

The journey from infertility to uterus transplantation: A mixed-methods study of the perspectives of participants in the Dallas Uterus Transplant Study (DUETS)

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Abstract

Objective: To study the impact of absolute uterine factor infertility (AUI) and uterus transplantation (UTx) on women, and UTx recipients' perceptions of Utx and reproductive autonomy **Design:** Convergent mixed-methods study. **Setting:** UTx program in a large academic medical centre in the United States. **Population/Sample:** 20 Utx recipients **Methods:** A medical chart review was conducted to collect patient demographic information, and clinical outcomes. Semi-structured interviews collected information regarding participants' experience. **Main Outcome Measure(s):** The outcomes of interest were participants' experience of infertility, experience with UTx, and general perceptions of UTx. **Results:** 7 participants were pregnant (one with a second child), 6 had experienced early graft failure and removal, 5 had delivered a healthy baby, and 4 had a viable graft and were awaiting embryo transfer. The primary themes identified were: the negative impact of AUI diagnosis on psychological wellbeing, relationships, and female identity; the positive impact of UTx on healing the emotional scars of AUI, female identity, and value of research trial participation; and the perception of UTx as an expansion of reproductive autonomy. All participants reported Utx was worthwhile, regardless of individual outcome. On bivariate analysis, disease aetiology, having a child after uterus transplantation, experiencing graft failure and current pregnancy were not significantly associated with the impact of AUI or of UTx on participants' identities. **Conclusion:** AUI has a negative impact on women from a young age, affects multiple relationships, and challenges female identity. UTx helps reverse this impact, transforming women's life narrative of infertility and enhancing female identity.

Running title: The journey to uterus transplantation

The journey from infertility to uterus transplantation: A mixed-methods study of the perspectives of participants in the Dallas Uterus Transplant Study (DUETS)

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Capsule

Absolute uterine factor infertility (AUI) has multiple negative impacts on women. Uterus transplantation helps reverse the impact of AUI, by transforming women’s life narrative of infertility and enhancing female identity.

Acronym list

AUI: Absolute uterine factor infertility

BUMC: Baylor University Medical Center

ET: Embryo transfer

MRKH: Meyer-Rokatsky-Kuster-Hauser

UTx: Uterus transplantation

Abstract (250/250 words)

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Design: Convergent mixed-methods study.

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Methods: A medical chart review was conducted to collect patient demographic information, and clinical outcomes. Semi-structured interviews collected information regarding participants’ experience.

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Results: 7 participants were pregnant (one with a second child), 6 had experienced early graft failure and removal, 5 had delivered a healthy baby, and 4 had a viable graft and were awaiting embryo transfer. The primary themes identified were: the negative impact of AUI diagnosis on psychological wellbeing, relationships, and female identity; the positive impact of UTx on healing the emotional scars of AUI, female identity, and value of research trial participation; and the perception of UTx as an expansion of reproductive autonomy. All participants reported Utx was worthwhile, regardless of individual outcome. On bivariate analysis, disease aetiology, having a child after uterus transplantation, experiencing graft failure and current pregnancy were not significantly associated with the impact of AUI or of UTx on participants’ identities.

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Keywords: Absolute uterine factor infertility, uterus transplantation, reproductive autonomy

Introduction

Uterus transplantation (UTx) is the only treatment for absolute uterine factor infertility (AUI) that allows women to carry a pregnancy. AUI affects 1-5% of women of childbearing age and is caused by either congenital (e.g., Mayer-Rokitansky-Kuster-Hauser Syndrome [MRKH]) or acquired (e.g., hysterectomy) absence of the uterus.¹ To date there have been at least 60 UTx reported throughout the world and 20 live births.²⁻⁴ Baylor University Medical Center (BUMC) has the largest worldwide experience with UTx, having performed 20 UTx resulting in 14 live births to date.⁵ The goal of UTx is to improve the quality of life for women with AUI by offering them the opportunity to experience pregnancy and childbirth. UTx has been shown to be reproducible, safe, and successful in terms of live births in multiple studies across the world. Despite the clinical success of UTx, many questions remain about the value of UTx given that its purpose is to improve patients' quality of life.

