can further influence the choice of a living donor. For example, it is known that feelings of guilt can play a role in prudent donor recruitment. In addition, a lack of social support can play a role in this [16].

*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 Nefrovisie [12].

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 (AB0 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 dialysis[17].

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 priority [18]. 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 care [20]. In phase 1, we accessed meaningful experiences, using in-depth interviews, in which stakeholders from the kidney field mentioned barriers in access to kidney transplantation (see Table 1). In phase 2, as presented in this current article, we shared the insights from the various stakeholders in the first phase with the same respondents from phase 1. This can lead to an integrated view in which stakeholders provide their own opinions regarding the barriers identified by others and directions can be given for possible solutions. In a following third phase, we will seek solutions with the same stakeholders as in phases 1 and 2 to establish a direction for future policy.

The results from the first phase revealed that several barriers are known to negatively affect access to kidney transplantation and increase inequality (see Figure 1, first column)[21]. 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. The aim of this research was to find directions for future solutions through reflection to gain more insight into what stakeholders consider as important to improve access to kidney transplantation. The following five domains, emerged from the previous research were addressed: policy, medical, psychological, social, and economic[21].

## Methods and analysis

### *Procedure*

The theoretical basis for this qualitative study was grounded theory, which emphasizes the neutral position of an interviewer [22]. The themes found in our previous study were used as discussion items in the current study (see Figure 1, first column) [21]. The interviews were conducted using a 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)[23].

### *Patient and public involvement*

Patients were not involved in the design of the study. Participating patients will be informed regarding the results of the study by 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 method [24]. 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 method [24]. 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 [22]. 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 | 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 | *N* = 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 content [25]. 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).

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 analysis [26]. 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 coding trees were integrated into a conceptual model (see Figure 1). The conceptual model shows the domains and underlying subthemes (on the left) about which stakeholders had been asked for opinions. The complexity gap (in the center) shows the priority stakeholders had placed on a follow-up for these domains and subthemes in the current study.

## Results

Of the 117 informants that had participated in the first phase, 87 were able 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. The conceptual model that we deduced from the analysis is presented in Figure 1. The results are presented below, along with brief introductions of the discussion items found in the first phase of the study and the outcome of the current study. Each result is supported with a quotation (see Appendix 3).

### *Policy-related*

### *Use of different guidelines*

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

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

### *Lack of clarity regarding roles*

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

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

*Medical*

*Use of different criteria for transplantation*

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

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

*Psychological*

*Motivating factors for (extended) dialysis*

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

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

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

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

### *Social*

### *Limited social network*

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

Respondents in the current study, especially health care providers, recognized this problem but simultaneously reported significant development in supporting patients and their social networks.

However, as expected, most respondents agreed that social support interventions still require further development.

*Language barriers*

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

### *Economic*

### *Differences in financial agreements and incentives*

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

Remarkably, in the current study, patients and donors expressed shock that economic factors can play a role in the kidney transplantation process. A group of health care providers, patients, and donors indicated that this is a difficult domain and that their knowledge of the subject was insufficient.

Health care providers agreed that optimal care should be prioritized in all cases; according to this group, economic motivations are not desirable. Many health care providers claimed that economic factors do not play a role in the care they deliver. Conversely, a small group of health care providers and nearly all policymakers and insurers stated that financial incentives are likely to play a role. They suggested that this fact is evident because of healthcare market forces, such as paying per treatment, in the Netherlands. Most stakeholders expressed doubts regarding the contribution to optimal care by a revenue model in favor of dialysis.

## 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 kidney transplantation.

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

Previous research has found that the division of roles and responsibilities within the entire transplantation process is not always clear for health care providers [21]. The present findings indicate that stakeholders agree that this lack of clarity leads to confusion and suboptimal care. It is also known that a clear division of roles leads to better care for the patient[28]. It is therefore understandable that stakeholders argued for a clearer division of roles in a center to optimize kidney care.

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

Fears of transplantation as well as social interactions and the structure offered by dialysis have led to more extended dialysis periods than necessary for a group of patients, despite the possibility of transplantation [21]. Previous studies have also revealed an association between fear of transplantation and a patient's choice to delay this treatment [29 30]. In the current study, stakeholders unanimously agreed that everything possible must be done to remove barriers that block the option of transplantation. Furthermore, some stakeholders questioned the non-committal nature of the choice patients make to continue dialysis for longer when a better and cheaper treatment, in this case a kidney transplant, is available for them. This observation is remarkable because shared decision-making in which the patient has an important voice in the desired treatment is becoming increasingly used in healthcare [4].

