

Straight out of the womb: the psychosocial implications of uterine transplant



Historically, women with absolute uterus factor infertility (resulting from the absence of the uterus) have been advised to explore in vitro fertilization (IVF) with a gestational carrier, adoption, foster parenting, or to adapt to a life without children. It was not until 2014 that the option to carry and give birth to their own child(ren) became possible, when the world witnessed a 35-year-old woman giving birth to a child born after uterus transplantation (UTx). The team behind this major reproductive achievement also started the world's first clinical trial of UTx, which has been following nine recipient women, their partners, and donors. In their latest article, Järholm et al. (1) offer the first insight into the medium-term psychosocial experience of UTx. More specifically, they report on the recipients' and their partners' general and fertility-related quality of life, mental health (anxiety and depression), and quality of the relationship 2 and 3 years after the transplantation. The descriptive statistics presented suggest there are no major impairments to recipients' and their partners' mental health and quality of partnership, however, they do show individual variability in anxiety and quality of life trajectories. Given the small sample size and diversity of events observed (transplant failure, miscarriage, divorce, unsuccessful IVF, and successful IVF followed by transition to parenthood), it is impossible to conclude about the specific impact of UTx. The authors discuss the less adaptive trajectories observed in light of the challenges of transplant failure and continued inability to conceive.

The American Society for Reproductive Medicine considers UTx to be an experimental procedure, but like many other reproductive techniques, it is expanding rapidly, with multiple surveys across countries suggesting it is socially acceptable and that women prefer it over surrogacy. Being still an evolving technique, early trials are essential to clarify its potential benefits and harms and maximize effectiveness. Psychosocial research during these early stages should be mixed-methods to serve multiple goals, namely, to understand women's motivations to use UTx (perceived benefits), identify barriers to acceptability (perceived harms), and clarify support needs of all parties involved (to maximize adherence and effectiveness). This work also should inform which psychosocial outcomes to monitor in subsequent larger-scale trials, to ensure these are patient-centered.

Research is already being conducted to clarify motivations for use. Semi-structured interviews conducted with 19 eligible individuals for a UTx trial revealed they valued the opportunity to take an active role regarding prenatal health of the baby, to experience pregnancy, and to have more control and privacy than with other options (e.g., adoption and surrogacy) (2). Surveys with health professionals indicate lower receptivity of UTx. For instance, a US survey showed they would choose surrogacy over UTx and a UK survey showed the majority do not think the benefits of UTx

outweigh its risks nor that it will lead to greater human happiness (3).

Predictable potential barriers to use UTx are the need for a donor, disclosure of the nature of conception, and concerns around the medical and surgical procedures. Indeed, potential UTx users express concerns regarding the health risks for the donor, with some being inclined to use a deceased donor (2). Potential donors may find the risks and impact on quality of life too severe. For instance, in the mentioned trial the average sick leave for donors was 56 days and 1 in 9 (11%) experienced complications after transplantation (4). In addition, we know from egg donation research that patients worry about setting clear roles and boundaries between the parties involved. Potential UTx users also worry about the dynamics of their own relationship with the donor when these are close family members or friends (2). Another issue is disclosure of the nature of conception. Egg donation research suggests that around 70% disclose to family and friends and two thirds to the child, and that these percentages do not change when the donor is a close person. Disclosure of UTx may be less complicated because of the absence of a donor's genetic tie to the child, but concerns about disclosure and strategies adopted by parents who have undergone UTx are still worth investigating. When asked about medical and/or surgical procedures, potential users seemed to put more emphasis on the psychosocial risks of the procedure than medical, for instance, they expressed concerns about sense of body and self with the transplanted uterus and about medical failures posing risks to the long-term stability of their relationship. It also seems these risks are not evaluated in isolation but in comparison with the other available options for parenthood (e.g., adoption and surrogacy) (2).

Existing guidelines for psychosocial care in infertility and assisted reproduction show fertility patients have different needs (behavioral, relational, emotional, and cognitive) at different stages of their treatment pathway and that these translate into tailored recommendations per stage (5). Mapping such needs across the whole UTx treatment pathway (which can extend for many years) for all parties involved will be of crucial importance to support patients in adjusting to UTx. There is already significant knowledge about patients' psychosocial needs during IVF, uterus hysterectomy, and the experience of high-risk pregnancies after reproductive treatment. Therefore, priority for research seems to be about the needs involved in adjusting to a transferred donated uterus and to pregnancy with a donated uterus. Although results reported by Järholm et al. (1) do not raise red flags, they do suggest specific challenges in need of in-depth investigation (e.g., rejection episodes and impact on physical quality-of-life).

In the longer-term, quantitative monitoring of psychosocial outcomes in larger-scale trials is necessary to establish UTx effectiveness and safety. Indeed, the effectiveness of UTx should not be based only on medical outcomes, such as organ function and healthy offspring, but also in terms of the quality of life experienced by all parties involved. This evaluation should balance short-term outcomes with longer-term ones and probably should be framed in

comparison with surrogacy and/or adoption. Although existing research on third-party reproduction suggests donors, prospective parents, and children fare well, it does not preclude empirical investigation in UTX. Examples of relevant research questions are as follow: do short-term advantages of UTX outweigh its long-term impacts; does psychosocial and cognitive development differ for children conceived with UTX versus surrogacy; and does the parent-child relationship quality differ between these two procedures?

Meanwhile it is important that the emergent knowledge is used to inform the development of psychosocial care strategies and tools. For instance, decision aids about using UTX, using a live or deceased donor, and donating a uterus can help patients navigate through extremely complex decision-making and ensure their decisions are value-based; implications counselling will be essential to ensure patients can anticipate and prepare for the multiple challenges they may face; and stress management tools delivered at key stressful stages can promote quality of life during the treatment process.

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