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ORIGINAL ARTICLE

"What if this is my chance to save my life?" A semistructured interview study on the motives and experiences of end-stage renal disease patients who engaged in public solicitation of a living kidney donor

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SUMMARY

The increase in patients using public solicitation (PS) to find a living kidney donor has generated a debate about the ethical complexities of PS. To investigate why patients engaged in PS and what they experienced during PS, we conducted semistructured interviews with 20 Dutch patients with end-stage renal disease who had publicly solicited a living donor. Transcripts were thematically analyzed. We identified ten themes on patients' considerations preceding PS: cautiousness in discussing living donation within social network; reluctance to accept a kidney from loved ones; rejection/withdrawal of related donor candidates; moral objections to paid donation; the ease of social media; encouraged by others; ends justifying the means; despair and urge to take action; public disclosure of vulnerability; fear of being (perceived to be) selfish. We identified nine themes on patients' experiences: positive emotions and support generated by action; genuine and ulterior motives for donation; patients acting as educators and screeners; time- and energy-consuming process; emotionally taxing process; positive interactions with donor candidates; feeling of dependency and obligation; limited cooperation from health professionals; demands a proactive attitude and media strategy. These results can inform and complement (existing) policies on PS and provide content for education of patients who are considering PS.

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Introduction

Due to continuing organ shortage and the increasing use of online media, a growing number of patients with end-stage renal disease (ESRD) choose to solicit a living kidney donor in the public arena. Public solicitation (PS) is defined as a public plea for an organ by patients or their representatives on social media, websites, television, radio, car stickers, billboards, newspapers, or other forms of advertising [1,2]. This results in a solicited

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specified donation, "whereby somebody donates an organ directly to the recipient specified in the PS, without being genetically or (initially) emotionally related to that person" [2]. Solicited specified donation is only legally permitted in a limited number of countries, such as the USA, Canada, the UK, and The Netherlands [3]. From clinical practice, we know that the number of patients who engage in PS in the Netherlands increases every year; however, the number of patients who engage in PS (worldwide) is unknown.

The inherent lack of anonymity between donor and recipient in solicited specified donation has given rise to a debate on the ethical complexities of PS. Concerns include the potential for creating a "beauty contest" [4] and organ trade [1,2]. On the other hand, PS generates a new source of living donors, which results in patients being removed from or bypassing the waitlist [5,6]. As PS will remain a reality, both because it has proven to work, and because social media is an integral part of modern life, it is of utmost importance that transplant centers (further) develop policies on how to manage education, screening, and counseling of patients who solicit donors publicly and solicited donor candidates [7–9]. To inform this process, we need to further explore and understand the phenomenon "public solicitation." Qualitative research methods are most suitable for this aim, because they allow for an in-depth understanding of the experiences of patients. Currently, empirical studies on PS are scarce and have only been conducted in, even for qualitative purposes, small samples [10]. Therefore, with this semistructured interview study, we wanted to give much-needed voice to patients in the discussion about PS by investigating why patients with ESRD decided to solicit a living donor in public and what they experienced during PS.

Materials and methods

Participants

We searched Google, Facebook, and Twitter for Dutch kidney patients and their representatives (e.g., family members/friends who initiated the public appeal) who publicly solicited a living kidney donor between 2011 and 2015. The following search terms (in Dutch) were used: "kidney donor," "find kidney donor," "find kidney," "found kidney donor online," "found kidney donor by social media," "Facebook donation," "Facebook donor," "kidney donor wanted," Patients were eligible for the study if they were over 18 years of age, had sufficient command of the Dutch language to participate in the interview and if their contact details were publicly available. Patients who could only be approached via an intermediary (e.g., newspaper editors) and patients who did not live in The Netherlands were excluded from the study.

Procedure and measures

Eligible patients were invited for the study by e-mail, telephone, or social media. Semistructured interviews were conducted between December 2015 and March 2016 by two female researchers who were not part of the treatment team (MP and DS). The interview took place at the participant's home or at an alternative location if desired, and lasted between 60 and 90 min. When PS was initiated by a relative/friend, interviews were conducted with the patient and their representative ($n = 3$). At the request of two patients a family member was present during the interview. Based on the previous literature [10,11] and clinical experience, the authors developed an interview schedule, which covered the patients' considerations when deciding about PS and their experiences during PS. The questions were pilot tested in the first two interviews (included in the analysis), after which they were further refined. Participants also completed a questionnaire on sociodemographic and medical characteristics. Table 1 presents these characteristics, Table 2 presents a brief overview of the topics addressed in the interview; the complete guide is provided in the Appendix S1. As we did not have access to the participants' medical records, objective information, such as duration of dialysis before PS, could not be verified. Interviews were audio-recorded, transcribed verbatim, and anonymized. A narrative summary of the transcript was sent to each participant so they could comment on it to check accuracy and interpretive validity [12]. All participants signed a written consent form. This study was approved by the Ethics Committee of the Erasmus MC, University Medical Center, Rotterdam, The Netherlands (MEC-2015-573). We reported the results in accordance with the COREQ guidelines [12].