Previous studies have demonstrated the importance of involving patients' social networks when discussing treatment options for kidney failure [31]. Our current findings show that even though many improvements have already been made (e.g., the Kidney Team at Home), the use of social media channels deserves more attention. Previous research has shown that language barriers can lead to patients' not being fully informed regarding the transplantation trajectory. The literature indicates that many initiatives exist regarding this subject, for example the deployment of an interpreter or the Kidney Team at Home, through which kidney patients can receive information about kidney failure and kidney replacement therapy together with their family and other members of their social network in a home environment [32 33]. A group of stakeholders was surprised that language problems still play a role because there are many (digital) possibilities to solve this deficiency (e.g., use of a translation application). According to the stakeholders, efforts to bridge potential language barriers should continue to be explored, and existing interventions can be better utilized. It should be noted that translation by a family member is not always the ideal solution because the translator may not understand the terminology of medical science.

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

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

### *Strength and limitations*

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

## Conclusions

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

## Implications for further research

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

## Practical implications

A solution-oriented approach to solving the economic barriers should provide a broader understanding of the functioning of economic systems in 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 [36].

## Acknowledgements

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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.

## References

1. Liem YS, Weimar W. Early living-donor kidney transplantation: a review of the associated survival benefit. *Transplantation* 2009;87(3):317-8. doi: 10.1097/TP.0b013e3181952710 [published Online First: 2009/02/10]
2. Schold JD, Mohan S, Huml A, et al. Failure to Advance Access to Kidney Transplantation over Two Decades in the United States. *Journal of the American Society of Nephrology* 2021;32(4):913-26. doi: 10.1681/ASN.2020060888
3. Asderakis A, Augustine T, Dyer P, et al. Pre-emptive kidney transplantation: the attractive alternative. *Nephrol Dial Transplant* 1998;13(7):1799-803. doi: 10.1093/ndt/13.7.1799 [published Online First: 1998/07/29]
4. Medin C, Elinder CG, Hylander B, et al. Survival of patients who have been on a waiting list for renal transplantation. *Nephrology Dialysis Transplantation* 2000;15(5):701-04.
5. Edwards EB, Bennett LE, Cecka JM. Effect of HLA matching on the relative risk of mortality for kidney recipients: a comparison of the mortality risk after transplant to

the mortality risk of remaining on the waiting list. *Transplantation* 1997;64(9):1274-7. doi: 10.1097/00007890-199711150-00007 [published Online First: 1997/11/26]

6. Wolfe RA, Ashby VB, Milford EL, et al. Comparison of mortality in all patients on dialysis, patients on dialysis awaiting transplantation, and recipients of a first cadaveric transplant. *N Engl J Med* 1999;341(23):1725-30. doi: 10.1056/nejm199912023412303 [published Online First: 1999/12/02]
7. Ogutmen B, Yildirim A, Sever MS, et al. Health-related quality of life after kidney transplantation in comparison intermittent hemodialysis, peritoneal dialysis, and normal controls. *Transplant Proc* 2006;38(2):419-21. doi: 10.1016/j.transproceed.2006.01.016 [published Online First: 2006/03/22]
8. Bastani B. The present and future of transplant organ shortage: some potential remedies. *Journal of nephrology* 2020;33(2):277-88.
9. Waterman AD, Robbins ML, Peipert JD. Educating prospective kidney transplant recipients and living donors about living donation: practical and theoretical recommendations for increasing living donation rates. *Current transplantation reports* 2016;3(1):1-9.
10. Vamos EP, Novak M, Mucsi I. Non-medical factors influencing access to renal transplantation. *Int Urol Nephrol* 2009;41(3):607-16. doi: 10.1007/s11255-009-9553-x [published Online First: 2009/04/08]
11. Batabyal P, Chapman JR, Wong G, et al. Clinical practice guidelines on wait-listing for kidney transplantation: consistent and equitable? *Transplantation* 2012;94(7):703-13. doi: 10.1097/TP.0b013e3182637078 [published Online First: 2012/09/06]
12. Richtlijnendatabase.nl. Moment screening transplantatie bij eindstadium nierfalen 2020 [Available from: https://richtlijnendatabase.nl/richtlijn/zorg_bij_eindstadium_nierfalen/timing_bij_eindstadium_nierfalen/moment_screening_voor_transplantatie_bij_eindstadium_nierfalen.html accessed 21 oktober 2021.
13. Roodnat JI, Laging M, Massey EK, et al. Accumulation of unfavorable clinical and socioeconomic factors precludes living donor kidney transplantation. *Transplantation* 2012;93(5):518-23. doi: 10.1097/TP.0b013e318243030f [published Online First: 2012/02/03]
14. Timmerman L, Ismail SY, Luchtenburg AE, et al. Exploring knowledge about dialysis, transplantation, and living donation among patients and their living kidney donors. *International journal of behavioral medicine* 2015;22(5):580-89. doi: 10.1007/s12529-015-9461-7
15. Keith D, Ashby VB, Port FK, et al. Insurance type and minority status associated with large disparities in prelisting dialysis among candidates for kidney transplantation. *Clinical Journal of the American Society of Nephrology* 2008;3(2):463-70.
16. Hanson CS, Chadban SJ, Chapman JR, et al. Nephrologists' Perspectives on Recipient Eligibility and Access to Living Kidney Donor Transplantation. *Transplantation* 2016;100(4):943-53. doi: 10.1097/tp.0000000000000921 [published Online First: 2015/10/02]
17. Nierstichting. Feiten en cijfers [Webpage]. 2022 [Available from: https://nierstichting.nl/leven-met-een-nierziekte/feiten-en-cijfers/ accessed January 10 2022.
18. Tong A, Sautenet B, Chapman JR, et al. Research priority setting in organ transplantation: a systematic review. *Transpl Int* 2017;30(4):327-43. doi: 10.1111/tri.12924 [published Online First: 2017/01/26]
19. Organization DT. Nederlandse Transplantatiestichting. 2018

