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## Living uterus donors' perceptions of decision-making and informed consent: a qualitative study of the Dallas Uterus Transplant Study participants



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#### ABSTRACT

Uterus transplantation is a growing field, but little is known about living uterus donors' perceptions of informed consent or their decision-making processes. This study used semistructured interviews to collect information regarding uterus donors' experiences with uterus donation, perceptions of the informed consent process, and information on how they decided to pursue uterus donation. Interviews were coded for thematic analysis. Three major themes emerged in this study. First, the decision-making process was based on individuals' motivations, rationale, and considerations of alternative contributions to help other women with infertility. Second, participants described how they felt about the process of informed consent, their decision-making processes, and how their experiences compared with their expectations. Third, participants discussed how uterus donation was a valuable experience. This study found that living uterus donors are motivated to give another woman the opportunity to experience pregnancy and childbirth. They were satisfied with the informed consent process, their experiences were in line with their expectations, and the value of uterus donation was associated with the act of donation itself. Our findings suggest that living donor uterus programs should develop robust informed consent processes that provide detailed information about uterus donation and encourage shared decision-making with potential uterus donors.

#### Introduction

patient information

Uterus transplantation (UTx) is a procedure that allows women with absolute uterine factor infertility to experience pregnancy and childbirth. Uterus grafts are from both living and deceased donors, and both types of donors have resulted in successful live births. Three centers in the United States have performed at least 1 uterus transplant. <sup>1-3</sup> Uterus transplant programs differ regarding which donors they prefer or are willing to use for UTx. <sup>4</sup> Because living uterus donation requires that an otherwise healthy woman undergo a surgical procedure for the benefit of the recipient, some programs prefer to use only deceased donors to avoid any risks that could be associated with living donation. <sup>5</sup> Other programs prefer living donors because they can provide an accurate obstetrical

history, undergo a detailed imaging workup, and the transplants can be scheduled electively.  $^{6}$ 

The primary ethical concerns about utilizing living donors for UTx are similar to concerns expressed about living organ donation in general: donors take on the risks of surgery for no personal medical benefit, donors may be pressured into donating (especially in cases where they can help a family member), and donors may experience psychological distress if their recipients have negative outcomes. Because the hysterectomy renders the donor unable to have more children, there is also concern that donors may regret their decision if they change their mind and want more children. Moreover, ethical concerns are magnified because UTx is not life-saving like other solid organ transplants from living donors.

Abbreviations: BUMC, Baylor University Medical Center; DUETS, Dallas UtErus Transplant Study; UTx, uterus transplantation.

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Studies addressing the psychological characteristics and outcomes of living uterus donors give some insight into the ethical concerns about living uterus donation. A report on the psychological characteristics of 11 nondirected uterus donors found that their baseline quality of life and resilience scores were above population norms. These donors reported that they were primarily motivated by giving recipients a chance to carry a child and secondarily motivated by the opportunity to advance science. The 3-year outcomes of directed donors from Sweden found that 3 of 9 had slight negative deviations in the mental health related to the quality of life; all 3 had recipients who did not have successful outcomes.

Although the above studies provide some insight into psychological baselines and changes over time, as well as motivations for donation, very little, is known about living uterus donors' decision-making process, perceptions of the donation experience, or the perceived value of the experience, all of which are essential considerations in the ethical analysis of living uterus donation. The current study addresses these aspects of living uterus donation and provides guidance for best practices for informed consent for uterus donation.

