



Strategies to address perceived barriers to timely kidney transplantation in the Netherlands: A qualitative study from a stakeholders' perspective

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ABSTRACT

Objective: We present strategies to perceived barriers to access to kidney transplantation (KT) in the Netherlands.

Methods: This qualitative study ($N = 70$) includes nephrologists, social workers, surgeons, nurses, patients, former living kidney donors, policy employees, and insurance representatives. Interviews were conducted both in focus groups and individually and coded with NVivo.

Results: Participants proposed strategies within five domains. 1.Policy: Making KT guideline more visible. 2. Medical: Increase access and transparency to KT medical eligibility criteria (e.g., age, BMI) for patients and healthcare providers. 3.Psychological: Support patients who continue to use dialysis because of social interaction opportunities associated with dialysis settings to find such interaction elsewhere. Link kidney patients with fears for KT to experienced experts or trained professionals. 4.Social: Support patients with language barriers with interpreters and visual explanations. Support patients using social media, e.g. Facebook, to identify potential donors. Better expectation management to reduce reports of inadequate aftercare for living donors. 5.Economical: Solving negative economic incentives for KT by changing incentives.

Conclusion: Stakeholders see strategies for barriers in the entire care pathway.

Innovation: This large qualitative study gives an important overview which strategies stakeholders see improving access to KT. Some strategies offer opportunities to solve barriers in the short-term.

1. Introduction

In kidney transplantation, many patients do not receive care as recommended by accepted clinical guidelines [1]. We followed three phases of qualitative research to investigate this unmet medical need with stakeholders (hereinafter participants) involved in kidney transplantation in the Netherlands. This article reports on the third phase [2]. In the first phase, participants from the various (professional or experience expert) groups involved in kidney transplantation field determined the perceived problems, while in the second phase, this collection of problems mentioned by the different groups was presented to all participants in order to achieve a comprehensive understanding [2-4]. In the third phase, as presented here, the participants propose strategies to break the barriers to accessing transplantation care. The aim of this current study is to achieve a more productive “ecosystem” in kidney transplantation whereby participants in this study that are involved in kidney transplantation come up with strategies to improve access to

kidney transplantation.

Transplantation is the optimal treatment for most patients with kidney failure [5-8]; however, there is a long waiting list. Theoretically, there is an infinite source of organs if living donations are used. Remarkably, there are still many dialysis patients, even though transplantation is the preferred alternative for many of them. In the Dutch setting regional (non-academic) nephrological centers refer kidney patients to one of the seven academic hospitals. These academic hospitals only perform a kidney transplantation. There is a waiting list for kidneys due to the shortage of living- and post-mortem donors with a waiting period of approximately 2.2 years [9].

Our previous research (phase 1 and 2) identified several factors that impede access to kidney transplantation [3,4]. Participants in that study believed these factors should be overcome to promote timely access to transplantation. After mapping, five topics emerged: policy, medical, psychological, social, and economic. First, a policy-related barrier is that the guideline for preparing a patient for kidney transplantations is not

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always clear to healthcare providers and patients. Healthcare providers are not always aware of the guideline, latest developments, eligibility criteria and the timing of transplant candidate assessment. For patients, not knowing about the guideline leads to them being unable to inform themselves properly. However, a guideline is available in the Dutch setting. This guideline indicates, among other things, when a preventive kidney transplant is recommended and what age or BMI is considered the norm to be eligible for a kidney transplant [10]. Second, a medical topic is that different transplant centers approach the medical criteria differently, and these differences are not always clear to healthcare providers and patients. This could lead to patients not being admitted to the hospital in time or for second opinion to receive a transplant. Third, psychological factors play a role in accessing kidney transplantation. As a small group of patients fear transplantation and/or experiences positive social effects at the dialysis unit, which make them want to continue dialysis longer than necessary. Fourth, our previous study revealed, in line with other studies, that patients with a language barrier (no or limited command of the Dutch language speaking) and/or low literacy experience prominent barriers to kidney transplant care [11]. This group of patients' access to kidney care is hampered because they cannot always properly understand the information received regarding the transplantation process. In line with other studies, patients with low socioeconomic status appear to face the same barriers [12]. Consequently, this leads to a delay in referral for kidney transplantation in these groups. Another remarkable finding in our previous study is that in the Dutch setting, some of the interviewed patients and donors perceive certain aspects of aftercare for donors as inadequate, often due to unmet expectations. For example, a group of donors expected more contact with the healthcare provider after the transplant. They expected more interest in how they are doing and, if applicable, an aftercare program that meets their needs as a result of the transplantation. An unmet expectation of aftercare can jeopardize a good reputation of the living donation program and deter future donors [9]. Fifth, economic factors play a role. For example, insurers charge different purchase prices for dialysis treatments, and financial incentives for the centers that perform dialysis do not always seem to stimulate the treatment that is in line with the patients' needs.