20. Mittendorff K. Leren reflecteren. *Het onzekere voor het zekere: Kwetsbaarheid als kracht in loopbaandialogen* 2014:37-60.
21. Factors Influencing Access to Kidney Transplantation (FIAT): An Integrative Multiphasic Stakeholders' Perspective. AMERICAN JOURNAL OF TRANSPLANTATION; 2022. WILEY 111 RIVER ST, HOBOKEN 07030-5774, NJ USA.
22. Corbin J, Strauss A. Basics of qualitative research: Techniques and procedures for developing grounded theory: Sage publications 2014.
23. 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;19(6):349-57.
24. Brewerton PM, Millward LJ. Organizational research methods: A guide for students and researchers: Sage 2001.
25. Strauss A, Corbin JM. Grounded theory in practice: Sage 1997.
26. Tracy SJ. Qualitative quality: Eight “big-tent” criteria for excellent qualitative research. *Qualitative inquiry* 2010;16(10):837-51. doi: 10.1177/1077800410383121
27. Feder G, Eccles M, Grol R, et al. Using clinical guidelines. *Bmj* 1999;318(7185):728-30.
28. Bittner CA. The importance of role clarity for development of interprofessional teams. *The Journal of Continuing Education in Nursing* 2018;49(8):345-47.
29. Steyaert S, Holvoet E, Nagler E, et al. Reporting of “dialysis adequacy” as an outcome in randomised trials conducted in adults on haemodialysis. *PloS one* 2019;14(2):e0207045.
30. Vamos EP, Csepanyi G, Zambo M, et al. Sociodemographic factors and patient perceptions are associated with attitudes to kidney transplantation among haemodialysis patients. *Nephrology Dialysis Transplantation* 2009;24(2):653-60.
31. Wuerth D, Finkelstein SH, Finkelstein FO. Psychosocial assessment of the patient on chronic peritoneal dialysis: an overview. *Advances in chronic kidney disease* 2007;14(4):353-57.
32. Ismail SY, Luchtenburg AE, Kal VGJA, et al. Modifiable factors in access to living-donor kidney transplantation among diverse populations. *Transplantation* 2013;96(6):586-90. doi: 10.1097/TP.0b013e31829b754c [published Online First: 2013/06/27]
33. Ismail SY, Luchtenburg AE, Timman R, et al. Home-based family intervention increases knowledge, communication and living donation rates: a randomized controlled trial. *Am J Transplant* 2014;14(8):1862-9. doi: 10.1111/ajt.12751 [published Online First: 2014/06/18]
34. Enthoven AC. Market forces and health care costs. *JAMA* 1991;266(19):2751-52.
35. Redeker S, Massey EK, van Merweland RG, et al. Induced demand in kidney replacement therapy. *Health Policy* 2022
36. Moore JF. Business ecosystems and the view from the firm. *The antitrust bulletin* 2006;51(1):31-75.