#### **Materials and Methods**

The study protocol was approved by the Baylor Scott & White Research Institute Institutional Review Board (study #019-216). The Consolidated Criteria for Reporting Qualitative Research checklist was used to ensure complete and transparent reporting (Supplemental Table 2). <sup>11</sup>

#### Setting and study population

Eligible participants included adult (aged >18 years), Englishspeaking women who had undergone uterus donation at Baylor University Medical Center (BUMC) in the Dallas UtErus Transplant Study (DUETS) clinical trial. Inclusion and exclusion criteria for uterus donation at BUMC are described elsewhere. 12 Inclusion criteria included donors aged 40 to 65 years (with consideration for donors aged <40 years who express no further desire for pregnancy), a negative infectious disease workup (gonorrhea, chlamydia, syphilis, human immunodeficiency virus, Hepatitis B, Hepatitis C), normal sonographic and computed tomography imaging of the uterus, at least 1 prior full-term live birth, and an acceptable psychological evaluation. Potential donors were excluded if they had cancer in the previous 5 years, risk factors for infectious disease, and pre-existing medical conditions that would pose increased risk per the investigator's discretion. BUMC is the largest living donor uterus program in the world, having performed 21 living donor uterus surgeries since 2016, with 18 as part of the DUETS clinical trial. The first 13 living donor hysterectomies were performed using an open technique, and all subsequent living donor hysterectomies were done using a minimally invasive, robotically assisted technique. 13,14

#### Recruitment

Potential participants were recruited from a convenience sample of women who were living uterus donors in the DUETS clinical trial (NCT02656550). Potential participants were approached during follow-up clinic appointments or over the phone for study participation. All participants had previously undergone a separate informed consent process for uterus donation, which involved meetings with the medical team and the provision of a binder with information about uterus donation and copies of consent forms. Participants were not compensated for participating in this study.

#### Data collection

We performed single, semistructured, one-on-one interviews with each uterus donor after a brief introduction of the purpose of the interview and the background of the interviewer. <sup>15</sup> Interviews were

conducted either in person or by telephone by 1 researcher (A.E.W.), a woman transplant surgeon and PhD bioethicist, who did not have a prior clinical relationship with any participant. Semistructured interview guides were grounded in the following 2 theoretical frameworks: (1) Leventhal et al<sup>16</sup> illness representations (focused on disease identity, timeline, consequences, causes, controllability, and perceptions of procedures) and (2) Kleinman and Benson<sup>17</sup> explanatory models of disease (focused on the meanings that participants ascribe to their experiences of illness and treatment through ethnographic methodology). These frameworks were chosen to assess how uterus donors understood and experienced their own pregnancies and how they approached the decision-making process for uterus donation. The interview guide was reviewed by content experts in solid organ transplantation, ethics, social science, ob-gyn, psychology, and UTx at BUMC, as well as members of the International Society of Uterus Transplantation. <sup>18</sup> The final interview guide consisted of 19 questions that addressed participants' experiences with pregnancy, experiences with uterus donation, and general perceptions of UTx (Supplementary Table 1). In addition to the open-ended questions, the interview guide included a closed-ended question in which participants were asked to "quantify how risky" they thought undergoing the uterus donation was on a scale of 1 to 100, with 1 being not risky and 100 being extremely risky (Supplementary Method) The interview guide was pilot tested with 2 uterus transplant nurse coordinators for face validity. At the end of the interviews, participants were asked to add any comments on topics that were important to them but not addressed in the interview. Patient demographics and pregnancy history were self-reported. Interviews were audio recorded, lasting from 30 to 60 minutes, and field notes were taken by the interviewer. Audio recordings were transcribed using NVivo transcription services (QSR International). 19

#### Analysis

Thematic analysis of the transcribed interviews was performed through an iterative process of inductive and deductive coding. Inductive codes were identified through topics that emerged from the transcripts, whereas deductive codes were identified a priori from previous research and the interview guide. Each transcript was independently coded by 2 of 3 team members (A.E.W., J.H., and V.R.), and memos were made to identify emerging themes and data interpretation. <sup>20-22</sup> All coding discrepancies were resolved via consensus discussions between the coders, and final coding assignments were made using NVivo 12. <sup>23</sup> Although thematic saturation was achieved at 12 interviews, we continued conducting interviews because we had a finite number of participants, all of whom had unique clinical experiences with uterus donation and whose insights, we believed, contributed to the study results.