Analysis

Using the constant comparison method, described in Grounded Theory, an inductive qualitative analysis of the transcripts was conducted [13]. Sections of text were coded by assigning descriptive labels; codes were categorized in overarching categories; and similar categories were grouped into themes. Transcripts were coded

Table 1. Sociodemographic and medical characteristics of participants ($N = 20$).

	n
Mean age (SD), range	46 (14.93), 26–74
Gender	
Male	12
Female	8
Education	
Primary/secondary education	7
Further education	13
Ethnicity	
European	20
Income*	
Below-modal	7
Modal	4
Above-modal	7
Missing	2
Media channels used by participants in their donor search†	
Facebook	15
Twitter	4
Newspapers	9
Personal website	6
Radio/TV	3
YouTube	3
Bumper sticker	3
Blood type	
O	12
A	5
B	3
Type of RRT before PS	
Dialysis/CAPD	15
No RRT (yet)	5
Mean months of dialysis before PS (SD), range	49.81 (60.50), 3–204
Transplants before PS	
0	13
1	3
2–4	4
Mean months of searching for a donor before PS (SD), range	23.29 (24.61), 4–84
Transplant status at time of interview	
Not transplanted (yet)	11
Transplanted via PS	4
Transplanted via unspecified donor	1
Transplanted via deceased donor waitlist	4

*The gross annual modal income of a Dutch household in 2015 was €35.500 [25].

†Participants used between one and five media channels.

independently by two authors (MP, DS) using NVivo (QSR International Pty Ltd., Version 11, 2015, London, UK). Coding discrepancies were discussed until agreement was reached. When necessary a third author (EM) was consulted. Patterns and conceptual links among themes were identified and mapped onto a thematic model.

Results

Based on our search criteria, we were able to identify 40 public solicitors, 20 of whom agreed to participate. In the final interviews, no new themes were observed; therefore, data saturation was reached. Participants came from eight of 12 Dutch provinces were mostly male ($n = 12$) and aged between 26 and 74 years (Mean = 47, SD = 14.6). See Table 1 for participant characteristics. Four patients refused to participate because they found participation too taxing ($n = 3$) or they had participated in a similar study ($n = 1$). Sixteen patients did not respond to the invitation for unknown reasons.

Considerations prior to PS

Table 3 presents quotations illustrating participants' considerations regarding PS.

Cautiousness in discussing living donation within social network

Participants experienced that relatives and friends often did not recognize the gravity of their situation. Nevertheless, few participants directly asked their social network to donate. They did not want to acknowledge the vulnerability of their situation to themselves and others, felt that a kidney is a great gift to ask for, or feared negative reactions.

Reluctance to accept a kidney from loved ones

Some participants were reluctant to accept a kidney from their loved ones, especially when the potential donor was a young adult or a parent of young children. Participants wanted to avoid feeling guilty if anything happened to the donor as a result of the donation and/or feared an unequal relationship with their loved one.

Rejection/withdrawal of related donor candidates

All participants had at least one specified donor candidate who had been screened for donation, but they were all found to be ineligible. Most were declined by the transplant center because of medical reasons or withdrew because they got scared. Some participants excluded potential donors who were not ABO-compatible.

Table 2. Topics addressed in the semistructured interview*.

Topics	Subtopics
Decision-making	
Experiences with finding a kidney donor in social network	Did patients discuss living kidney donation with the social network? If yes, how? Where those in the social network of patients willing to donate? Why (not)? Were patients willing to accept an emotionally or genetically related kidney donor? Why (not)?
Considerations before public solicitation	What were the expected pros and cons of public solicitation? What was the opinion of significant others about PS? Did patients think about ethical aspects of PS? (Fairness of allocation; commercialization)
Experiences	
Experiences with public solicitation	How did patients experience PS? (Positive and negative experiences) How did their social network and transplant professionals react to their appeal? What kinds of responses were received from the public? (Kidney offers, positive/negative reactions) How did patients manage the responses (logistically/emotionally)?
Experiences with a potential donor (if applicable)	How was the contact between the recipient and the (potential) donor(s)? In case of several potential donors, how was the final donor selected?

*The complete interview guide is available as Appendix S1.

Moral objections to paid donation

The majority of participants disapproved of buying a kidney, because they feared blackmailing, believed this would be unfair to patients who do not have the money to buy a kidney, or because they did not want to violate the law. They also believed it would be too risky to be transplanted with a traded kidney and did not want to benefit from someone else's poverty. Some participants reported that they would buy a kidney if they would have the means to do so or if their medical situation became more urgent, implying that they perceived PS as a step that can be taken prior to exploring paid donation.

The ease of social media

Participants thought that asking for a kidney on social media (both within and outside their social network) would be easier than asking face-to-face given the enormity of the request. The accessibility of social media was also appealing: They could post their appeal and immediately reach a wide audience.

Encouraged by others

Some participants were encouraged to engage in PS by their relatives or friends; some of whom had initiated and coordinated the appeal. Many participants were encouraged to try PS by positive experiences of other patients who had publicly solicited a donor and consulted them for advice. Some wanted to solicit a kidney before PS became more popular, fearing their appeal would then get lost in the crowd. One participant was encouraged to try PS by a transplant coordinator.

