

# EXPloring attitudes and factors influencing reproductive Choices in kidney Transplant patients (The EXPECT-study)

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The data underlying this article will be shared  
 on reasonable request to the corresponding  
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## Abstract

Pregnancy can have risks after kidney transplantation (KT). This mixed-methods study aimed to identify the percentage of women getting pregnant after KT and explore motives for and against pregnancy together with psychosocial and medical factors involved in decision making. Furthermore, experiences of pregnancy and child-raising were explored. Women who got pregnant after KT were matched with women who had not been pregnant after KT. Semi-structured interviews were conducted, transcribed verbatim and analyzed using directed content analysis. After KT, only 12% of women got pregnant. Eight women with pregnancies after KT were included (P-group) and matched with 12 women who had not been pregnant after KT (NP-group). Women after KT experienced a high threshold to discuss their pregnancy wish with their nephrologist. The nephrologists' advice played an important role in decision-making, but differed between the groups. In the P-group, a desire for autonomy and positive role models were decisive factors in proceeding with their pregnancy wish. In the NP-group, disease burden and risk perception were decisive factors in not proceeding with their pregnancy. Nephrologists need to be proactive in broaching this subject and aware of factors influencing the decision and outcomes. Standardized preconception guidelines on pregnancy counseling are recommended.

## KEYWORDS

counseling, kidney transplantation, mixed-methods, patient education, pregnancy, women

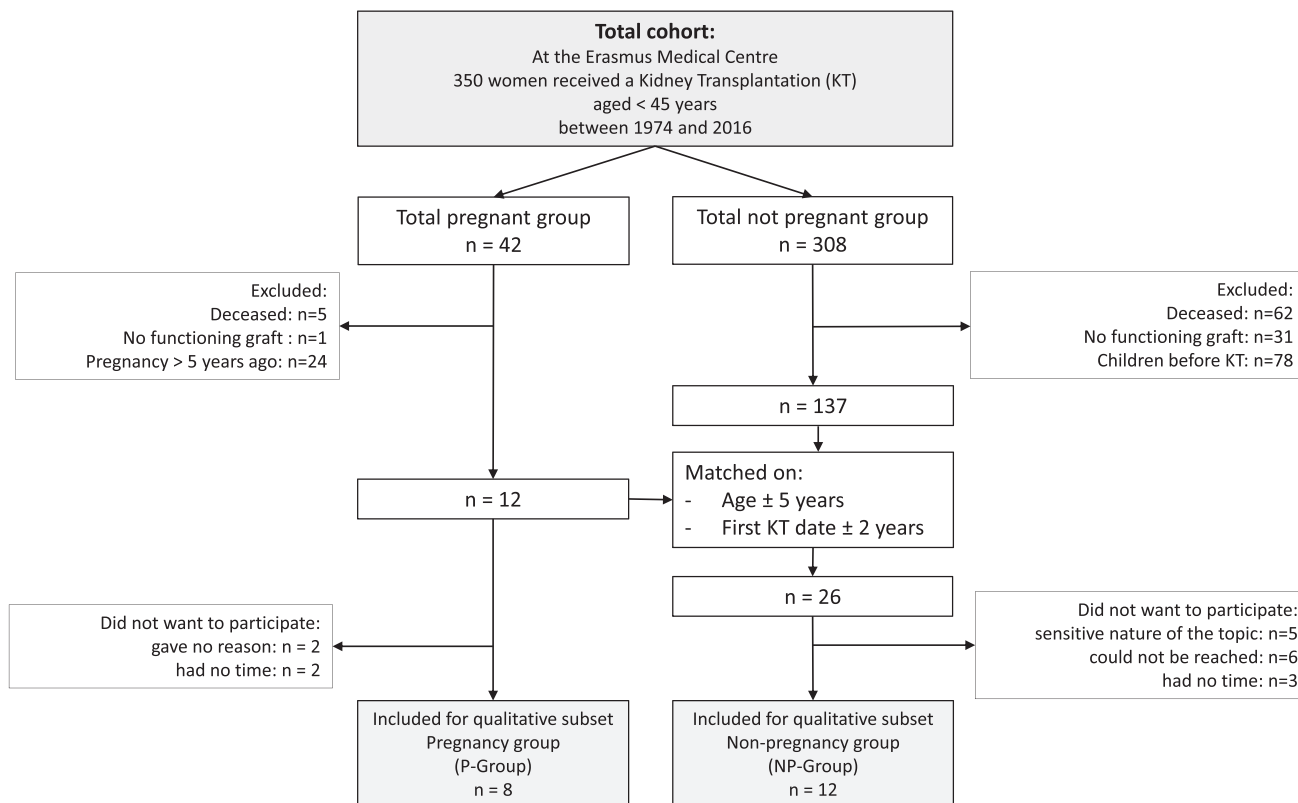
## 1 | INTRODUCTION

Chronic kidney disease (CKD) negatively affects fertility. One of the benefits of kidney transplantation (KT) is the potential recovery of fertility. Women after KT have the same desire to become mothers as those in the general population.<sup>1,2</sup> Successful pregnancy after KT is possible but there is an increased risk of complications for mother and child.<sup>3,4</sup> Pregnancies after KT compared to the general population are associated with higher rates of preterm deliveries, growth