#### Results

#### Participant demographics

A total of 17 of 18 eligible uterus donors participated (94% participation rate). The mean age of participants at the time of the interview was 40.5 years, all were White, and 15/17 were non-Hispanic (Table 1). All had post–high school education, and 13 (76%) were in the medical or nursing field. All participants had at least 1 viable pregnancy. Three participants had the following pregnancy complications or infertility issues: (1) one had an early miscarriage, (2) one required intrauterine insemination for 1 pregnancy, and (3) one had an ectopic pregnancy. Sixteen participants were nondirected donors who had no prior relationship with their recipients, and one was a friend of her recipient.

#### Major themes

Three themes emerged regarding uterus donors' decisions to pursue donation, perceptions of the informed consent process, and the perceived

 $\label{eq:continuous} \textbf{Table 1} \\ \textbf{Participant demographics and clinical characteristics (N=17)}.$ 

Characteristic	N (%)
Age, y, mean (range)	40.5 (31-59)
Ethnicity	
Non-Hispanic	15 (88)
Hispanic	2 (12)
Race	
White	17 (100)
Education	
Some college	2 (12)
2-y degree	1 (6)
4-y degree	9 (53)
Postgraduate degree	5 (29)
Profession	
Medical or nursing field	13 (76)
Stay-at-home	2 (12)
Scientist	1 (6)
Office Manager	1 (6)
Pregnancy history <sup>a</sup>	
Spontaneous vaginal delivery	14 (82)
Prior Cesarean section	4 (20)
Pregnancy and infertility	
Miscarriage	1 (6)
Intrauterine insemination	1 (6)
Ectopic pregnancy	1 (6)
Relationship with recipient	
Unknown, altruistic	16 (94)
Known, friend	1 (6)

<sup>&</sup>lt;sup>a</sup> One participant had both Cesarean and vaginal deliveries.

value of the donation experience. The decision-making process was based on individuals' motivations, rationale, and considerations of alternative contributions to help other women with infertility (eg, surrogacy and egg donation). Participants described how they felt about the process of informed consent, their decision-making processes, and how their experiences compared with their expectations. Participants discussed how uterus donation was a valuable experience. Representative illustrative quotations of these themes are presented below.

#### Decision-making

Participants described their decision-making to become a uterus donor in terms of 6 factors. First, all participants described how their personal experiences with pregnancy, childbirth, and motherhood motivated them to give another woman a chance to have that same experience. Second, all discussed that part of the rationale for donating stemmed from the conclusion that they had completed their own families and no longer needed their uterus. Third, many were motivated to donate, partly by their professional experiences as nurses, midwives, and medical providers in which they saw other women struggle with infertility and pregnancy losses. Fourth, several participants' motivations reached beyond helping a specific individual to a broader desire to advance science through involvement in the DUETs clinical trial. Fifth, participants viewed uterus donation as consistent with their identity as organ donors. Lastly, participants reported having considered options to assist others with infertility, such as by being surrogates and egg donors and decided to pursue uterus donation instead of these alternatives. Table 2 provides representative quotations for 4 of the 6 subthemes.

Personal pregnancy experiences. Participants reported how their personal pregnancy experiences impacted their lives and motivation for uterus donation (Table 2). They related the joys they felt when the fetus started kicking and when they saw their babies for the first time. They described the intimate and unique experience of pregnancy as something that cannot be replicated. Participants explicitly and consistently connected their pregnancy and motherhood experiences to their motivation for uterus donation.

Completed reproduction. Several participants reported having already decided that they were finished with having their own children before considering uterus donation (Table 2). They had concluded that they did not want to have more children or pregnancies and, therefore, did not have the desire to keep their uterus. Some of these participants had previously decided to undergo a hysterectomy before learning about the option of uterus donation. However, they recognized that uterus donation was a way to make something good come out of having a hysterectomy. As 1 woman (UTD\_13) stated, "It feels kind of wasteful to just get a hysterectomy and have somebody throw it in the trashcan. So, I got really excited about the idea that I could do something useful with this whole thing."