Three qualitative studies about uterus transplantation have examined the motivations of women with AUI to consider UTx, the impact of UTx on the lives of recipients, and recipients' perceptions of informed consent and decision-making for UTx. Richards and colleagues interviewed 19 women with AUI who expressed interest in UTx clinical trial participation but had not undergone uterus transplantation. They found that the diagnosis of AUI negatively impacted self-identity in terms of perceiving themselves as less female and relationships with family, peers, and partners at different life stages. Participants conceptualised UTx as a way to regain reproductive autonomy that was not feasible with adoption or surrogacy.⁶ Jarvholm and colleagues interviewed 9 UTx recipients up to 5 years following UTx to examine the impact of UTx on recipients' lives in terms of how UTx changed self-perception, body-image, and sexuality.⁷ Wall and colleagues interviewed 20 UTx recipients about their perceptions of informed consent and decision making.⁸ Participants were well informed, motivated primarily by the desire to achieve motherhood through pregnancy, and felt that surrogacy and adoption did not offer the same perceived value as UTx. Wall and colleagues also reported a case series of the pregnancy experiences of the first two UTx recipients at their centre to successfully deliver a child.⁹ These UTx recipients perceived their pregnancies as similar to other women, and derived significant personal value from their experiences.

To date, no studies have compared how women who chose to undergo UTx experience AUI and UTx or how UTx recipients perceive their experience with UTx in terms of reproductive autonomy. To examine these aspects of UTx, we conducted a mixed methods study of 20 UTx recipients from the Dallas Uterus Transplant Study (DUETS) focused on advancing our understanding of how AUI impacts women who undergo UTx, how UTx impacts women with AUI, and how UTx recipients view UTx in terms of their reproductive autonomy.

Materials and Methods

The study protocol was approved by Baylor Scott & White Research Institute IRB (Study #019-216). The study was developed and conducted using the Consolidated Criteria for Reporting Qualitative Research (COREQ) checklist to ensure complete and transparent reporting.¹⁰

Study Design

We performed a convergent mixed-methods study of uterus transplant recipients that concurrently gathered qualitative data through open ended interview questions and quantitative data from medical records and closed ended interview questions.¹¹ Semi-structured interviews were conducted using an interview guide that was grounded in two theoretical frameworks: Leventhal's illness representations and Kleinman's explanatory models of disease.^{12, 13} These frameworks were chosen to assess how UTx recipients understand, experience, and cope with infertility and approach the decision-making process for UTx. The interview guide was reviewed by content experts in solid organ transplantation, ethics, ob-gyn, psychology, and uterus transplantation at BUMC, as well as members of the International Society of Uterus Transplantation and the United States Uterus Transplant Consortium.¹⁴ The final interview guide consisted of 13 questions that addressed

the experience of infertility, the experience with UTx, and general perceptions of UTx.⁸(Appendix 1) It was pilot tested with two uterus transplant nurse coordinators. Additionally, participants were asked to add any comments on topics that were important to them but not addressed in the interview.

Setting and Study population

Eligible participants included adult (age 18 years +), English-speaking women who had undergone UTx at Baylor University Medical Center (BUMC). Inclusion and exclusion criteria for UTx at BUMC are described elsewhere.¹⁵ BUMC is the largest UTx program in the US, having performed 20 UTx resulting in 14 live births since the program began in 2016.¹⁵⁻¹⁸

Recruitment

Participants were recruited either face-to-face in clinic or through email communication from a convenience sample of women who underwent UTx at BUMC. All participants had undergone an informed consent process prior to UTx, which involved meetings with the medical team and the provision of a binder with information about UTx and copies of consent forms.

Data collection

Interviews were conducted either in person or by telephone by one researcher (AW), a female transplant surgeon and a PhD bioethicist, who did not have a clinical relationship with any participants. Participants were informed of the interviewer's role and research interest in understanding the experiences of women who undergo UTx. One-on-one interviews were conducted over the phone, audio-recorded and lasted 30 to 60 minutes. Audio recordings were transcribed using NVivo transcription services¹⁹ and verified by one researcher (AW). Field notes were made during and immediately after each interview. A medical chart review was also conducted to collect patient demographic information (e.g., age, education level, and number of children), and clinical outcomes (e.g., graft failure, miscarriage, failed embryo transfer, pregnancy, and live births after UTx). In addition, closed-ended interview questions (e.g., "Was UTx worth it?"; "How risky was your experience on a scale of 1-100%?") were treated as categorical variables.²⁰⁻²²

Analysis

Thematic analysis of the transcribed interviews was performed through an iterative process of inductive and deductive coding.²³ Inductive codes were identified through topics emerging from transcripts, while deductive codes were identified a priori from prior research and the interview guide.⁸ Each transcript was independently coded by two researchers (AW/MS) and memos were made to identify emerging themes and data interpretation.(Appendix 2) All coding discrepancies were resolved via consensus discussions between the coders and final coding assignments were made using NVivo 12.¹⁹ 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 UTx and whose insights, we believed, were additive to the study results.