All these factors lead to differences in access to kidney transplantation and are located across the entire range within the kidney transplantation care pathway. Therefore, there is a need for a broad perspective of strategies formulated by participants involved in kidney care to implement timely (pre-emptive) transplantation. In the present article, we aim to contribute to change by asking participants, that are involved in kidney care, to debate and formulate strategies on policy, social, economic, medical, and psychological barriers that pave the way for an efficient kidney transplantation ecosystem. No distinctions are made between race and sex, although these characteristics were mixed in most of the groups.

2. Methods

2.1. Procedure

The theoretical basis for this qualitative study is grounded theory, which emphasizes the neutral position of the interviewer [13]. After the first unguided phase, follow-up themes were used as discussion points in the second, more guided research. In the second study, all identified bottom-up factors from the individual interviews were presented to previously interviewed participants for comments to form an integrative view. Opinions on the factors were obtained from other participants in the in-depth interviews. With these insights, we provided an overview of the differences and similarities from the perspective of participants on the emerging themes for the third phase of the research. In this third and final phase, participants were asked to suggest strategies for the integrated factors to promote access to kidney transplantation. We report this third phase in this paper.

2.2. Participants

The third phase interviews were initially conducted in homogeneous focus groups of patients, donors, social workers, nephrologists, surgeons, nurses, policy employees, and insurance representatives. Later, one-to-one interviews supplemented the focus groups to include participants who could not attend the planned focus groups.

The interviewees were selected according to the chosen sample method, as was the case in the first phase of the study, and included all participants of phases 1 and 2 [3,4,14]. Because dialysis in the Netherlands may be performed in academic, non-academic and private centers, but transplantation may only be performed in academic centers, healthcare providers have been selected based on their position in the pathway towards transplantation in both academic and non-academic hospitals. In this way, an attempt has been made to represent the barriers experienced by all the different healthcare providers as fully as possible. Furthermore, we ensured geographic variance. The kidney patients were adults 18 years or older, pre-emptively and non-pre-emptively transplanted, and identified by the participating healthcare providers. Participants helped point out or actively searched for other relevant participants to arrive at sufficient variance – the snowball method [14]. New participants were added until a point of saturation was reached, as is common in grounded theory [15].

All participants provided informed consent, and the protocol was approved by the Medical Ethical Committee of Erasmus MC Rotterdam, registered under MEC-2018–1473.

2.3. Data collection

The interviews were conducted on the following topics (in terms of grounded theory: sensitizing concepts): policy, medical, psychological, social, economic regarding access to kidney transplantation. The interviews were conducted using an interview guide (see Appendix A.1).