*Professional experiences.* Participants described how their professional experiences motivated them to donate (Table 2). Of the 17 participants, 13

 Table 2

 Motivations and rationale for uterus donation.

Motivations and rationale for uterus donation.		
Theme	Representative quotations	
Personal experience with pregnancy	"I felt the best during pregnancy, and I always wanted someone else to be able to experience that. I know not everyone has an amazing pregnancy, but the intimacy of growing a human in your bodyIt's absolutely amazing." (UTD_14)  "Feeling them kick and the first time you see their face, just that little moment of feeling that you can't explain to anybody and you can't ever recreate." (UTD 17)	
	"Women are the only ones that can carry a baby and bring life into this world. And just being blessed with that ability is an indescribably feeling. And when they get here, that's an indescribable feeling. They lay him on your chest and there's not prouder, happier moment that you can have." (UTD_4)	
	"My primary motivation was the fact that I see so many women struggle getting pregnant and having babies. I have family members who have struggled and it's just heartbreaking month after month not getting pregnant. And that honestly was my primary motivation –to give her some hope to have a baby someday and experience everything that I experienced." (UTD_14)	
Completion of childbearing	"And I was finished. I was done with my uterus so you can take the whole thing." (UTD_5)  "I have something in my body I'm not using anymore. And why shouldn't someone else be able to use it?" (UTD_6)  "And if I have all the working parts and there is a way for me to get what I wanted, which was essentially I don't want to have any more children, but to also then move forward with science or possibly help somebody to have a baby, why would I not?" (UTD_9)	
Professional experience as a motivating factor	"I work in egg donation and surrogacy so I'm pretty passionate about helping people have babies." (UTD_17)  "Being a midwife, I see a lot of loss. I thought this might be kind of cool to help women who want pregnancies." (UTD_8)  "I'm in the medical profession and to be able to watch that process happen and the amazing ability that medicine has [to allow for uterus transplantation] has made it even more intriguing for me." (UTD_15)	
Consideration of alternatives	"And I just knew that for me, specifically, I don't know that [surrogacy] would be something that I could do emotionallyit would be hard for me to separate the 2. Like, yes this is my body but this is not my baby." (UTD_9) "I didn't want to do egg donation because I didn't want the option of having my DNA out in the world and potentially meeting my children later in life." (UTD 14)	
	"I was giving somebody the oven to carry the baby. It was completely detached from me. There's no DNA, there's no carrying this child for 40 weeks, there's no going through labor, going through the after effects of delivering a child and all of the hormonal changes, and milk coming in and just all of those things that happen. I don't have to do any of that but I still get to give somebody the opportunity to have their own child." (UTD_15)	

were in the medical or nursing field. These participants conceptualized uterus donation as an extension of their professional work and an opportunity to contribute to their professional field personally.

Contribution to science. Participants were also motivated to donate by the opportunity to contribute to science by participating in the clinical trial. One stated that she wanted to "propel science forward." (UTD\_11) Although not a primary motivation for participants, the additional benefit of being able to contribute to medical science through clinical trial participation provided extra motivation to donate beyond that of helping their own recipients to experience pregnancy.

Support for organ donation. Some participants were also motivated by their identity as registered organ donors. The uterus, for these participants, was similar to any other organ they could donate. One participant who was registered to be an organ donor on her driver's license commented: "I'm an organ donor myself. It's [the uterus] just another organ and you're just trying to let someone achieve their dream." (UTD\_16) Another talked about her personal experience with organ transplantation as a motivating factor: "My father has been on the liver transplant list for years. So, I am a big fan of donating organs, live donors, and donation after death... if you can, do it!" (UTD\_11)