Quantitative data analysis entailed descriptive statistics (e.g., frequencies, medians, interquartile ranges, and means) for patient demographic and outcomes data. In addition, qualitative codes were transformed into categorical variables (e.g., perceived high or low risk of UTx, information needs, and expectations of UTx). Bivariate analysis, performed using *R*, tested associations between transformed qualitative data and quantitative demographic and outcomes data.²⁴ Statistical significance was defined as $p < 0.05$.

Results

Participant Demographics

All twenty women who were invited to participate agreed to take part. Participant demographic and clinical characteristics have been previously reported and are detailed in Table 1.⁸ Participants received a uterus from a living, unknown donor (n=17), a deceased, unknown donor (n=2), or from a living, known donor (n=1). Interviews were conducted at least two months after UTx. At the time of the interview, 7 participants were

pregnant with the transplanted uterus in place (one of whom was pregnant with a second child), 6 had experienced early graft failure and removal, 5 had delivered a healthy baby, and 4 had a viable graft and were awaiting embryo transfer.

Primary Themes

We identified three primary themes related to AUF, UTx and reproductive autonomy. The first theme was the negative impact of the diagnosis of AUF on psychological wellbeing, relationships with family, peers, and partners, and on participants' female identity. The second theme was the positive impact of UTx on healing the emotional scars of AUF, enhancing female identity and the value of research trial participation. The third theme was the perception of UTx as an expansion of reproductive autonomy.

Experiences with Absolute Uterine Factor Infertility

Participants described their experiences with absolute uterine factor infertility in terms of three factors: the immediate emotional impact of the diagnosis on their psychosocial wellbeing, the effect of the diagnosis on family, peer and partner relationships and the impact of the diagnosis on their female identity. The immediate emotional impact of the AUF diagnosis was overwhelmingly negative. Because most participants had MRKH, they were diagnosed during their teenage years when they did not start having menstrual periods. Participants were given the diagnosis and told that because of AUF, they would not be able to carry their own child. Words used to describe the emotional impact of the AUF diagnosis included "devastating" (UTR14.-GF), "difficult" (UTR02_CP) and "shocking" (UTR20_VG). One participant described her experience with the diagnosis of AUF as follows: "When you're told at a young age that it's just not an option for you to have your own child— it feels like part of you is just ripped out and completely taken away." (UTR20_VG)

Participants also described how AUF impacted their relationships with peers, family members and romantic partners. AUF made participants feel different and isolated from other teenage girls because they were not part of the common experience of menstruation. One participant described her experience as a teenager with AUF in the following way: "You kind of close yourself off to other girls early from my experience because you couldn't talk about when you got your first period. You weren't the girl with a pad or a tampon." (UTR02_CP)

Family members, particularly the parents of our participants, were also affected by the AUF diagnosis. Participants described parental guilt whereby their parents thought that they had done something wrong to cause the patient to have AUF. Participants also described how the AUF diagnosis affected their experiences of dating, marriage, and starting a family. One participant talked about the challenge of disclosing her diagnosis to a person she was dating, her fear that she would not be accepted, and how the burden of AUF altered her outlook on life from a very young age.

Whereas when you're dating, you're like, oh, I have to tell somebody I can't ever have kids. And that's a really big thing to accept. I mean, I would put myself in other people's shoes and was like, could I accept that if the guy that I was dating told me he could never have children? Because I feel like most people would like to have a family. So I think that's probably the biggest thing with my infertility experience is I was just really young. It progressively got worse with age. I figured I would probably be single my entire life. I really didn't see myself getting married. It kind of closed off this door of what I'd always imagined — getting married and having a family. (UTR10.SP)

Participants described the diagnosis of AUF as a challenge to their core female identity, resulting in a personal perception of being "not a real woman" (UTR04_GF). One commented:

For a really long time I felt maybe not good enough, like I wasn't fully a woman. I felt like there was this huge piece of me missing, and I would never relate to having a period or being pregnant or just ... all these huge things that are just attached to being a woman, even just having to buy pads and tampons. There is this huge part of being a woman that I would never get to experience. (UTR10.SP)

The impact of uterus transplantation on recipient's lives

Participants described the impact of uterus transplantation in terms of four factors. First, uterus transplantation was perceived as a healing process that allowed them to begin the recovery from the negative impact of AUI. Second, participants described the positive psychological impact that uterus transplantation had on their lives as a contrast to the negative impact of AUI. Third, uterus transplantation allowed participants to regain the opportunity to be a part of common female experiences, which had been lost with the diagnosis of AUI. Finally, participants related the value of participation in uterus transplantation as an opportunity to help others and actively advocate for women with AUI.

The value of the option of uterus transplantation was empowering for participants and for many, began a healing journey. Participants described the theme of healing in terms of changing their life trajectory which was dominated by infertility and its consequences to a life with more control over their reproductive choices. Moreover, healing was not merely realised by those participants who had a successful pregnancy, but was a stepwise process that started with transplantation and continued with each new experience in the UTx process: menstruation, embryo transfer, clinical pregnancy, delivery and motherhood. One participant described how she conceptualised the value of UTx as an option as follows:

I was never born with this option [UTx]. So, for it to even be on the table was an instant like, wow, I have the choice. Do I want a uterus? Do I want to try for this? I had a choice which I never had when I was first diagnosed... So that was healing in itself. (UTR08_SP)

UTx had a strong healing effect on participants. UTx transformed participants' self-identity and perceptions of their life trajectory as women with infertility who would never have the option to have their own children. One participant said that with UTx, this was the first time in her life she could envision herself becoming a mom and be excited about the prospect of starting a family.(UTR09_SP) Another described her reaction to learning about the uterus transplant clinical trials as "my soul kicked back".(UTR15_CP) Even those participants who did not have a successful transplant described a positive psychological impact of having gone through the UTx procedure. They were able to walk away with a new perception of personal resilience and strength. One participant talked about how she was incredibly proud of having attempted UTx and that this will be part of the story that she tells her daughter (through surrogacy) one day about how hard she worked to become her mother.

Whereas participants perceived that AUI took away a part of their female identity, uterus transplant enhanced that facet of their identity in multiple ways. First, participants described how having a menstrual cycle was a normalizing experience. One participant commented that she would now be able to relate to her adopted daughter when she starts her menstrual cycle.(UTR18_CP) Second, the fact that participants had a uterus and were trying to get pregnant was also normalizing. They were now a part of this larger cohort of women who were dealing with the trials and tribulations associated with assisted reproductive technologies and were better able to relate to and identify with the reproductive struggles of other women through this shared experience.

Participants also took pride in the impact of their participation in the UTx clinical trial on other women with AUI. Beyond the personal value of the UTx experience, participants believed that their participation in UTx was helping to make UTx an option for other women with AUI in the future. It was a way to give young women with a new diagnosis of AUI hope for their future in terms of having another option for parenthood. When describing her perception of the value of undergoing UTx, one participant commented:

And there is now that sixteen or seventeen-year-old finding out, that is getting diagnosed, and now has hope for the future. Now she has options. So, was it worth it? Yes. (UTR05_GF)

Impact of UTx on Reproductive Choice

Participants were asked about the impact of UTx on reproductive choice, specifically about if it expands options or puts pressure on women to pursue UTx instead of alternatives. They uniformly believed that: uterus transplantation expanded parenthood options for women with AUI, reproductive decisions including the choice to pursue uterus transplantation are highly personal, and the option of uterus transplantation

does not create pressure on women with AUF1.

Participants strongly believed that the choice to pursue uterus transplantation was personal and should not be judged by others, especially those who do not have problems with infertility. One commented: “It makes me crazy because they [people without AUF1] are not us. They cannot put themselves in our shoes for a second because they don’t understand and they won’t fully ever comprehend what it’s like to have infertility like we do.” (UTR03-GF)

Participants also felt that the option of uterus transplantation did not pressure them to pursue this course. If anything, they felt that there was more pressure to pursue the alternative option of adoption. One participant described her frustration with the question of why she did not opt for adoption as follows:

I’m like, why don’t you adopt? ... What makes my situation different from yours? The same children need a home and the same children are out there. There’s a bigger pressure, bigger stigma [to UTx] because of adoption. (UTR05-GF)

Bivariate analysis

All participants were asked if AUF1 affected their identity, if UTx affected their identity, and if UTx was worthwhile. Because all participants responded that UTx was worthwhile, no statistical differences emerged among participant characteristics for this variable. Disease aetiology, having a child after uterus transplantation, experiencing graft failure and current pregnancy were also not significantly associated with the impact of AUF1 or of UTx on participants’ identities.