2.4. Data analysis

The interviews were held in 2022. Participants were selected based on geographic spread. For example, healthcare providers came from different regions and healthcare authorities in the Netherlands. All interviews were recorded and then transcribed verbatim, and all textual data were coded using NVivo software, and text elements as spoken by the respondents were given codes representing their content [16]. Based on this inductive approach, a conceptual model was built based on the codes (see Fig. A.1). Codes were grouped into themes in several steps to finally arrive at a model. In the first phase, text elements were labeled and sorted into open codes [13]. In the second phase of the coding process, open codes were grouped if they were closely related. If the code was eventually considered irrelevant, it was eliminated after being on hold in a miscellaneous category. Axial coding was applied in the third part of the coding process. In this phase, open codes were categorized into subthemes. The fourth and final phase of the coding process involved selective coding. This grouping of codes resulted in a code tree with branches. This classified the material into key themes that were used in the final analysis. Two researchers coded all interviews independently, leading to two code trees. The use of a second coder eliminates any blind spots the first coder may have [17]. To further improve reliability, several input meetings were organized with the project team and both coders to discuss and identify possible blind spots. This was done each time 20 interviews had been coded, and a consensus meeting was held after each input meeting. The consensus meeting identified similarities and differences between the two coding trees after which the following discussion led to integration into a final code tree. Moreover, during these consensus meetings similarities and differences were discussed over the various types of participants were discussed. Based on these findings, we developed a conceptual model (see Fig. A.1). The first and second columns of this conceptual model present barriers that have

been mentioned (first column) and participants direction for future strategies (second column) by the same participants in previous studies. The third row presents the sub-themes of the strategy phase that emerged in this current study, by the same participants.

3. Results

Seventy participants were enrolled (see Table A.1): nephrologists ($n = 14$), patients ($n = 12$), former living kidney donors ($n = 7$), social workers ($n = 11$), surgeons ($n = 5$), nurses ($n = 5$), policy employees ($n = 12$), and insurance representatives ($n = 4$). The five themes are discussed below. Each theme is illustrated by a quote from a participant (see Appendix A.2).

3.1. Policy related

The previous study showed that there is not always clarity among participants about the presence of a guideline in the preparation of a kidney transplantation. In this current study, participants suggested as a strategy to raise awareness of the guidelines by making them more widely known to healthcare providers and patients. They saw this as the most important proposal and suggested making the guidelines widely available on well-known websites that healthcare providers and patients visit regularly. Furthermore, participants argued for the guidelines to be frequently mentioned in newsletters. A small proportion of the participants thought that more attention could be paid to the education that healthcare providers receive, for example during training or courses regarding the content and use of guidelines, both before and during professional practice.

The previous study revealed that there is sometimes a lack of clarity among healthcare providers about their role in the preparation to kidney transplantation. For example, who provides what information to the patient, or who does the final weighting on the criteria for kidney transplantation. The current study reveals that participants believe that the treatment center should clarify and document the division of roles within the care path. This means that they must make agreements at a local level about who is responsible for which part of the kidney transplant care path. Some participants suggested employing a transplant coordinator for each center.

3.2. Medical

The previous study showed that it is not always clear among healthcare providers and patients which medical criteria are used by transplant centers, for example on age and BMI. This current study shows that participants sometimes have differing views on whether there should be unity in medical acceptance criteria for transplantation. However, they expect transparency regarding these differences to allow healthcare providers and patients to self-guide to ensure more efficient access to transplantation. Participants argued for more accessibility to the criteria on various centers' websites. In this way, patients can see whether specific criteria could result in them being ineligible for transplantation before they are referred to a center.

3.3. Psychological

In the previous study it emerged that a group of patients are motivated to continue dialysis for longer than necessary, because of the experienced social interaction with the healthcare provider. In this current study participants suggested helping these patients find an alternative social network. Participants indicated that having (frequent) consultations with healthcare providers and peer-to-peer meetings can help motivate patients towards having a transplant. One strategy many participants proposed was to set up a buddy system in which a transplanted patient is linked to a dialysis patient. Furthermore, the professional could help people find social interactions elsewhere (e.g., at a

community center). In this scenario, the role of social workers is particularly important.

The previous study showed that there is a group of patients with fears for kidney transplantation. In this current study healthcare providers noted that kidney failure after transplantation can increase the fear of transplantation. All the participants agreed that healthcare professionals should endeavor to address and reduce this fear. This group of patients can best receive support from experienced and trained professionals (e.g., psychologists). Participants suggest that the "fear surrounding transplantation" should be managed by the professional intervention of a psychologist or by introducing a buddy system of already transplanted patients. Most participants believed that fearful patients should be informed of both the positive and negative aspects of transplantation neutrally.