Consideration of alternative options. Several participants talked about having considered alternative options to help other women with infertility, specifically surrogacy and egg donation (Table 2). One participant who had previously donated eggs and been a surrogate knew that she wanted to contribute more to infertility but wanted an alternative option. She described her decision to pursue uterus donation: "And I thought, what a great opportunity to still be able to help in the infertility world and not have to carry, as that had such a burden on my own family." (UTD\_10) Those who decided against egg donation as an alternative were mostly concerned about having genetically related children with whom they did not have a relationship. Participants perceived surrogacy as a more intense process than uterus donation, which would be burdensome on their own families, especially younger children, and would be more emotionally and physically challenging. One participant commented: "I don't think that I have the mental capacity to carry a child to term and just completely cut ties. I think that would have been very challenging for me." (UTD\_15) Compared with these alternatives, uterus donation was perceived differently in that the donors would not have any genetic or gestational relationship with the children of their recipients.

#### Informed consent

Participants reported their perceptions of their steps for involvement in the DUETS clinical trial, their perceptions of the informed consent process, their concerns about risks, and how their experiences with uterus donation compared with their expectations.

DUETS clinical trial through news media. They described their trial involvement as a stepwise process starting with information gathering through the Internet, followed by signing up for the initial screening on the website, receiving a phone call with more information, and deciding to undergo a medical and psychological workup. Participants reported that they made a conscious decision to move forward at each step after obtaining the information they needed.

Steps toward trial participation. Most participants learned about the

#### Informed consent process

Table 3 presents representative quotations about the informed consent process. Several participants commented about how they were comforted by their consultation with one of the physicians who tried to dissuade them from proceeding. Although most participants did not have any suggestions for improving the informed consent process, one commented that she could have been better informed about what the recovery would be like. She felt that she did not know how to prepare since she had never had anesthesia or major surgery.

#### Risk perceptions

Participants expressed concerns mainly about the immediate risks of surgery and anesthesia, such as bleeding, blood clots, infection, and death. Others expressed concerns about how much time they would have to take off work, long-term complications, and scar formation. Participants were also concerned about the negative impact that uterus donation might have on their sex lives. The median perceived risk of the uterus donation operation was 50%, ranging from 2% to 70% (Figure). Participants who quantified their risk as 50% based this assessment on the 50/50 chance that they would have a complication. One described her perception of risk as follows: "I would say there is a 50/50 risk of absolutely nothing happening or something happening." (UTD\_11)

#### Communication expectations

Participants felt that their expectations were met regarding the transplant team's professionalism and communication throughout the donation experience. They described communication as open, immediate, and encouraging. Specifically, they reported valuing their direct communication with the uterus transplant nurse coordinator as a key factor in their ability to get answers in a timely fashion.

#### Postoperative expectations

Overall, participants related that their experiences were aligned with their expectations for uterus donation. Those who felt that their experience with a donation was different from their expectations described differences regarding magnitude rather than unexpected events. For example, one participant found that it took her longer than expected to feel "like herself" again and it took her longer to bounce back than she had expected (UTD\_11). Others commented that their postoperative pain

Table 3
Informed consent and value.

Theme	Representative quotations
Perception of informed consent	"When I look back, there is not anything that I regret or wish anything had been done differently or that I should have been more informed on. I think I was very lucky to have gotten all the appropriate information before so that after I was prepared for anything that may have come up or anything that happened. I don't feel like I was ever blindsided or confused." (UTD_9)  "I'm not sure there is any improvement that can be made because they were very thorough on explaining everything in the doctor's appointments and tests." (UTD_5)
	"One specific thing that I can appreciate was my visit with the gynecologist. he basically said, 'Look, I'm here to talk you out of it.' Just that blunt honesty was very reassuring that they had my best interests in mind in that if you were to say no, I'm not comfortable with it, there wasn't going to be any sort of ill feeling toward that." (UTD_10)
The value derived from uterus donation	"The knowledge that I was able to contribute to someone else having their baby in such a cool and unique way and being a part of groundbreaking clinical research is pretty amazing." (UTD_6) "One-I don't have periods anymore and to be honest, that alone might have been worth it. I definitely think it was worth it because it gave someone else hope in being a mom." (UTD_1)