retardation and low birth weight.<sup>3</sup> Maternal complications can include hypertension and increased risk of pre-eclampsia.<sup>5</sup> Preconceptional international guidelines recommend that women after KT should have (1) stable kidney function, (2) no active infections, (3) are not taking teratogenic medications, and (4) immunosuppressive medications (IM) are at maintenance levels.<sup>6,7</sup> Although evidence suggests that pregnancy does not decrease graft survival,<sup>8</sup> mothers can be faced with dialysis or re-transplantation and their families can be faced with the loss of a parent/partner.<sup>9</sup>

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**FIGURE 1** Flowchart included women

Despite the importance of the topic, there are only a few qualitative studies on perspectives on pregnancy among women who have undergone KT. One review described decision-making themes among women with CKD, however, studies included were limited by the fact that pregnancy was not the primary focus and heterogeneity of their samples.<sup>10,11</sup> To date, only one qualitative study has focused specifically on pregnancy among women with CKD in Australia.<sup>12</sup> The authors concluded that decisions about pregnancy in the context of CKD require women to think about their own survival, disease status, and possible guilt towards their family. This study was informative, however, patient in all stages of CKD were grouped together and experiences of raising children after KT were not investigated.

Given the limited research on pregnancy after KT, this mixed-methods study aimed to explore (a) which percentage of women transplanted at a fertile age get pregnant after KT; (b) the motives and decision-making regarding pregnancy after KT among women who got pregnant compared to women who explicitly chose not to get pregnant; and (c) the experience of being pregnant and child-raising after KT.

## 2 | METHODS

### 2.1 | Study design

This was a single-center, mixed-methods study. We conducted a quantitative retrospective review of medical records to create the total

cohort of women who were transplanted to describe childbearing after KT. We conducted a descriptive analysis of the characteristics of this cohort. From this total cohort, we generated a subset of patients for the qualitative analysis to explore pregnancy decision-making and child-rearing experiences after KT. Guidelines for qualitative research as described in the Coreq guidelines and the Patient and Educational Counseling editorials were followed.<sup>13–16</sup>

Ethical approval from the Institutional Review Board of the Erasmus Medical Centre was obtained (MEC-2016-144). Procedures were conducted in accordance with the Helsinki Declaration (version 2013).

### 2.2 | Participant selection and setting

We created a total cohort from patients transplanted at the Erasmus Medical Center between 1974 and 2016 using the following inclusion criteria: female, aged 45 years, or younger at the time of KT (Figure 1).

For the qualitative subset of the cohort, women were selected using the following inclusion criteria: a pregnancy of at least 20 weeks after KT, and a functioning graft at time of screening. We excluded women who already had children before KT because this might have influenced the decision-making process. Patients who were cognitively impaired, could not speak Dutch or were diagnosed with primary infertility were also excluded.

We approached women for participation in 2016. To avoid recall bias we only included women who were pregnant in the previous

5 years (Pregnancy group (P-group)). These women were matched on age ( $\pm 5$  years) and time of first transplantation ( $\pm 2$  years) with women who had not become pregnant (Non-Pregnancy group (NP-group)).

We anticipated that the number of women who satisfy the criteria for inclusion in the P-group would be small. The goal was to include a minimum of six participants to have sufficient information power.<sup>17-19</sup> We anticipated that there would be a larger pool who would be eligible for the NP-group, however, as this group was matched with the P-group the same goal of six participants was set.

### 3 | DATA COLLECTION

#### 3.1 | Total cohort

Medical records of women aged 45 years or younger at the time of KT were examined to assess diagnosis of CKD, year of first KT, age at first KT, presence of children before KT, death, age at death, years KT to death, years delivery to death, years since last KT, number of grafts lost, age at last KT, graft loss since last KT, years KT to graft loss, years first delivery to graft loss.

#### 3.2 | Qualitative subset

Potential participants were approached by letter. Patients could indicate their wish to participate by returning the signed informed consent form in the pre-paid envelope supplied. If no consent form was returned after two weeks, women were approached by telephone to assess willingness to participate. Women who consented to participation were contacted by telephone to make an appointment for the interview. The interviews were performed at the outpatient clinic.

The interview guide was developed based on literature and expert opinion (Appendix 1). Two researchers independent from the care team conducted semi-structured interviews between April and November 2016 (MB, DB). The women who participated in the interviews were asked to complete a questionnaire on demographic and obstetric characteristics.