Discussion

In this study we describe the contrast between participants’ overwhelmingly negative experiences with the diagnosis of AUF1 with the positive transformative experience of UTx. Specifically, AUF1 challenged the female identity of participants while UTx enhanced it. Moreover, we found that participants conceptualised UTx as an expansion of reproductive freedom. They emphasised the intensely personal nature of reproductive decisions and did not believe that the option of UTx created undue pressure on them to choose UTx over alternative parenthood options. Our findings inform the ethical discourse on the value of UTx, the role of UTx in discussions of reproductive autonomy, and strategies for expanding the field of UTx.

Impact of AUF1 on life

In our study, we found that the diagnosis AUF1 negatively impacted participants from a young age, in their personal lives and their relationships, that AUF1 was isolating and that it fractured the female identity. Our findings are similar to prior studies of women with AUF1.^{6, 7} For example, Richards and colleagues found that AUF1 presented challenges at the time of diagnosis as well as throughout different life stages, and with different relationships.⁶ Their participants conceptualised AUF1 as a life-framing experience that affected how participants viewed themselves.⁶ Our findings provide a richer description of how AUF1 affected self-identity of participants by making them feel as though something was missing from their female identity.

Impact of UTx on Recipients lives

Our findings suggest that women with AUF1 derive value from UTx that goes beyond their experiences with pregnancy and motherhood. UTx is a healing process that helps recipients overcome the negative impact of AUF1 and provides an opportunity to transform their social identity by enabling women to share common female experiences of menstruation, pregnancy, and childbirth. The concept of UTx as an avenue to the common female experience is similar to the findings of an interview study of the first 9 UTx recipients in Sweden.⁷ One unique theme that we identified was the value of participation in the UTx clinical trial in helping women in the future.

Reproductive autonomy

Similar to the study by Richards and colleagues, we found that our participants believed that the option of UTx is highly personal and that, along with other considerations about reproductive options. Participants

felt that people, especially those who had not experienced challenges with infertility, should not pass negative judgement on women or couples who chose to pursue UTx because these individuals do not have a personal understanding of how it feels to struggle with infertility. Moreover, participants did not believe that the option of UTx created undue pressure. Echoing Richards and colleagues, we also found that choice and privacy were central to how women conceptualised UTx within their and experiences of reproductive decision-making. Because UTx is now a proven therapy, participants believed that it should become a routine part of providers' discussions about parenthood options with women diagnosed with AUI.

Limitations

Our study advances understanding of the impact of AUI and UTx in women who undergo this procedure as well as how they perceive UTx in the context of reproductive autonomy. Although 20 participants is an acceptable number for achieving thematic saturation in qualitative research, this study is limited by the homogeneity of the sample. All women in this study had undergone UTx, so they were positively biased toward this procedure and had chosen it over other parenthood options. However, not all participants had a successful outcome so there was heterogeneity in the post-transplant course which provided different insights into the impact of UTx.

Conclusion

UTx is now a technically successful and reproducible procedure that offers the option of motherhood through gestation and childbirth to women with AUI. We found that AUI has a negative impact on women from a young age, affects multiple relationships, and challenges the female identity. UTx helps reverse the impact of AUI through healing, by transforming women's life narrative of infertility and enhancing their female identity. These findings advance the ethical discourse on the value of uterus transplantation and its role in reproductive autonomy for women with AUI.

Disclosure of Interests:

The authors have no conflicts of interest to declare.

Contribution to Authorship

Dr. Wall was responsible for the study design, data collection, data analysis, and manuscript preparation. Dr. Sok assisted in data analysis and interpretation. Drs. Johannesson, Warren, Gordon and Testa reviewed the study design, analysed data and performed critical revisions of the manuscript.

Details of Ethics Approval

The study protocol was approved by the Baylor Scott & White Research Institute IRB (Study #019-216).