Ends justifying the means

Given the perceived unfairness of the situation in which participants found themselves (i.e., being responsible for finding a donor in the context of the organ shortage), they strongly believed that they should be free to choose how to find a donor and that new means to shorten the waitlist are justified.

Despair and urge to take action

Despite rational consideration of the pros and cons, it was despair elicited by a rapid decline in physical health, the thought of having to start dialysis soon and/or a fear of premature death that urged participants to engage in PS. Participants wanted to take control over their donor search, to do everything they could to improve their situation and prevent any regrets.

Public disclosure of vulnerability

Participants realized that engaging in PS would mean they had to disclose very personal information in public. They struggled with the idea of exposing themselves

Table 3. Illustrative quotations reflecting patients' considerations about PS.

Theme	Quotations*
Cautiousness in discussing living donation within social network	"I wasn't used to talking about my disease that much. I felt that I had already been too much of a burden to others. (. . .) It always hurts me when people say: 'wow, I admire you for having a job and for having studied'. I don't like to hear from people that I'm special. It somehow stresses the severity of my disease." I10 "It's not a bag of sugar you want to borrow for a while. It's a part of someone's body. It is a lot to ask and you ask it of a healthy person. It is not something to ask lightly. That is the reason I eventually put it on Facebook. I felt I could ask it that way." I42 "Firstly, I'm scared of getting no for an answer and getting no every time makes me feel more down. And secondly, I feel like people know what situation I'm in. They know I'm looking for a donor. So if you want the best for me, do it yourself. And I think that the offer should come from them." I46
Reluctance to accept a kidney from loved ones	"My son also said to me: 'dad, you are going to get a kidney from me'. Yes, but I don't want that. We're not going to do that. I'm not gonna ask for a kidney from a 21-year old boy who has his life ahead of him and could potentially have a kidney disease himself." I32 "I already accept a lot from my sister. (. . .) I feel like if I would accept her kidney, I would have to be even more eternally grateful and do everything she says." I05 "I wouldn't want it from my children. And even if it would match, I would think: I'd rather stay on dialysis, or wait for a deceased donor, or for the developments that the Kidney Foundation are doing such a great job on. That, no, they have their lives ahead of them." I42
Rejection/ withdrawal of related donor candidates	"And there's no one in my network who is eligible. They don't match in any case. And there are a few that have a chronic illness themselves so can't donate. So I really didn't have anyone."I34 "So I have had 5 family members tested, my father, mother, brother, cousin and second cousin. None of them were a match."I07 "There was a friend of mine who said I'm going to help you. And she was approved, but in the end she withdrew, she couldn't take it. Didn't dare to do it. And I understand that, I respect that." I26
Moral objections to paid donation	"Of course people say to me: 'I often go to Indonesia, I could easily bring along someone who wants to donate a kidney'. Those people would do it out of pure poverty and I don't want that. That's my limit. (. . .) Then I would have the feeling that I was taking advantage of someone else's poverty. I don't want that." I05 "We have certainly considered the option of buying one. But we decided that it would be too risky. (. . .) If it had gotten that far we might have done it. Because it's not nice to have to face death. (. . .) Initially we chose not to buy a kidney, but that was because of Twitter and Facebook in the Netherlands, that [the responses they received to the appeals] brought a bit of joy." I12 "I am fundamentally opposed to paid donation. Buying health just because you have the means, that's not in my vocabulary. I believe that everyone should have the same rights to health as all the rich people in the world." I14
The ease of social media	"Yeah Facebook was just easily accessible. You just have to have a good text, photo and you can post it the same evening." I10 "We thought that Facebook would be less intensive. (. . .) This was actually a way to reach out to more people, but also to spend less energy on it. You put it on there and then you see what happens." I24
Encouraged by others	"I felt I had to save Dad. I felt that the only thing I could do was to put it on Facebook and then I would have done everything I could." I14 (patient representative) "The transplant coordinator asked me: 'have you got a donor?'. No, I said. 'OK. Have you possibly considered finding a donor yourself?' I said: what do you mean? 'Well', she said, 'there is this thing, we still have to get used to, but we're starting to get used to it a little bit'. It sounded really strange the way she said it. 'That people make an appeal on Facebook'." I43 "I remember when he (a public solicitor) was on TV in February that year and I thought about it, again and again, for a few months. I talked about it with those closest to me, with my mother. She said: 'Nothing ventured, nothing gained. Just try it'. I then sent a Facebook message to the person I saw on TV: 'I think it's great and admirable what you did. How did you do it and have you got tips for how I could do it?'" I26

Table 3. Continued.