#### 3.3 | Data analysis

The total cohort was analyzed using SPSS 27.0. Firstly, we tested whether women who got pregnant after KT differed from women who did not get pregnant after KT on type of kidney disease, year of first KT, age of first KT, children before KT, death, age at death, years KT to death, years since last KT, total number of KT, age at last KT, graft loss since last KT, years KT to graft loss using Chi-square tests, or Mann-Whitney tests.

The interviews conducted among the subset of the cohort were recorded, transcribed verbatim and imported into ATLAS.ti software.<sup>20</sup> We used direct content analysis, which is a combination of deductive and inductive analysis, according to the Coreq guidelines.<sup>10,16,21,22</sup> MB

and DB coded the transcripts independently. After coding the transcripts, the individual codes were compared and discussed until consensus was reached. When necessary, a third researcher was involved (EM).

Descriptive statistics were used to describe the sociodemographic and pregnancy outcomes (if applicable) of the women in the subset of the cohort.

## 4 | RESULTS

### 4.1 | Total cohort

Between 1974 and 2016, 350 women  $\leq 45$  years underwent a KT at the Erasmus MC (Figure 1). Only 42 women (12%) gave birth after KT. In this cohort, women who got pregnant after KT were transplanted at a younger age and therefore had longer follow-up time than those who did not get pregnant ( $P = .00$ ). Mortality did not differ significantly between the groups although time between first KT and death was significantly longer in the group who got pregnant after KT ( $P = .05$ ) (Table 1). Women who got pregnant after KT had undergone a greater total number of transplants than women who did not get pregnant ( $P = .04$ ).

### 4.2 | Qualitative subset

In total 20 women were interviewed. Enough information power was reached in both groups.<sup>19</sup> Women in both groups had median age of 20 years (IQR 14) at their first KT and a median age of 36 years (IQR 7) at the time of the interview. At their most recent KT women had a median age of 30 years (IQR 15).

### 4.3 | Pregnancy group (P-group)

During the study period we identified 12 eligible patients who had been pregnant in the last 5 years, and had a functioning graft; eight participated. The characteristics of participants and outcomes of their pregnancies are shown in Table 2. The majority of pregnancies were complicated by preeclampsia. There was a trend towards higher education in the P-group compared to the NP-group ( $P = .07$ ).

### 4.4 | Non-pregnancy group (NP-group)

We matched 26 women who had not been pregnant (NP-group) after KT based on time of transplantation and age. Twelve of these women agreed to participate. Table 2 shows that study participants of the NP-group had a higher number of co-morbidities ( $P = .03$ ), and were less likely to be in paid employment at the time of the interview than the P-group ( $P = .04$ ).

**TABLE 1** Characteristics of the total cohort of women transplanted < 45 years at the Erasmus Medical Centre

	Total pregnant group (n = 42) n (%)	Total not pregnant group (n = 308) n (%)	PX <sup>2</sup> / Mann-Whitney test
<b>Basic characteristics At time of screening: 01-07-2016</b>			
CKD diagnosis/cause (n)			.16
Diabetes 1 or 2	1 (2%)	27 (9%)	
Systemic lupus erythematosus	2 (5%)	19 (6%)	
Focal segmental glomerulosclerosis	3 (7%)	18 (6%)	
other immunological disease	7 (17%)	51 (17%)	
Urological	11 (26%)	39 (13%)	
Other congenital	3 (7%)	11 (4%)	
Cystic Disease	0	22 (7%)	
Hypertension	1 (2%)	23 (7%)	
Other	10 (24%) <sup>a</sup>	59 (19%) <sup>b</sup>	
Unknown	4 (10%)	39 (13%)	
Age at first KT (median, IQR)	21 (13)	34 (16)	.00
Age at last KT (median, IQR)	29 (18)	36 (15)	.00
Years since first KT (median, IQR)	25 (13)	13 (12)	.00
Years since last KT (median, IQR)	14 (19)	11 (11)	.06
>1 KT	21 (50%)	104 (34%)	.04
Women who had children before KT	0	114 (37%)	.00
Death	5 (12%)	62 (20%)	.20
Age at death (median, IQR)	40 (11)	45 (17)	.36
Years first KT to death (median, IQR)	19 (13)	9 (8)	.05
Years first delivery to death (median, IQR)	6 (17)	n/a	
DCGL since last KT	1 (2%)	64 (21%)	.00
Years last KT to DCGL (median, IQR)	.04 (n/a)	2 (6)	.43
DCGL after first delivery	20 (48%)	n/a	
Years first delivery to DCGL (median, IQR)	6 (6)	n/a	

X<sup>2</sup>, chi-square; CKD, chronic kidney disease; KT, Kidney Transplantation; IQR, interquartile range; DCGL, Death Censored Graft Loss.

<sup>a</sup>Tubular interstitial nephritis ECI (6), Rapidly progressive glomerulonephritis without systemic disease (2), Acute tubular necrosis (1), Bartter/Gitelman (1).