REFERENCES

1. Practice Committee of the American Society for Reproductive Medicine. American Society for Reproductive Medicine position statement on uterus transplantation: a committee opinion. *Fertility and sterility* . 2018;110:605-10.
2. Johannesson L, Testa G, Putman JM, McKenna GJ, Koon EC, York JR, et al. Twelve Live Births After Uterus Transplantation in the Dallas UtErus Transplant Study. *Obstetrics and gynecology* . 2021;137:241-49.
3. Jones BP, Saso S, Bracewell-Milnes T, Thum MY, Nicopoulos J, Diaz-Garcia C, et al. Human uterine transplantation: a review of outcomes from the first 45 cases. *BJOG : an international journal of obstetrics and gynaecology* . 2019;126:1310-19.
4. Tummers P, Goker M, Dahm-Kahler P, Brannstrom M, Tullius SG, Rogiers X, et al. Meeting Report: First State-of-the-Art Meeting on Uterus Transplantation. *Transplantation* . 2019;103:455-58.
5. Testa G, McKenna GJ, Bayer J, Wall A, Fernandez H, Martinez E, et al. The Evolution of Transplantation From Saving Lives to Fertility Treatment: DUETS (Dallas UtErus Transplant Study). *Ann Surg* .

2020;272:411-17.

6. Richards EG, Agatista PK, Davis AC, Flyckt R, Mabel H, Falcone T, et al. Framing the diagnosis and treatment of absolute uterine factor infertility: Insights from in-depth interviews with uterus transplant trial participants. *AJOB empirical bioethics* . 2019;10:23-35.
7. Jarvholm S, Enskog A, Hammarling C, Dahm-Kahler P, Brannstrom M. Uterus transplantation: joys and frustrations of becoming a 'complete' woman-a qualitative study regarding self-image in the 5-year period after transplantation. *Hum Reprod* . 2020;35:1855-63.
8. Wall AE, Johannesson L, Sok M, Warren AM, Gordon EJ, Testa G. Decision making and informed consent in uterus transplant recipients: A mixed-methods study of the Dallas uterus transplant study (DUETS) participants. *Am J Surg* . 2021.
9. Wall AE, Johannesson L, Testa G, Warren AM. Two Cases of Pregnancy Following Uterine Transplant: An Ethical Analysis. *Narrat Inq Bioeth* . 2020;10:263-68.
10. Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *Int J Qual Health Care* . 2007;19:349-57.
11. Creswell JW, Plano Clark VL. Designing and Conducting Mixed Methods Research. Thousand Oaks, CA: Sage Publications; 2007.
12. Kleinman A, Benson P. Anthropology in the clinic: the problem of cultural competency and how to fix it. *PLoS Med* . 2006;3:e294.
13. Leventhal H, Benyamini Y, Brownlee S, Diefenbach M, Leventhal EA, Patrick-Miller L, et al. Illness representations: Theoretical foundations. In: Petrie KJ, Weinman JA, editors. Perceptions of health and illness: Current research and applications. London: Harwood Academic Publishers; 1997. p. 19-45.
14. Wall AE, Johannesson L, Testa G, Warren AM, Gordon EM. Developing interview guides for a mixed methods study of uterus transplant recipients, their living donors, and their respective partners. Ethical issues in Uterus Transplantation and Innovative Research in Reproductive Medicine, Preconference of the International Society of Uterus Transplantation. Cleveland, OH.; 2019.
15. Testa G, Koon EC, Johannesson L, McKenna GJ, Anthony T, Klintmalm GB, et al. Living Donor Uterus Transplantation: A Single Center's Observations and Lessons Learned From Early Setbacks to Technical Success. *American journal of transplantation : official journal of the American Society of Transplantation and the American Society of Transplant Surgeons* . 2017;17:2901-10.
16. Johannesson L, Koon EC, Bayer J, McKenna GJ, Wall A, Fernandez H, et al. DUETS (Dallas UtErus Transplant Study): Early Outcomes and Complications of Robot-Assisted Hysterectomy for Living Uterus Donors. *Transplantation* . 2021;105:225-30.
17. Ramani A, Testa G, Ghouri Y, Koon EC, Di Salvo M, McKenna GJ, et al. DUETS (Dallas UtErus Transplant Study): Complete report of 6-month and initial 2-year outcomes following open donor hysterectomy. *Clinical transplantation* . 2020;34:e13757.
18. Testa G, McKenna GJ, Gunby RT, Jr., Anthony T, Koon EC, Warren AM, et al. First live birth after uterus transplantation in the United States. *American journal of transplantation : official journal of the American Society of Transplantation and the American Society of Transplant Surgeons* . 2018;18:1270-74.
19. QSR International Pty Ltd. NVivo (Version 12). 2018 [cited 11 June 2021]; Available from: <https://www.qsrinternational.com/nvivo-qualitative-data-analysis-software/home>
20. Srnka KJ, Koeszegi ST. From Words to Numbers: How to Transform Qualitative Data into Meaningful Quantitative Results. *Schmalenbach Bus Rev* . 2007;59:29-57.