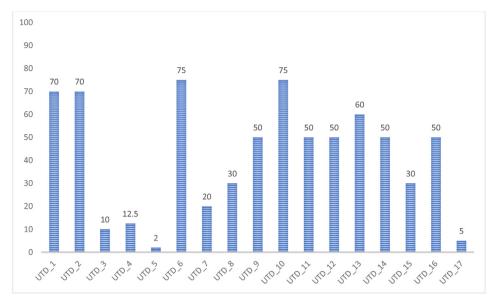


Figure 1. Perceived risk of uterus donation on a scale of 0 (not risky at all) to 100 (extremely risky).

was more severe than they had anticipated (UTD\_8; UTD\_1). One thought that the process from UTx to having a baby would move faster than it did (UTD\_14). A couple thought that their length of stay in the hospital was longer than expected (UTD\_4, UTD\_12).

#### The value of uterus donation

When asked if uterus donation had been "worth it," all participants responded positively (Table 3). One participant commented, "I would do it again if I could. If I had an extra one or could grow one, I would absolutely do it again. One hundred percent." (UTD\_14) Uterus donation was valuable to participants in terms of giving another woman the opportunity to experience pregnancy and contribute to medical science through the clinical trial. Those whose donation was not successful maintained that their personal experience was valuable because it helped improve UTx in the future.

#### Discussion

This is the first qualitative study to identify the characteristics of decision-making in living uterus donors. Our participants were primarily motivated by the ability to give another woman the opportunity to experience pregnancy and childbirth because participants valued their pregnancy and motherhood experiences. This motivation is consistent with the motivations of other living donor populations to improve the lives of their recipients. However, the goal of improving the life of the recipient in UTx is through pregnancy and childbirth, whereas with solid organs, it is to restore or improve health. Because all but one of the participants were nondirected donors, they were not motivated by the specific outcomes. One study of nondirected kidney donors in the UK described their motivations as developing a "connectedness with others," a similar sentiment to what we observed.<sup>24</sup> By contrast, related kidney donors report being motivated by altruism, inherent responsibility, accepting risks, family obligations, personal benefit, and spiritual confirmation.<sup>25</sup> Living liver donors are primarily motivated by the severity of their recipients' illnesses, their relationship, and the opportunity to improve their recipients' medical conditions. 26,3

The benefits that our participants received from uterus donation were different from those described by other living donors, both directed and nondirected. For example, living kidney donors with an interdependent relationship with their recipients gain tangible benefits regarding health, wellness, time, finances, and interpersonal relationships.<sup>28</sup> In contrast, nondirected living kidney donors also report a high degree of satisfaction

linked to the opportunity to help someone with a chronic disease, despite not knowing the outcomes of their recipient.<sup>29</sup> Our donors reported that their satisfaction with uterus donation was associated with the ability to help another woman achieve her fertility goals. Specifically, our participants gained personal value from a donation because they gave another woman the opportunity to carry a pregnancy and contributed to science. Donors whose recipients were agreeable to providing updates were informed of recipient outcomes, including pregnancies and live births; therefore, some donors were apprised of the results of their donation. Although recipient success was important, donors did not feel that poor recipient outcomes diminished the value of their own donation experience: they had still created an opportunity for their recipient to have a child and furthered the field of UTx. Moreover, given that the desired outcome of uterus transplantation is a healthy live birth, uterus donors may be more satisfied with their role even in the face of graft failure than nondirected kidney donors; however, more research is needed on this topic.