<sup>b</sup>Glomerulonephritis ECI (15), HUS-TTP (13), Bartter/Gitelman (5), amyloidosis (4), rapidly progressive glomerulonephritis without systemic disease (4), HELLP/preeclampsia (3), acquired obstructive nephropathy (3), Acute tubular necrosis (2), drug-induced acute interstitial nephritis (2), nephrectomy due to trauma (2), nephron-calcinosis (1), post-streptococcus glomerulonephritis (2), primary oxalosis (1), renal-vascular not specified (1), ciclosporin toxicity (1).

## 4.5 | Themes

### 4.5.1 | Post-transplant pregnancy decision-making

We identified 10 themes on pregnancy decision-making: desire for children, timing, risks, role of the nephrologist, role of the social network, autonomy, disease burden, alternatives for pregnancy, religion, and positive role models. Illustrative quotations are provided in Table 3 per theme.

### 4.5.2 | Desire for children

Women in both groups wanted to have children since they were young. This desire grew with age and increasing number of peers establishing

their own families. This desire encompassed caring for a child as well as being looked after in their own old age. Women also described wanting to do the things normal ("healthy") women do.

### 4.5.3 | Time pressure

Time pressure was a theme reported by both groups. In the NP-group, women had the feeling they had limited time to get pregnant. Additionally, these women described that by the time they felt emotionally ready for pregnancy their kidney had failed. Some concluded that they were already too old (>40 years) to start trying to conceive. In the P-group, women described the lengthy duration of the preparation phase, for example, adjusting IM. Furthermore, attempting to get pregnant takes time. Some women received contradictory information about the

**TABLE 2** Demographic characteristics and pregnancy outcomes of qualitative subset

Women	Pregnancy group "P Group" (n = 8)	Non pregnancy group "NP group" (n = 12)	PX <sup>2</sup>
Age at time of interview (median, IQR)	36 (12)	36 (4)	.91
Age at first KT (median, IQR)	21 (13)	19 (14)	.10
Age at last KT (median, IQR)	30 (12)	26 (16)	.47
Living with partner <sup>c</sup>	8 (100%)	10 (83%)	.22
Higher education <sup>d</sup>	7 (100%)	7 (64%)	.07
Paid job	6 (86%)	4 (36%)	.04
Declared unfit for work	0	4 (36%)	.07
Adoption/foster child	0	4 (33%)	.07
CKD diagnosis or cause			.84
immunological disease	3 (37%)	7 (58%)	
urological/congenital	3 (37%)	4 (33%)	
other	2 (25%) <sup>a</sup>	1 (17%) <sup>b</sup>	
Comorbidities	2 (25%)	9 (75%)	.03
Pre-emptive KT	2 (25%)	7 (58%)	.14
Living donor KT	7 (88%)	11 (92%)	.76
>1 KT	3 (38%)	8 (67%)	.20
<b>Pregnancy Outcomes</b>			
Total pregnancies	13		
Live birth	12 (92%)		
IUFD at 20 weeks	1 (8%)		
Assisted Pregnancy <sup>e</sup>	3 (23%)		
Hypertensive disease in pregnancy	10 (77%)		
Gestational hypertension	2 (15%)		
Preeclampsia	8 (62%)		
Gestational age, weeks (median, IQR)	37 (2)		
Birth weight, g (median, IQR)	2775 (848)		
Hospitalization during pregnancy <sup>f</sup>	11 (85%)		
Mode of delivery			
Spontaneous vaginal delivery	7 (54%)		
Vacuum assisted vaginal delivery	2 (15%)		
Cesarean delivery	4 (31%)		

X<sup>2</sup>, chi-square; IQR, Inter Quartile Range; KT, Kidney transplantation; CKD, Chronic Kidney Disease; IUFD, Intra Uterine Fetal Demise.

<sup>a</sup>Focal segmental glomerulosclerosis, nephronophthisis.

<sup>b</sup>Hodgkin lymphoma.

<sup>c</sup>at time of the interview.

<sup>d</sup>Senior general secondary education/secondary vocational education.

<sup>e</sup>IVF (In Vitro Fertilization)/ICSI (Intracytoplasmic Sperm Injection)/hormone treatments.

<sup>f</sup>Antepartum.

length of time required to wait before getting pregnant after KT, differing from one year to a few years. One woman said that if she had known the risks associated with pregnancy after KT beforehand she would have wanted to have a child before KT.