Theme	Quotations*
Ends justifying the means	"At this point there is a dire lack of donors, so every method that convinces someone to become a donor is positive. (. . .) I find it unethical that people have allowed this situation to occur. Because everyone is lax; the government is lax, the medical world is lax, the health insurance companies are lax; it's shifted on to the patients to find a donor. (. . .) In my opinion it's unethical to saddle them with that choice. Because if I have to choose between dying or surviving, I'll fight with everything I've got to survive." I07 "Isn't that the case with everything you do in life? If I go sit on a chair and wait, nothing will happen really. How can I say that if I start a business or come up with a nice idea, that I should feel guilty for coming up with a nice idea while someone else didn't?!" I35 "If you could only do it (living kidney donation) anonymously, then I think you'd exclude a whole group. Once more, the most important thing is that the waiting list gets shorter." I34
Despair and urge to take action	"After my father got rejected as donor we said: 'we will put it on Facebook'. At least my partner said: 'now I'm just gonna put it on Facebook'. I didn't want that. Somehow begging for a kidney. But I thought: well, go for it, because after all it's my life at stake." I06 "The necessity became more and more clear to me. I grew up with three dialysis buddies. They all died within a year. They were my peers. (. . .) And that contributed to me being more open about it. To me starting searching for a donor again. Using controversial methods to find my match." I10 "My transplant nurse came to talk to me and said: 'You'll be put on the waitlist soon. (. . .) That can take 2 months, but also 10 years. And you don't have 10 years anymore. Don't you have a donor?' (. . .) That struck me so hard that it kept running through my head all night. The next day I plucked up courage and put my appeal online."I46 "At some point I thought: do I really want this? Am I going to do this? Eventually I thought: 'dear god, what if this is my chance to save my life?!'. Then you start to think differently. Then it is not a dilemma anymore. Then you start to see it as something that crossed my path. Any chance you get, that's how I saw it at that time." I26
Public disclosure of vulnerability	"OK, do I really want to go as far as to putting my story out there? 'Cause people will recognize you on the street. People will approach you. People will comment. That's what I found difficult. I mean, I've have always been pretty closed and private and suddenly it's all out there." I26 "For example with looking for a job. A potential employer will search for you online. If they find the first hit to be 'searching for a kidney', that's not really promising." I23 "If I wouldn't have done it, it would be because of that: being vulnerable. That you need to share a lot of information you actually don't want to share in order to achieve the best possible result. We considered that for sure, but it doesn't offset what is yet to come: the possibility to get help. So you just have to make this investment. You just have to go three steps back in order to take six steps forward." I24 "What I did think about was that there might be people who ask for money 'for a kidney'. I did think about that." I05
Fear of being (perceived to be) selfish	"I was very afraid of getting negative reactions. 'How do you dare to ask?' 'Are you nuts?!' Or religious people (. . .) who think: 'that's not allowed, God will determine the time of our death', you know. I expected these kind of reactions." I05 "I thought to myself that all the people who had solicited for a kidney in public have been on dialysis for a long time. Then I thought: aren't I being a bit selfish to appeal straight away? I haven't even been on dialysis yet." I43 "It was quite a step for me, to put it on Facebook, to ask for a kidney. I thought about it for quite a while. I was still working, at least four times a week. And still up to about a week before I heard that things were going really badly. At that point you think, you know, maybe you are taking someone away for someone else who really needs it ." I08

I, interview.

*For privacy reasons, participants' quotations used in this article are all written in the masculine form. All quotations were translated from Dutch to English by a native English speaker (EM).

as a kidney patient and were aware that people might attempt to take advantage of their dependency.

Fear of being (perceived to be) selfish

Some participants wondered if it was fair to engage in PS, while other patients were in more urgent need of a kidney. They considered that PS might lead to competition among patients and that some might have a higher chance of finding a donor than others, depending on their (social) media skills or on how much sympathy their story generated.

Participants feared being judged by fellow kidney patients and society if they would engage in PS, but reassured themselves that if they would find a donor, another patient would move up the waitlist.

Experiences with public solicitation

Table 4 presents quotations illustrating participants' experiences with PS.

Positive emotions and support generated by action

Participants received an overwhelming amount of empathy from a wide range of people (acquaintances and strangers) who saw the public appeal. Some people participated in the donor search, for example, by "sharing" the appeal on social media. Participants felt that their disease was finally understood by their social environment and were touched that so many strangers considered donating their kidney to them. They described that it felt good to take action and that the offers of a kidney in response to their public appeal brought back hope of finding a donor. Additionally, patients felt good about raising awareness for the organ shortage in general.

Genuine and ulterior motives for donation

Participants reported that some potential donors wanted to do something meaningful in their life. Others had considered donating before but had never had a reason to actually do it or were not able to help their relative/friend in need of a kidney at that time. Almost all participants received offers of a kidney in return for money or payment in kind (such as employment, residency, or sexual favors). Participants also received offers from prisoners who wanted to do something good for another person. Offers for payment (in kind) appalled participants and were ignored or turned down. They wanted a kidney to be an unconditional gift from a donor.

Patients acting as educators and screeners

Participants felt that they had to take on an all-consuming role as educator and donor screener. They tried to decipher the motives of potential donors, direct candidates to sources of information, and assess which potential donors they should refer to the hospital to enter screening (first). For example, participants preferred persons with the same blood type; persons without certain contraindications such as diabetes; and middle-aged participants preferred middle-aged candidates over young adults.

Time- and energy-consuming process

Some participants received so many responses that they struggled to respond to them all. In some cases, managing the contact with potential donors had a negative influence on their physical health. Participants quickly discovered that it was not feasible to meet all potential donors, as they had intended to. They had to save their energy to meet the ones who had already undergone at least part of the donor work-up process.