3.4. Social

In the previous study it emerged that there is a group of patients who have reduced access to kidney transplantation due to a language barrier. In this current study participants noted that interpreters are often not available, and some participants added that it was the patient's responsibility to learn the native language. Nevertheless, the participants unanimously agreed that language barriers should continuously receive attention. According to participants, a professional interpreter should always be present. Furthermore, they also see an opportunity to bridge this gap by using visual educational materials (pictures and videos) for more general information.

The previous study showed that there is a group of patients who have difficulty finding a living donor because of a limited social network. The study showed that much is being done in supporting patients and their social networks, such as the Kidney Team at Home program (a tailor-made, home-based educational intervention program). This current study shows that according to participants, patients who cannot find a living donor in their social network can get help using social media or via someone else with a more extensive social network.

Donors are of great importance for patients with kidney failure. It is preferable to transplant patients both pre-emptively and with a kidney from a living donor because of the negative influence of dialysis time on patient survival and the higher quality of the kidney from a living donor which is reflected in, among other things, a much better average graft survival [5]. In the Dutch setting, a patient is placed on the transplant wait list after eligibility assessment by a transplant nephrologist. Generally, due to the large wait list in the Netherlands for a kidney from a deceased donor, pre-emptive transplantation is only possible with a kidney of a living donor, very rare pre-emptive deceased transplantations aside. The previous study revealed that there is a group of patients and donors that perceive certain aspect of aftercare for donors as inadequate. For example, donors indicated that they expected to have more contact with the healthcare provider after the transplantation about how they are doing or expected an offer to discuss a personalized after care path, if applicable, in line with their needs as a result of the transplant. According to participants this could also lead to a negative publicity for future donors. In this current study participants agreed that donor aftercare should be more attuned to the needs of the donors, for example because the perceived lack of aftercare could negatively affect the willingness of future donors. According to these participants poor promotion of living kidney donation due to disappointment experienced by previous donors can be reduced by more clearly discussing expectations pre-donation. Most participants in this study believed that aftercare could be solved by thoroughly discussing the expectations of aftercare with the donor in advance. Some participants also saw a role for dedicated donor case managers who could regularly monitor donor needs post-donation. A few participants see room for private clinics to provide (partly) aftercare since they are used to spending more time and resources on high service. Another group of participants suggested a special day for donors or a gift for donors to remember and celebrate

their acts. All participants agreed that donors deserve good aftercare.

3.5. Economic

The previous study showed that different prices are used for a dialysis treatment. It also showed that in some cases production agreements are made between the care provider and insurer. In this current study, according to a group of participants, removing market forces could resolve the observed negative economic motives for transplantation. These participants argued that insurers should set a fixed price for dialysis for all centers. According to another group of participants, market forces should stay in place. These participants did not see a problem with having differences in prices between the different centers.

The largest group of participants in this current study believed that making a profit in healthcare is not in line with the intended social goal of care. Another group of participants believed that making a profit in healthcare is possible. According to this group, this could lead to innovation. Most participants in this group saw a strategy for market forces: profits flowing back into healthcare could facilitate innovation and benefit patients. Notably, participants found it difficult to formulate strategies for the economic barriers as they felt they needed to be more competent on this topic.

4. Discussion and conclusion

4.1. Discussion

This study found several new ways to solve barriers to accessing kidney transplantation and confirmed strategies mentioned in the literature. Below we combine our findings with those reported in the literature.

Regarding policy, the apparent no unambiguous thinking about guidelines regarding the care of patients with kidney failure can be partially resolved by making the guidelines easier to find. Stakeholders consider sending newsletters and making guidelines available during education, both before and during professional practice, as strategies. Previous research indicates that ongoing education for medical professionals requires attention, partly to promote a well-timed transplantation [18]. The present study also adds that existing guidelines, which are constantly evolving, should be actively offered to professionals involved in the field. It is surprising how straightforward the strategy proposed by stakeholders in this domain looks. This evokes the question of why such seemingly simple strategies have not been implemented already and raises the suspicion that not yet have a complete picture of the problem. This current study suggests that a more coercive approach to the guidelines seems desirable, for example by imposing an obligation to attend sessions when discussing guidelines at conferences, or for example by making more time available for this topic in the schedules of healthcare providers. Policy makers, for example representatives on behalf of nephrologists and/or patients, could take the lead to give further direction to these strategies.