Figure legend:

Figure 1 – Conceptual model

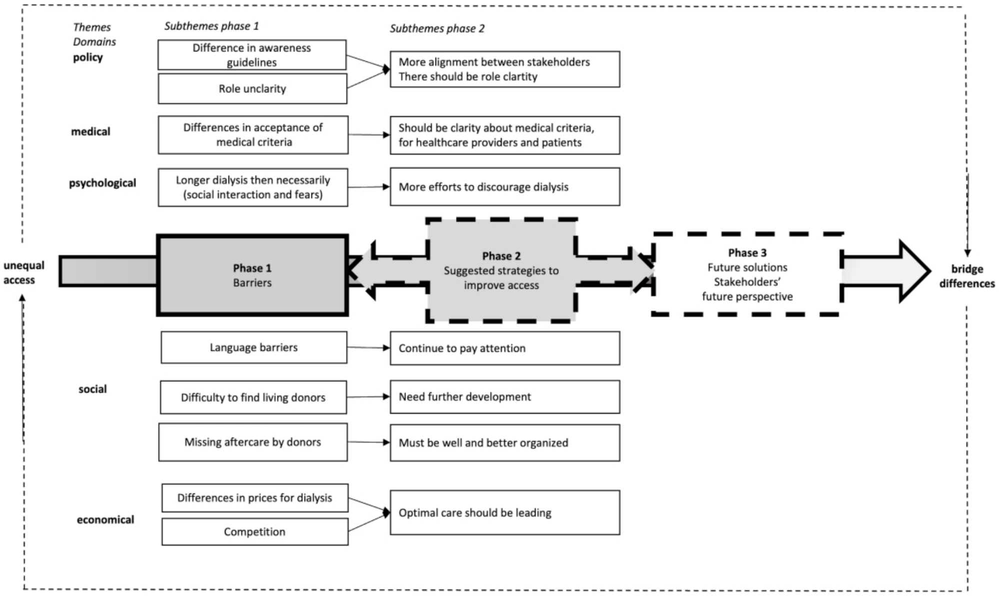

Figure 1

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:<br>a. Difference in awareness guidelines.<br>b. Role unclarity. | What is your reaction on these subtopics? |
| **2. Medical** | An introduction to the following subtopic:<br>a. Difference in acceptance of medical criteria. | What is your reaction on these subtopics? |
| **3. Psychological** | An introduction to the following subtopics:<br>a. Longer dialysis the necessarily.<br>b. Fears for transplantation. | What is your reaction on these subtopics? |
| **4. Social** | An introduction to the following subtopics:<br>a. Language barrier.<br>b. Difficulty to find a living donor.<br>c. Missing aftercare by donors. | What is your reaction on these subtopics? |
| **5. Economical** | An introduction to the following subtopics:<br>a. Differences in prices for dialysis.<br>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** | | | |
| *Personal characteristics* | | | |
| 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? | |
| *Relationship with participants* | | | |
| 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 inter viewer/facilitator? e.g. Bias, assumptions, reasons and interests in the research topic | |
| **Domain 2: Study design** | | | |
| *Theoretical framework* | | | |
| Methodological orientation and Theory | 9 | What methodological orientation was stated to underpin the study? e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis | |
| *Participant selection* | | | |
| 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? | |
| *Setting* | | | |
| 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 | |
| *Data collection* | | | |
| Interview guide | 17 | Were questions, prompts, guides provided by the authors? Was it pilot tested? | |
| Repeat interviews | 18 | Were repeat inter views 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 inter view or focus group? | |
| Duration | 21 | What was the duration of the inter views 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** | | | |
| *Data analysis* | | | |
| 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? | |
| *Reporting* | | | |
| 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 |
|---|---|
| **Policy** | |
| Subtheme: Guidelines | *Participant, social worker: "[Er] Yes, of course it would be nice if there were just [eh] the same guidelines for everyone."* |
| Subtheme: Role unclarity | *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."* |
| **Medical** | |
| Subtheme: Medical criteria | *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."* |
| **Psychological** | |
| Subtheme: Dialysis for longer than necessary | *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."* |
| Subtheme: Fears for kidney transplantation | *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."* |

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|---|---|
| **Social** | |
| Subtheme: Language barrier | *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."* |
| Subtheme: Finding living donor | *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."* |
| Subtheme: Missing aftercare | *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]."* |
| **Economic** | |
| Subtheme: Market forces | *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."* |