21. Onwuegbuzie AJ, Teddlie C. A Framework for Analyzing Data in Mixed Methods Research In: Tashakkori A, Teddlie C, editors. Handbook of Mixed Methods in Social and Behavioral Research. Thousand Oaks, CA: Sage; 2003. p. 351-83.
22. Caracelli VJ, Greene JC. Data Analysis Strategies for Mixed-Method Evaluation Designs. *Educational Evaluation and Policy Analysis* . 1993;15:195-207.
23. Creswell JW, Creswell JD. Qualitative methods. Research design: Qualitative, quantitative, and mixed methods approaches. Thousand Oaks, CA: Sage; 2018. p. 179-212.
24. R Core Team. R: A language and environment for statistical computing. 2014 [cited 11 June 2021]; Available from: <http://www.R-project.org/>

Tables

Table 1: Participant Demographic and Clinical Characteristics (N=20)

Characteristic	
Age, years, mean (range)	31.9 (26-38)
Body Mass Index, mean (range)	24.5 (19-34)
Time from UTx to interview in months, mean (range)	18.9 (2-41)
Ethnicity	N (%)
Non-Hispanic	19 (95) 1 (5)
Hispanic	
Race	
White	16 (80) 3 (15) 1 (5)
Asian	
African American	
Education	
4-year degree Some college Post-graduate degree	10 (50) 4 (20) 3 (15) 2 (10) 1 (5)
High school 2-year degree	
Aetiology of AUI	
MRKH Acquired	18 (90) 2 (10)
Children prior to UTx by participant	
No children	15 (75) 3 (15) 1 (5) 1 (5)
Adopted	
Step-child	
Surrogate	
Current UTX stage	
Pregnant	7 (35) 4 (20) 6 (30) 3 (15)
Viable graft awaiting embryo transfer	
Early graft loss	
Graft hysterectomy after pregnancy	
Pregnancy outcomes	
Healthy live birth	5 (25) 4 (20) 3 (15)
Failed ET	
Miscarriage	
Donor type	
Living, unknown	17 (85) 2 (10) 1 (5)
Deceased, unknown	
Living, known	

Characteristic	
UTx – Uterus transplant; AUFU – absolute uterine factor infertility; MRKH – Mayer-Rokitansky-Kuster-Hauser Syndrome; ET – Embryo Transfer	UTx – Uterus transplant; AUFU – absolute uterine factor infertility; MRKH – Mayer-Rokitansky-Kuster-Hauser Syndrome; ET – Embryo Transfer

Appendix 1: Interview guide for uterus transplant recipients

Diagnosis of infertility, effect on the recipient's life and decision to pursue uterus transplantation

What was it like to be diagnosed with infertility? What did that diagnosis mean to you? How has the diagnosis of infertility affected your life?

Experience with uterus transplantation

What do you wish you had known prior to uterus transplantation? How did your experience of UT compare to what you were told?

General perceptions of uterus transplantation

Women undergoing uterus transplant and medical researchers have many ideas of what counts as a successful transplant. What are some of these ideas?

Appendix 2: Example codes from UTx recipient interviews

Life experience with absolute uterine factor infertility

Events surrounding diagnosis Effects on life and life stages Effect of AUFU on identity Cause of AUFU Effect on others Reproductive choice

Experience with uterus transplant

Motivations for transplant Conceptualization of risks Uterus transplant trial involvement process Reactions of others to UT

Conceptualization of the uterus transplant enterprise

Measurements of success Reproductive choice Financial considerations in clinical utx The importance of stories and sharing

Living versus deceased donor approaches

Donor preference Experience with donor Knowledge gap Living donor motivation