Emotionally taxing process

Participants struggled with "having to beg for a kidney to stay alive," and to manage the uncertainty regarding their chances of finding a donor. Some participants were disappointed with the low number of responses they received or that, in contrast to the many reactions from strangers, very few relatives and friends responded to their appeal. Others received many offers from potential donors who eventually withdrew or were found to be ineligible. At the beginning of the process, participants reported allowing themselves to feel hope and joy at each offer of a kidney, whereas later they repressed this initial emotional reaction to prevent subsequent disappointment. Participants felt shocked about judgmental reactions they received, which often came from fellow kidney patients who felt it was unfair that participants tried to push to the front of the "queue." The constant need to justify their decision to engage in PS to strangers was exhausting for participants.

Positive interactions with donor candidates

Participants were generally happy with the kind of contact or relationship they had with their (potential) donor(s). They tended to let the donor determine the

Table 4. Illustrative quotations reflecting patients' experiences with PS.

Theme	Quotations*
Positive emotions and support generated by action	"Yes, suddenly we got a lot of support for finding a kidney. That is how we saw it. (. . .) Hope, there was hope again. Because the waitlist you were on for all those years does not give hope." I12 "I received so many lovely, heartwarming, sweet reactions. That is very special. Even more than I ever received from people in my own environment. You know. That is really great." I42 "I felt understood, like oh, she is really sick. (. . .) It's just the ignorance of people who make comments that immediately cut deep and can hurt. And that's less now." I46 "It was also to bring it to people's attention. Think about how important it is to register as a donor. But of course also with the idea: who can give me one?" I19
Genuine and ulterior motives for donation	"Half a year ago I received an e-mail from a woman. She said: 'well if you can offer me a job, then I will donate my kidney to you'. In fact that is the same as buying it, eh." I19 "Yeah very strange reactions. Like I'll give you a kidney in return for a one night stand." I34 "Or people, lots of people, most of them, say I was already thinking about [donating a kidney], but I never had a reason to do it. And your story was a reason for me to do it." I26 "People do it really, at least in my experience, mostly for themselves. What I often hear is: I feel restless or I want to mean something for someone, or I was touched by your story." I10
Patients acting as educators and screeners	"I made sure that they receive an email or sms with the details of the website, and links to the right brochures and other webpages for education and so on, so that they can see all that." I07 "The first people I referred to the hospital, I knew beforehand that they didn't have anything, medically speaking, and that they were just healthy. So these are the people who I referred first." I26 "Yeah, you select the ones first who have the right blood type. I needed exactly the right blood type." I24
Time and energy-consuming process	"I was spending each night answering all the e-mails at a certain point. I was sick and tired of it. It was a full time job." I05 "Yeah my girlfriend actually took on all the reactions to take the pressure off me." I24 "Because there is so much to deal with, a lot to deal with. Look, you have to understand there are hundreds of people who send you messages. All those hundreds of people you have to keep responding to, because otherwise it just dies a death."I43
Emotionally taxing process	"It shouldn't actually have to be this way. That you have to beg to stay alive this way. It's really, really terrible." I05 "You're left in suspense either way, but you also have that when you're on the waitlist. That's worse than the [physical] deterioration itself. The suspense of whether it's gonna be a success. Will I find someone. That has been the most difficult during this whole time." I34 "Oh 1200 offers, literally, so you think everything is going to be okay. Well, I had that feeling until March. I thought in 2 months' time I be there. But that's very misleading. The first feeling that you have is actually totally wrong." I10 "Yeah, they were kidney patients themselves. And they was like, you should wait your turn on the waiting list, because I have to too. Then I sent a message back to them: are you jealous or something that you didn't think of it yourself? I mean, if my spot comes free, then you can take my spot if you don't want to do something like this yourself. But also things like: I know where you live, I'm waiting for you. You aren't worth it and stuff. That sort of thing." I28

type and frequency of contact. Even though some participants initially felt scared about meeting a (potential) donor, for example, because they feared donor withdrawal, actual meetings were experienced positively. The four participants who, at the time of the interview, had received a kidney from a solicited donor were

Table 4. Continued.