Uterus donors' decision-making process differs from that described for directed liver donors, a population whose decision-making processes have been extensively studied. Our participants had not made up their minds to donate before the evaluation and used the evaluation process to gain the information they needed to decide about donating. This differs from adult-to-adult living liver donors, who are motivated by their recipients' illness and commonly decide to donate before the evaluation.<sup>30</sup> Decisions are even less informed in adult-to-pediatric living liver donors who describe their decision to donate as "an automatic leap." It is likely that the nature of UTx, as a quality-of-life enhancing transplant rather than a life-saving transplant, affects the decision-making process of potential donors. They do not feel the same pressure as other solid organ donors who can save the life of a loved one, friend, or stranger. No studies specifically address the decision-making process of nondirected living kidney donors despite the considerable focus on their motivations; thus, comparing our findings to another donor cohort is not feasible.

Our participants reported that they were well-informed and able to make decisions. They were concerned about immediate surgical risks, financial risks, and the impact of donation on their sex lives. In addition, several donors were comforted by the emphasis that the transplant team placed on donation being the women's choice, not something they were obligated to do. Although our participants felt they were adequately informed, they were not asked to demonstrate comprehension. One study of living liver donors found that their comprehension of the information provided was inadequate despite the perception that they were

adequately informed.<sup>32</sup> Further research is needed to determine if potential uterus donors comprehend the information they receive in the informed consent process.

The risk perceptions recipients reported ranged from 2% to 70%, which may be explained by the open-ended nature of the question. Because uterus donation is a new procedure, uncertainty regarding all possible known risks was communicated to participants during the informed consent process, which may have increased risk perception in some participants. As more data are obtained on surgical and psychological risks of living uterus donation, further research is needed to assess pre- and post-donation risk perceptions as well as information needs and preferences. By comparison, when retrospectively asked about information needs based on the Organ Procurement & Transplantation Network guidance for 29 elements required for the consent process for living donation,<sup>33</sup> kidney donors desired more information about the impact of donation on insurance, changes in relationships with their recipients, feeling angry or resentful after donation, and the possibility of feeling bloated after surgery.<sup>34</sup> Rather than making assumptions about potential donor's concerns about risk, one strategy that can be implemented into the clinical evaluation is to ask potential donors what they think their risk is going to be with donation, what specific risks they are concerned about, and if they desire more information regarding specific types of

The strengths of this study include that it is the only cohort of nondirected living uterus donors in the world to date and 17/18 total donors participated in this interview study. The data presented provide insight into how living uterus donor decision-making and motivations compare with other cohorts of living donors. It is valuable for helping uterus transplant centers design informed consent processes that meet the unique needs of potential uterus donors.

Certain limitations should, however, be kept in mind when interpreting our results. Our sample was homogeneous in that all participants were White, mostly non-Hispanic, highly educated women, many of whom were in the medical field. Thus, our study population may not reflect other uterus donor populations. Our participants were also highly motivated and positively biased toward uterus donation.

In this study, we found that living uterus donors are motivated by the ability to give another woman the opportunity to experience pregnancy and childbirth, they were satisfied with the informed consent process, their experiences were in line with their expectations of uterus donation, and the value of uterus donation was associated with the act of donation itself, not primarily influenced by the outcome of recipients. The motivations of living uterus donors to give another woman the opportunity to experience pregnancy and childbirth differ from other cohorts of living donors who are generally motivated to improve the quality and quantity of life of a loved one or stranger. Unlike directed living liver donors, 30,31 we found that our participants did not make an automatic decision to donate and went through the evaluation process with an open mind, ultimately deciding to donate based on the information they received from the uterus transplant team. Our findings suggest that living donor uterus programs should develop robust informed consent processes that provide detailed information about uterus donation and encourage shared decision-making with potential uterus donors. However, further studies are needed to determine if the guidelines for informed consent for living donation fit the needs of uterus donors.

#### Disclosure

The authors of this manuscript have no conflicts of interest to disclose as described by the *American Journal of Transplantation*.

#### Data availability statement

Data available on request from the authors.

#### Appendix A. Supplementary data

Supplementary data to this article can be found online at https://doi.org/10.1016/j.ajt.2022.12.006.

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