#### 4.5.4 | Perception of and coping with risks

Perception of risk differed between the two groups. In the P-group, women described that they were aware of the risks, however, the wish

to become a mother weighed heavier than the risks. The possibility that children might be born small and/or early was seen as acceptable as long as the child is healthy. Nevertheless, anxiety about the risks to the baby were reported. A greater number of negative considerations were reported among the NP-group compared to the P-group, including the future impact on the kidney. The NP-group described that life after KT is hard enough without children and that they did not have the energy to raise children. They also took the effect of a sick mother on a child into consideration as well as the risks of changing IM before

**TABLE 3** Considerations prior pregnancy after kidney transplantation

Themes	Quotations Pregnancy (P) group	Non-pregnancy (NP) group
<b>Desire for children</b>		
Reason of child wish?	<p>"so that if you're grown up or may grow old, that there are people who can take care of you"</p> <p>"that was how I saw myself, with children"</p> <p>"to make our family or happiness complete"</p> <p>"to seal the love between us"</p>	<p>"if I was healthy, I would have wanted kids"</p> <p>"it is lonely not having kids; it is hard when you stay together without kids"</p>
<b>Timing/ preparation</b>		
Timing	"it is best to become pregnant within 5 years after your kidney transplantation"	"I still want to get pregnant but now I am 43 and I am not going to start with it anymore."
<b>Risks</b>		
Heredity	<p>"we did not want to get a child who has the same disease"</p> <p>"inherited disease not a reason not to have children"</p>	"the risk of giving an inherited disease to a child is 50%, so that is quite something..."
Medication switch	<p>"medication switch not a problem"</p> <p>"first we both got tested if we were fertile, then we switched the medication"</p>	"the risk for the kidney..., when you change your medication for pregnancy, it's not worth the risk"
Risk for the child	<p>"it can be born small and too early; I don't mind this if the child is healthy"</p> <p>"medication is the only risk for the child"</p> <p>"medication not a problem, without medication it is not possible at all"</p>	"I use tacrolimus and mycophenolate acid and I read on the internet that the child would not have ears or fingers... That's when I thought, forget it..."
Risk for the graft	"to have a child is worth the decline in kidney function"	<p>"I just want to keep my kidney! I absolutely don't want to lose it"</p> <p>"I think it would take more effort for the kidney to support two body's and I think it will get crushed..."</p> <p>".. the chance that my kidney function stays good forever isn't already that big... and I have already lost a kidney..."</p>
Trust in good outcome	"I just took a leap of faith"	
<b>Nephrologist</b>		
Influence of nephrologist	<p>"it is possible but they don't recommend it... That was a real downer... that bothered me for quite a long time..."</p> <p>"I did not want to let him/her down"</p> <p>"very discouraging"</p> <p>"the nephrologist did not bring the subject up him/herself"</p> <p>"the nephrologist was very positive, I wonder if they knew the real impact"</p> <p>"I got pregnant against his/her advice"</p>	<p>".. if you do get pregnant you should take into account that you are not able to see it grow old. That sentence had a huge impact on me"</p> <p>"the decision not to have children was decision of my own, but nephrologist agreed with me"</p>
<b>Social network partner/donor/peers</b>		
Involvement of others	<p>"I took the decision with my parents"</p> <p>"only my husband was involved"</p>	"together we decided not to have a child"
Influence of living donors	<p>"my brother (donor) thought... what are you doing..."</p> <p>"my mother (donor) asked me why do you want another child, you are very lucky that you have one!"</p>	
Peer contacts	"I shared my experiences with my transplant friend"	"someone I know who is a kidney patient did not see her child reach one year old"
Reactions from the social environment	<p>"people react very harshly, while it's none of their business, who are you to decide?"</p> <p>"you have already taken the risk why do it again?"</p> <p>"enthusiastic reactions on pregnancy"</p>	"A good friend said, but you would be great parents!"

(Continues)

**TABLE 3** (Continued)

Themes	Quotations Pregnancy (P) group	Non-pregnancy (NP) group
Parents (in law)	"it is important for our parents that they become grandparents" "my mother found it very scary"	"hard that I can't give my parents grandchildren"
Partner	"on the same page as my partner" "he wasn't ready yet, he thought it would take years to get pregnant" "he also wanted children but not on my expense"	"it's possible that your relationship gets compromised when all your energy goes to the child instead of to my partner" "my partner would have been afraid of staying alone with the child"
<b>Autonomy/wish for normality</b>		
Autonomy	"it's hard when someone else decides whether or not you can have a child." ".. what I want is just going to happen!"	"it was my own decision not to get pregnant" "the disease is mine; others should not interfere with it"
Wish for normality	"because you have a kidney disease, you can't get pregnant... I thought what you can do; I can do too"	"... I don't want to be dependent on my transplant, it is quite hard for me..."
<b>Disease burden</b>		
Impact on daily life	"the KT has a positive impact on my life"	"at half past seven I am already asleep on the couch, raising kids would be too exhausting"
<b>Alternatives to pregnancy</b>		
Adoption/Surrogate	"if you are transplanted you can't adopt, because the countries of origin think that you are going to die soon" "surrogacy goes against my religion"	"adopted children have more problems, that makes raising a child only harder" "they said to me that surrogacy is only possible if you have cervical cancer" "Since we have our foster child, I feel so good"
<b>Religion</b>		
	"you can lose your renal function but you don't get a child from above just like that" "then we left it to God, we gave it 6 months.	"God has the last word"
<b>Positive role models</b>		
	"pregnancy of other kidney patients was a motive to go further with pregnancy" "on TV I saw a lady who already had 2 children after kidney transplantation so that's when I thought it is possible"	"...when I read on the forum that other kidney transplant patients did get successfully pregnant, it made me doubt my decision not to become pregnant.."

pregnancy. One woman in the NP-group switched her IM in order to prepare for pregnancy but experienced rejection of the graft and decided not to proceed with pregnancy for fear rejecting her second kidney. Some women and their partners underwent fertility testing, to avoid unnecessarily switching of IM in case of infertility. In the P-group some women underwent genetic testing but did not have a hereditary disease.