Theme	Quotations*
Positive interactions with donor candidates	"We had such good contact with the donor, we were kept up to date about, oh then I'm having that test, then that test, and this is the result. The result was positive. To be kept up to date like that. Otherwise we wouldn't have known anything because everything was anonymous." I14 "Nobody asked me if I smoke or drink. Nobody asked what kind of job I do. It was always just about the donation. How does it work, who will I deal with. How long does the recovery take. Where can I go with my questions. Those kind of things." I10 "The night before the transplantation I went to visit [my donor]. We talked for a while about, yeah, lots of things, and wished each other luck. Gave each other a big hug." I35
Feeling of dependency and obligation	"Of course, you don't want to push people at all or give them the feeling that they have to do all kinds of things. So I had to watch out that I don't put on too much pressure." I42 "You don't want to think about them taking the kidney out and then something going terribly wrong during the operation or something." I35 "And the most annoying thing of all is that you have to put on a happy face all of the time. You really can't let anyone see when you're down. And people often think: I am helping you, be grateful. And of course I am grateful, but at some moments it is just not your day. You are just in a slump." I43 "Yes because yes, how grateful do you have to be? How grateful CAN you be? And how do you express that? It is REALLY difficult. I, erm, all those people who contacted me and were tested. Yeah I email with them. And then they have to give blood and get test-tubes sent to them. To have their bloods taken. It's amazing that they do that. You know? Well, do you send them a gift voucher or something for their effort. They find that ridiculous. So you know, yeah, It's... You just don't know what you should do." I05
Limited cooperation from health professionals	"Well, 9 of them withdrew because of the manner in which the transplant center communicated with them. Because people felt offended, were reacted to in a disturbing way during the intake, or the process was taking too long." I07 "And why don't I hear anything. Does it have to go through the donors? They could have called me as well, you know. Yes, they weren't used to this. (...) They found me to be a pain in the neck. I was on the phone almost every day. It was all new to me too, so I had to find out things out too. " I05 "If you end up in the transplant center then they are ready for the donors, but for the patient there is almost nothing. You know, I'm hardly kept informed, if at all, and I have to do all the running myself. (...) I've got the feeling that he [health care professional] was discouraging people, rather than encouraging them." I42
Demands a proactive attitude and media strategy	"Sometimes you have to be really alert. That's why I also say taking this path, I wouldn't advise it to everyone. Because when it gets going, once the ball starts rolling it can be really intense. That's what I think, and I think it's the same for everyone, if you want it to be successful, a search via social media, that it's really a lot of work." I10 "What I regularly do, if I go to the hospital for a checkup, that I write a message every time about what happened. With the dialysis catheter and everything. Recently I put up a photo, my husband took a photo of me. Well, I got loads of reactions to that. Look, that's how you keep up interest for it, so to speak." I43 "All those people that didn't react then, I'm approaching them all once again, to ask them again if they are still seriously considering donating a kidney. In the end it took the whole weekend. Yesterday I was at it the WHOLE day. And now I'm getting all kinds of reactions to that. (...) I am a [name job] by profession. So I know a bit about how to manage it; how to establish contact, writing e-mails, you know? How you do all that. And I'm glad that I am and can do all that, because otherwise it would have been hard I think. It's a lot to take in." I42

I, interview.

*For privacy reasons, participants' quotations used in this article are all written in the masculine form. All quotations were translated from Dutch to English by a native English speaker (EM).

happy to share feelings, experiences, and the outcome of the transplantation with their donor. They also reported that they did not experience any form of pressure from the donor, for example, to behave healthily or to compensate them for their deed.

Feeling of dependency and obligation

Participants' dependency on a (potential) donor influenced their behavior in interactions with them. On the one hand, participants were cautious to ask donors about their decision to donate or the status of the donor work-up process, so as not to pressure them into donation, while on the other hand, they felt obliged to be continuously available for all potential donors during the whole process. Some participants struggled with (potentially) putting the health of another person at risk. They did not know how to thank the (potential) donors for their offer and felt like they should give something back or reimburse donation-related costs. Although according to participants, (potential) donors did not want any compensation or reward, some participants gave their (potential) donor(s) small gifts, such as a voucher or dinner.

Limited cooperation from health professionals

Participants often felt frustrated about the slow donor work-up process with potential donors being tested consecutively over months rather than simultaneously. They were also frustrated by the perceived lack of transparency about the status of the donor work-up process. If participants asked questions about the procedure, they often felt that the transplant team found them to be bothersome. Some participants feared that potential donors may withdraw because of the slow process and the (perceived) poor communication.

Demands a proactive attitude and media strategy

Participants described that managing the PS process demanded personal resources, such as staying positive, being assertive, and proactive. They felt they had to keep on communicating with a potential donor or the transplant center in order to keep themselves updated and to keep potential donors involved. They also invested in keeping their online followers involved, by posting regular updates. Participants also educated potential donors by sending them leaflets and referring them to websites about living kidney donation and donor work-up procedures. Participants with little knowledge about these topics experienced managing the PS as more difficult.

A thematic scheme representing the considerations prior to the decision of patients with ESRD to engage in PS and their experiences with PS is presented in Fig. 1.

Discussion

The main findings of this qualitative study on the patient experience of public solicitation are that, despite rational consideration of the pros and cons of PS as well as the ethics involved, despair was the driving force behind participants' decision to engage in PS. Participants perceived PS as one of their last options to find a donor as other strategies had been unsuccessful. The public search for a donor brought participants hope for a better life without dialysis, and support from a wide audience, but was also perceived as an emotionally and practically taxing process.

Our results revealed that PS allowed participants to bypass barriers they encountered in finding a living donor, such as their reluctance to discuss their need for a living donor with relatives and friends. This "noncommunication" regarding living donation among patients with ESRD has previously been documented [14–16]. Some participants also excluded potential, but ABO-incompatible donors, even though they could have been screened for inclusion in the national paired kidney exchange program. These findings highlight the importance of systematic education for all patients with ESRD about living donation programs, and a need for support in raising the topic of living donation, for example, on hospital websites [17] or by home-based educational initiatives [26–28].