Regarding medical acceptance criteria for transplantation, some of the stakeholders initially believed that these criteria should be the same everywhere. However, not allowing differences also hinders innovation and gaining experience with exceptions. Centralized care for exceptional cases, through which experience and knowledge can be built up, can lead to progress in the development of different treatment options. After discussing this topic with the stakeholders, they believe that if there are any differences, they should be transparent for healthcare providers and patients, so that a patient with special needs can be referred immediately to the right place or referred for a second opinion. Also previous research has recommended greater transparency of medical criteria for patients [3,4,19]. Lack of transparency could lead to delay or failure to refer for transplant. Clear information, which is available to both the professional and the patient, about acceptance criteria and special treatment options with regard to kidney transplantation on e.g., the website of the different

transplant centers, or a common platform, could contribute to solve this problem. Notably, it will be necessary that for such an initiative that a respectable authority takes the lead, for example a national quality register, to avoid professionals and centers not participating, due to unfavorable outcomes or lack of capacity or interest. Policy makers, such as representatives on behalf of nephrologists or patients, could give direction to the implementation of the strategies proposed by stakeholders. The strategies proposed by stakeholders may impose a burden on patients. However, transparent information about medical criteria helps the patient to find information easier and faster, also when patients want to be able to inform themselves.

For psychological issues, stakeholders suggested linking a psychologist or a buddy to a patient could expedite a referral for a kidney transplantation. Previous research has shown that the use of a psychologist has proven to be effective in referral for kidney transplantation [20]. Furthermore, previous attempts to match patients with a buddy who assist the patient during the illness, such as patients with diabetes, have shown positive results in patients [21]. These patients actively started working on strategies for their illness. This can be explained because patients seem to value the common understanding and experiences of peers. This study adds that pairing a buddy with a kidney patient may also help patients to find ways to socialize other than in the dialysis ward. However, contact with fellow sufferers may not always be successful. Unlike other examples where peer contact is used, a kidney transplant is not always successful [22]. That can result in a peer with a negative experience. This negative experience can therefore further inhibit a kidney patient's enthusiasm to be referred for kidney transplantation. If such a system were to be adopted, one must therefore ensure that there are trained peers with a realistic representation of a kidney transplant treatment in which both positive and negative experiences can be properly discussed. The healthcare provider could have a signaling role, for example during the consultation hour, in this need which could lead to referral to a trained peer.

With regard to social theme, stakeholders proposed different strategies to improve information provision for non-native speakers. A significant proportion of kidney recipients have a low literacy [23], which means that providing information in text is not a good option. In this current study stakeholders therefore suggest for more visual representations instead of only offering the information in text format. It has been proven that providing information in visual ways can make an important contribution to a better understanding of what is being told [24]. It has also been proven that images are processed much faster than text and, when presented well, also linger longer in memory [25]. Given the complexity of the information that kidney patients receive during their treatment process, it is therefore obvious to make use of this among other methods to inform patients. In addition to the above suggestions for improvement, a professional interpreter is important. Although in the current and previous studies an interpreter is mentioned as an important means of properly informing patients with a language barrier, it is remarkable that this is often not yet available in the preliminary phase of a kidney transplant [3,4,26]. Most stakeholders prefer a medically trained interpreter to ensure that the information is communicated correctly. A professional interpreter who understands the medical language well and has no emotional relationship with the patient, is preferred to inform patients properly and contributes to cost-efficiency and higher quality of care [27,28]. It is not clear from the current study why the deployment of these professional interpreters remains limited. One can imagine that the costs of using a professional interpreter could play a role or that the available time of the healthcare provider for a consultation constitutes an obstacle to the standard use of an interpreter for low-literate people or patients with a language barrier. These patients are therefore highly dependent on what the treatment center has to offer in this area, and this creates inequality in this group.