#### 4.5.5 | Role of the nephrologist

Nephrologists were reported to play an influential role in decision-making among both groups. All women described that they had to take the initiative to talk about the possibility of having children. This was often perceived as a difficult discussion to initiate. The P-group reported receiving more positive advice and collaboration from their nephrologists than the NP-group. One woman in the NP-group dis-

cussed her wish for pregnancy but felt defeated by all the negative information and did not dare to bring up the subject again, for fear of disappointing her nephrologist.

#### 4.5.6 | Role of the social network

In both groups partners played the most prominent role in decision-making. Partners were often concerned about the health of their partner and did not want a child at expense of the mother. For some women in the NP-group, guilt towards their partner was the decisive factor. Parents played a less important role in the decision, but were in most cases supportive of pregnancy. Living donors were reported to have expressed their concerns about the risks to the kidney during pregnancy. In both groups women reported feeling a sense of responsibility towards their living donor and reluctance to take unnecessary risks. Women also described they

would like to come in contact with other recipients to discuss this subject.

#### 4.5.7 | Autonomy

Autonomy was a commonly reported theme in the P-group. They expressed the need to be autonomous and take responsibility to avoid the feeling that someone else (health care professionals) has control over decisions regarding their body. In the NP-group women described how difficult it is when someone else decides whether or not you can have children. In the P-group women felt that despite the KT they still had an element of choice. The NP-group felt dependent on their transplant and thus less autonomy to decide.

#### 4.5.8 | Disease burden

The P-group described that CKD had (initially) little impact on their daily lives. However, CKD started to play a bigger role when they developed a wish for children. While in the NP-group CKD already had a big influence on their daily lives; complaints included fatigue, side-effects of the medication and stress about the functioning of the transplant. Also, they described having undergone multiple KT's from multiple living donors and not wanting to put their kidney at risk. This is in line with the differences illustrated in Table 2.

#### 4.5.9 | Alternatives for pregnancy

In both groups women had explored other options to pregnancy during the decision-making process such as adoption and IVF. These options were seen as less preferable. In the NP-group, four women had a foster child and one was planning on adopting a child at the time of the interview. None of the participants chose surrogacy, partly because the Dutch law and regulations are very strict. Adoption was not always possible, because of their CKD. Of the women who did not opt for an alternative, reasons were fatigue, not wanting a child to have a sick mother, and partners being against it.

#### 4.6 | Religion

Some women in both groups reported having a religious affiliation but that religion did not play a role in their desire for children and pregnancy. Religion did play a role in the decision not to go forward with surrogacy as that would be against their religion. Additionally, women with a religious affiliation reported the belief that having a child is in the hands of God.

#### 4.7 | Positive role models

Women in the P-group described that when they saw stories in the media about pregnancy after KT they realized that it was possible. Sto-

ries of other transplant recipients who had gone through pregnancy were a source of information and support. These role models triggered them to proceed with their wish for pregnancy. In the NP-group these stories made them doubt their decision not to get pregnant.

##### 4.7.1 | Experiences of pregnancy, delivery and raising children after KT

In the second part of the study, we focused on the experiences of pregnancy, delivery, and child-rearing among women in the P-group. In general, women were happy with their decision to have children, although some felt that they had underestimated the impact and at times even regretted their decision. These themes are described in the following section and illustrative quotations are provided in Table 4.

##### 4.7.2 | Experience of complications during pregnancy

Most of the women had a good start to their pregnancy, complications begun when they were  $\geq 20$  weeks pregnant. In the majority of the pregnancies in this cohort, preeclampsia was diagnosed. Women who were asymptomatic found it difficult to understand or accept the treatment recommendations or the need to be admitted to the hospital. Women reported that communication between gynecology and nephrology department was not always transparent for them.

##### 4.7.3 | Fear of damage to kidney transplant

Women described being afraid of potential damage to their kidney during contractions and labor. One woman worried about pain at the location of her transplanted kidney at the end of her pregnancy because her child was pushing on it.

##### 4.7.4 | Deterioration graft function after delivery

Impairment in graft functioning was something multiple women experienced after their delivery. This differed from mild to severe deterioration for which dialysis was required. Some had emergency deliveries due to fetal distress and reported the feeling that their graft was damaged during the delivery. Dialysis was very hard for one young mother as she described not feeling part of her family anymore. Also, some women had to be re-transplanted soon after their delivery. This was something they had not taken into account when they considered pregnancy.