Even though 25% of patients had not yet started dialysis, all participants felt desperate about their situation. They were indignant about the fact that it is left to individual patients to come up with a solution to the organ shortage. They hoped to avoid (death on) dialysis and perceived the probability of finding a donor via the standard routes as so low that they believed it was worth the risk of PS for potential, albeit uncertain, benefits.

Nevertheless, participants were concerned about relinquishing their privacy and about "jumping the queue." From an ethical viewpoint, PS has been argued to be unfair as the success of a public appeal depends on the skills of patients [4,18]. However, this is no different to the skills needed to find a living donor in one's own social network (i.e., regular specified

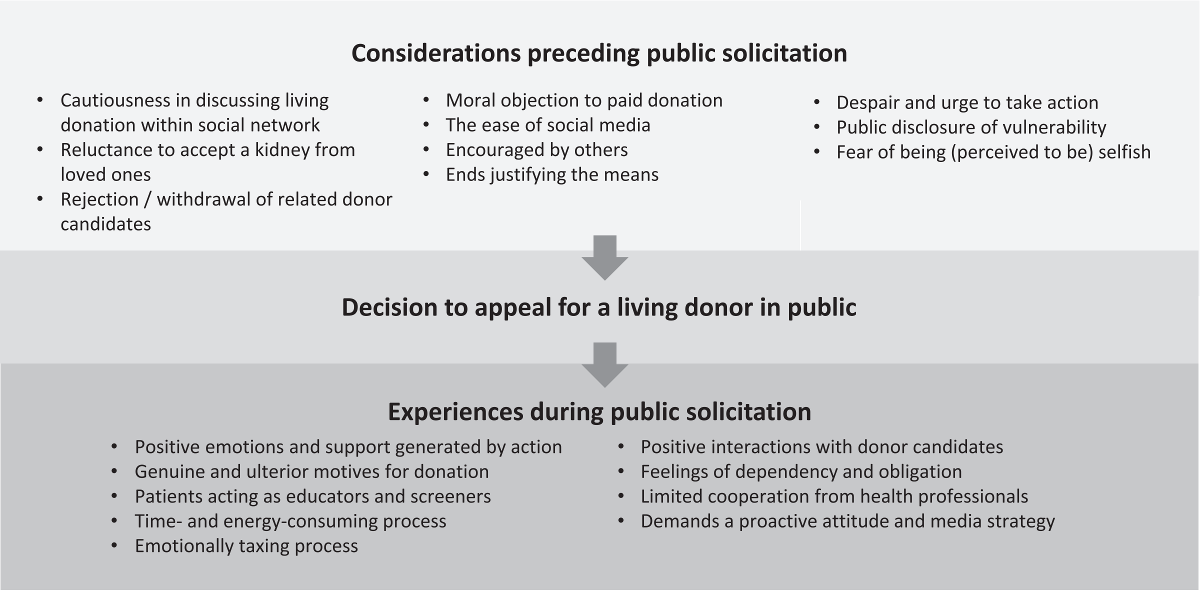

Figure 1 Factors influencing the decision of patients with end-stage renal disease to engage in public solicitation and their experiences with public solicitation.

donation) [19]. Those who are more socially skilled or have larger networks are more likely to find a donor. In addition, it is the solicited donor's identification with the recipient that motivates him to donate; without that felt relationship, there might be no donation at all.

Frunza *et al.* [2] have suggested that the possibility of PS might decrease the temptation to illegally obtain an organ. In our study, some participants implied that they consider PS as a first step; a next step could be transplant tourism and/or paid donation. Suggesting that some participants would be prepared to expand the boundaries of what they find acceptable if their health deteriorates (e.g., buy a kidney or accept a kidney no matter from whom). Previous studies have shown that when there is greater value at stake, people are willing to take greater risks and/or pay more money to achieve their goal [29]. On the other hand, the level of risk people are willing to accept to achieve their health goals differs per individual. This might explain why some patients engage in PS, while others do not. Studies among patients who consciously refrained from PS could help clarify this but are currently lacking.

In general, PS was experienced as an emotionally and practically taxing process that required many resources, such as time, energy, resilience, skills, and support from others. Participants took on different roles, such as a promoter, social worker, and educator to effectively manage the PS. Some experiences reported by participants are similar to experiences reported in "regular" specified donation. Participants often developed a good relationship with their (potential) donor. Like in related donor-recipient pairs [20], some participants wanted to reimburse donation-related expenses and/or rewarded the (potential) donor(s) for their efforts. No mention was made of exploitation before or after transplantation. Nevertheless, the increased risk of reward or coercion, often mentioned as objection against PS, is and will remain a risk of all living donation programs. This emphasizes the importance of standardized psychosocial screening of all living organ donors [21,22,23].

Participants experienced limited cooperation from health professionals during their PS process. However, some of these experiences, such as the frustration about the slow donor work-up process, are not bound to solicited donation but might also occur in regular specified donation. Even though avoidance of simultaneous donor assessments is, like in the UK, agreed upon in the Netherlands, patients seem to lack awareness of this policy. Participants were also frustrated most by a lack of transparency about the status of the donor work-up process. However, confidentiality is a cornerstone of live donation procedures and should not be compromised. Rather, the lack of transparency should be addressed by managing patients' expectations by improved education on national policy regarding solicited specified donation; (the timeline of) the donor work-up procedure; and the importance of mutual confidentiality.