Finding a potential living kidney donor remains an obstacle to timely transplantation [3,4]. Stakeholders see opportunities to find living donors by using social media better. However, during the interviews with

the stakeholders, it was emphasized that before posting a call on social media to find a living kidney donor, it is important to point out the advantages and disadvantages of recruiting via social media, such as how to deal with disappointments when expectations are not met. Disappointment can contribute to a kidney patient becoming less enthusiastic about continuing to look for a living donor. It is therefore particularly important to properly guide patients in their online search for a living donor, for example separating serious offers from impulsive offers from potential donors in a timely manner. However, they note that the patients' networks are often small; therefore, professionals may be able to help by locating others with a more extensive network. Previous research demonstrates that supporting people with a small social network is accomplished by linking a patient with a small network to someone with a larger network [29].

Some former kidney donors who participated in this study indicated that they had different expectations of the (post) donation process and that they were sometimes really disappointed in the care. It is obvious that well-coordinated, adequate care is of great importance for donors and, of course, for all other patients. In line with previous research, stakeholders seem convinced that care after kidney donation deserves a different approach [30].

The current study adds that professionals and donors should make mutual expectations and decisions clearer before the donation or transplantation take place in order to better match the (after)care with donors' needs. It is expected that this will not only benefit current donors, but also contribute to a positive experience for future donors and improve the image of transplant and donation care in general. Hence, healthcare providers, in particular nephrologists, should take on the role of clearly discussing and expressing expectations regarding donor aftercare. Moreover, it seems desirable that patients should be given the opportunity to contact the hospital if their expectations about aftercare are not met.

Finally, from an economic point of view, different purchasing rates between dialysis centers are undesirable for most stakeholders. Many stakeholders called for this to be stopped or made more transparent. Previous research indicates that a kidney transplantation, in general, is significantly less costly compared to dialysis [31]. It is noteworthy that currently, financial incentives are not directed towards the best treatments option for most patients, namely kidney transplantation. A dialysis generates more long-term turnover and a (referral for) kidney transplant much less. In the discussion with stakeholders, they agreed that this kind of incentive should change but stakeholders found it difficult to suggest an alternative reimbursement scheme.

In our view, one could propose a system that rewards the right treatment for the right patient at the right time, rather than cutting back on budget and staff when sub-optimal treatment is continued. For example, centers that refer suitable candidates for (preferably pre-emptive) kidney transplantation, as soon as possible would be rewarded well or better.

4.2. Innovation

The large number of participants ($N = 70$) and variance in stakeholder groups provide an important overview how stakeholders see room for improvement by themselves. Many strategies seem possible to implement on the short term, for example more awareness of the guideline among healthcare providers, or more transparency of the medical criteria among stakeholders, including patients. Through more cooperation between stakeholders, in which they work together on the strategies addressed in this paper, the added value to the kidney patient can be maximized.

4.3. Conclusion

This study shows that the strategies proposed by stakeholders for the perceived barriers to access to kidney transplantation need to be found

in the entire spectrum of the care pathway. This indicates that the problem extends beyond the consultation room, but also, for example, in the training of professionals and into the financial systems.

4.4. Practice implications

Since these strategies have been formulated bottom-up by the stakeholders, relatively rapid implementation can be expected. In addition, more cooperation between stakeholders seems necessary and stakeholders should take joint responsibility for this. It is surprising that so many proposed strategies actually seem easy to imagine and implemented in practice. Follow-up research could focus on the implementation of the mentioned strategies, the possible obstacles to this, the effect of the implementation and, from a business economic model, exploring strategies to optimize collaborations between stakeholders which creates opportunities to look differently at the current market forces.

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Authors' contributions statement

R.G. van Merweland: Conceptualization, data curation, formal analysis, validation, formal analysis, methodology, writing, data curation, , visualization, and investigation, project administration, writing - original draft, writing - reviewing and editing. J.J. Busschbach: supervision, conceptualization, validation, methodology, formal analysis, writing - reviewing and editing, data curation, funding administration . J. van de Wetering: supervision, conceptualization, validation, methodology, formal analysis, writing - reviewing and editing, data curation. S.Y. Ismail: supervision, conceptualization, validation, methodology, formal analysis, writing - reviewing and editing, data curation, project administration, funding acquisition

Declaration of Competing Interest

There are no conflict of interests.

Data availability

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

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Appendix A. Supplementary data

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