##### 4.7.5 | Child raising burden

Experiences of raising children varied from feeling very capable to the feeling that they were struggling; ranging from a great experience to



**TABLE 4** Experiences of pregnancy, delivery, and raising children after kidney transplantation

Themes	Quotations
<b>Pregnancy</b>	<p>"pregnancy was only complicated at the end"</p> <p>"it went well but suddenly there was preeclampsia"</p> <p>"only at the end of my pregnancy it affected my kidney because the child was pushing on it"</p> <p>"... you need to hang in there, at 26 weeks it is possible, then they performed an ultrasound and there was nothing anymore..."</p> <p>"despite the complications I did not feel bad during my pregnancy"</p>
<b>Delivery</b>	<p>"I was afraid to push because of my kidney therefore I finally got a caesarian section"</p> <p>"I lost 3 liters of blood"</p> <p>"the delivery should happen very quickly because the baby had shortness of oxygen and hadn't descended, it all ended well, but my kidney has been majorly damaged by it all"</p>
<b>Deterioration graft function after delivery</b>	<p>"when I was on dialysis it was like I was not part of family life anymore..."</p> <p>"I thought my baby would be older when I would need another kidney"</p> <p>"then my kidney got rejected, and there I was in the hospital with my little baby"</p>
<b>Raising children</b>	<p>"they ask me if I could handle it all in my situation, but I did not want to hear that..."</p> <p>"I was afraid that I would not see my child grow up"</p> <p>"now I understand why people choose deliberately not to get pregnant"</p> <p>"tiredness is a handicap"</p> <p>"when it all goes well it is fine, but it just doesn't always go well"</p> <p>"I am not looking forward to the moment when they get teething problems..."</p> <p>"it is often at my expense; I have largely disappeared. I really just survive now"</p> <p>"I am afraid of what the effect of a sick mother has on my children"</p>
<b>Second child</b>	<p>"one child is enough for me"</p> <p>"raising my first child went fine, with a second child it is very tough"</p> <p>"I would have wanted to know beforehand, what the impact was of a second child"</p> <p>"with my first pregnancy I was not afraid to lose my kidney, but now with my second pregnancy I am worried, because I am a mother now"</p>
<b>Children, transplantation and work</b>	<p>"working and also have kids was too much"</p> <p>"when you have cancer there are guidelines how much you can work, on working after KT there are no guidelines, this uncertainty was a real problem for me"</p>
<b>Importance of social network</b>	<p>"it is hard, because my partner is my new donor..."</p> <p>"after dinner, my partner takes over"</p> <p>"it is very important to have a social safety net"</p>

not being able to handle it physically and mentally. Mothers who suffered from fatigue, in particular, described raising children as very hard. Women also worried about what the impact of having a sick mother might be on a young child. Another fear was not getting to see their child grow up.

#### 4.8 | Second child after KT

Half of the woman in the P-group had had a second child after KT. With their second child mothers were more concerned about the risks because they understood the responsibilities of being a mother.

Women who did not proceed with trying to have a second child stated that they did not want to deliberately put their health at stake, fearing they cannot be a good mother anymore. Women who had two children described high levels of child raising burden.

##### 4.8.1 | Impact on employment

Mothers described that, after they had children, working was too much because they lacked the energy. The majority sought alternative employment that required less effort and some stopped working altogether.

## 4.8.2 | Social network

Having a supportive social network was described as very important by all mothers. Women relied on their network when they were too tired to look after their child(ren) or when they were hospitalized. Women highlighted the necessity of a helpful partner that can take over when they are low on energy.

## 5 | DISCUSSION AND CONCLUSION

### 5.1 | Discussion

This is the first study to explore the thoughts of both women who decided to try to get pregnant after KT and those who decided not to. This mixed-method study demonstrated that only 12% of the women transplanted at a fertile age got pregnant after KT. Furthermore, women who became pregnant after KT were generally more healthy than those who did not. One of the most striking findings is that, even now at a time when patients are more empowered than ever before, patients in our study still experienced reluctance to discuss their pregnancy wish with their nephrologist. Nephrologists played a crucial role in both groups but differed in their attitude towards pregnancy after KT. Women reported feeling defeated by all the negative information. This emotionally overwhelming situation was also described by Wiles.<sup>23</sup> In this study the type of advice and the decision to try to get pregnant depended very much on the knowledge and attitude of the nephrologist towards pregnancy. Advice on timing of the pregnancy varied.