While this is an initial explorative study, information gained from these interviews could inform and complement (existing) policies on PS [7–9]. The finding that not all participants were prepared to successfully manage the PS process indicates a need for improved education for patients with ESRD considering PS. Based on the patients' experiences, we found in this study, we translated the findings into suggested content for patient education (Table 5). This content complements the current guidelines on PS, which primarily focus on the procedural aspects of PS, and can be used to help patients make a well-considered decision whether or not to engage in PS. Such content could be included in verbal or written patient education provided by transplant centers or patient advocates. Using patient advocates, transplant centers can avoid direct involvement in PS and a potential conflict of interests, while still contributing to an expanded access to living kidney donation [24].

Future studies should investigate the attitude of health professionals toward PS and their ideas on how to support (future) patients who embark on this process. As PS is known to place a logistical and financial burden on transplant centers, it should also be examined how the influx of potential solicited donors could best be managed. In addition, this study should be replicated among patients with ESRD who engaged in PS in other countries. Finally, a similar study should be

Table 5. Suggested content for education on public solicitation.

The public search for an organ donor (e.g., on social media, websites, in newspapers, or other public notice) is often referred to as "public solicitation." To help you make the decision whether you want to make a public appeal, it might be useful to know how other patients have experienced this. Below you can find advice based on the experiences of 20 patients who have made a public appeal for a living kidney donor.

Getting ready

1 Discuss your search for a living donor with your transplant team. They may be able to offer you guidance and/or educational meetings to support you in this search in your own social network or in the public arena. Things you could discuss include the advantages and disadvantages of a public appeal, your expectations, and the likelihood of success given your specific medical situation

2 Know the facts on living donation and your center's policy on screening (publicly solicited) living donors. For example, concerning the number of potential donors that can be evaluated simultaneously. Be aware that professionals will not be able to give you information about the (results of the) donor screening/work-up for privacy reasons

3 Think about how you will handle requests for information on living donation. People who react to your appeal will ask questions about all aspects of living donation, such as the requirements for donor eligibility, the risks of donation, and the donor work-up process. Referring potential donors to the transplant center/hospital means that they will have the latest and most accurate information

Defining your (personal) boundaries

4 Before you make your appeal, consider which information you find acceptable to have in the public arena. To a certain extent, your privacy will be compromised by sharing your story online and/or in the media. Information online is difficult to remove. Both people who you know and people you do not know will have information about you and your illness

5 Think about your expectations and limits of the relationship you have with strangers who react to your appeal. For example, what kind of contact do you want to have, and under which circumstances and when in the process you might want to meet them. Discussing mutual expectations will help manage expectations for both parties

Potential reactions

6 Be prepared for mixed reactions. As a result of your public appeal, you will probably receive positive and supportive reactions; however, you will probably also receive negative or judgmental reactions. These people may not understand your situation or the reasons for your appeal. It is also possible that you will receive both positive and negative reactions from fellow patients

7 Think about how you will react to offers of a kidney for payment (in kind). Be aware that it is against the law to pay for an organ

General experiences

8 Being proactive in the search for a living donor can generate positive feelings such as hope, satisfaction, and a sense of control

9 Be realistic regarding your chances of success. Of the potential donors who react to your appeal, some will not be a good match due to medical reasons and some may withdraw because, for example, they underestimated the process or because their family does not agree with them donating. When this happens, it can be difficult for all involved

10 Let your family or friends help. Managing a public appeal can be time-consuming and emotionally taxing so recruiting others may help ease the burden

conducted among (potential) donors who responded to such appeals.

This study gained unique information on this relatively new phenomenon that could be used to inform quantitative studies on experiences and needs of all parties involved in PS. Some limitations should however be considered when interpreting the findings. Firstly, we were not able to analyze potential differences between responders and nonresponders. Therefore, caution is warranted in generalizing the findings of this study to all patients who engage in PS. Secondly, the results of our study could have been influenced by social desirability bias or recall bias, for they are based on what participants decided to tell us and may not necessarily reflect their true experiences. In addition, we were not able to verify or add clinical characteristics of our sample, as we did not have access to the participants' medical records. Thirdly, given that some participants were reporting on experiences with PS up to 5 years ago, it is plausible that patients' experiences or attitudes of transplant teams have already changed.

In conclusion, this study demonstrates that the decision to engage in PS was mainly driven by a lack of organs from other living and deceased donors, and a need for action in a hopeless situation. PS was experienced as an emotionally and logistically taxing process. These findings highlight the need for improved education and support for patients with ESRD considering and undertaking PS.

Authorship

MCP, DS, WCZ, MTH, FJMFD, MB, WW, JvdW and EKM: contributed to study design. MCP and DS: collected the data. MCP and EKM: analyzed data and wrote paper. DS, WCZ, MTH, FJMFD, MB, WW and JvdW: reviewed the paper.

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Conflict of interest

The authors of this manuscript have no conflict of interests to disclose as described by Transplant International.

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SUPPORTING INFORMATION

Additional Supporting Information may be found online in the supporting information tab for this article:

Appendix S1. Complete interview guide (translated from Dutch to English).

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