Arguments for pregnancy were positive role models, desire for normality and autonomy. It is a known effect that individuals who are more autonomous and want to pursue desirable outcomes are most inspired by positive role models.<sup>24</sup> Women were striving for normality and felt that being able to bear children made them feel closer to normality. This phenomenon was also described in a study in which women described their chronic illnesses as deviations from normality and their pregnancies brought them closer to normality.<sup>25</sup>

In our study women reported disease burden, comorbidities and perception of/and coping with risks as decisive reasons for not trying to get pregnant after KT. Perception of risks also appeared to differ between the two groups. As the NP-group experience a higher disease burden than the P-group, they were more focused on minimizing risks and preventing poor outcomes. Women in the NP-group seemed to look beyond the pregnancy itself, they thought more about their ability to raise a child, as well as the impact on the graft, child, and partner. Of interest was that the arguments the NP-group used against pregnancy were the same arguments the P-group used when they were considering having a second child after KT. After their first pregnancy, women seemed to be more aware of the risks.

Women who got pregnant after KT reported experiencing the same difficulties as most families with young children experience. However, compared to mothers without a chronic condition they must also deal

with additional considerations and limitations, such as treatment and fear of health loss. Yoshikawa and colleagues have concluded that these additional considerations and limitations do not seem to affect the quality of life in this group.<sup>26</sup> Among transplant recipients, quality of life is lower than the general population. Whether having children contributes to a higher or lower QoL after KT requires further investigation.<sup>27,28</sup>

### 5.2 | Strengths and limitations

This is the first study to address pregnancy decision-making from the perspectives of women who chose to have children and those who did not, as well as their experiences of childrearing after KT. A possible shortcoming of this unique study was that the groups were not completely comparable with regards to socio-economic status. Women who got pregnant after KT had a higher education and the majority had a paid job. Matching to control for this variable was not possible due to the low incidence of pregnancy after KT. Furthermore, financial arguments for or against pregnancy were not mentioned by the women in the interviews. Additionally, women in the NP-group had more comorbidities and a lower rate of pre-emptive transplantation than women in the P-group. While our sample with a high rate of living donors was representative of our population, we acknowledge that this may not be representative of all populations in other settings. Pregnancy after a longer period of dialysis may raise new themes. Another limitation is the small number of women included in the P-group however this reflects the small number in the cohort. Moreover, there was sufficient information power in this cohort.

### 5.3 | Conclusion

Even now, despite increasing patient empowerment, women still experience reluctance to discuss their pregnancy wish with their nephrologist. The nephrologist's attitude towards pregnancy played an important role in the decision-making process but differed between women who got pregnant after KT and women who did not. In the P-group a greater desire for autonomy, normalcy and positive role models were decisive factors in proceeding with their pregnancy. Social support was an important condition for pregnancy. In the NP-group disease burden and perception of risks were decisive factors for not proceeding with their pregnancy wish. Our mixed-methods study demonstrated that pregnancy after KT is related to both objective measures of health and subjective perceptions of health.

New themes not previously described in the literature emerged from the analysis of experiences of pregnancy and raising children after KT such as dialysis or hospital admissions with young children, and trying to be a good mother when you have a chronic condition. Concessions had to be made in other areas such as career in order to be able to fulfil the chosen role as a mother alongside maintaining health and graft functioning.

## 5.4 | Practical implications

This study shows that it is not always clear to patients what the possibilities are regarding pregnancy after KT and that advice received may depend on the knowledge and attitude of the professional. Therefore, we have four suggestions for clinical practice based on our findings:

Firstly, it is important to lower the threshold to discuss pregnancy after KT. Professionals must be aware of this problem and be proactive as women may not initiate this conversation themselves. Counseling must encompass the pros and cons and support well-informed decision-making.<sup>29</sup> Additionally, the period after pregnancy should be discussed. For such counseling, professionals require up to date knowledge on the subject. Further research is needed on attitudes of nephrologist and obstetricians towards pregnancy after KT. Each (transplant) center should have clear recommendations and the transplant societies need to update preconception guidelines so that clinicians have a clear and consistent message regarding parenthood after transplantation.

Secondly, to promote equal access, there is a need for accurate and standardized educational materials on becoming pregnant and having a child after KT and the implications thereof. This study shows some women seemed to think that pregnancy outcomes are generally worse than the literature supports, at least for women with adequate graft function and stable IM regimen. The gravity and consequences of this decision make it even more imperative that the advice women receive is not dependent on personal attitudes and is tailored to the patient's specific circumstances.

Thirdly, peer support programs may be beneficial for women considering pregnancy after KT. Peer support programs have been implemented amongst chronic illness patients with good results.<sup>30-32</sup> The extent to which peer support programs are useful and effective in this population on this topic requires further investigation.

Lastly, this study gives a voice to women who choose not to have a family after KT. Women made their decision not to get pregnant, but some were clearly doubting and in need of psychological support. Counseling should also be available to these women who may have difficulty accepting their decision.

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### CONFLICT OF INTEREST

None.

### DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available from the corresponding author upon reasonable request.

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#### SUPPORTING INFORMATION

Additional supporting information may be found in the online version of the article at the publisher's website.

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