

An insider perspective from Mayer-Rokitansky-Küster-Hauser syndrome patients on uterus transplantation



As uterus transplantation continues to evolve within the field of reproductive medicine, it is vital to understand the perspectives of those who are the most impacted: women with absolute uterine factor infertility who seek to have biological children. The study by Fischer et al. in this issue of *Fertility and Sterility* succeeds in doing so by eliciting the views of patients with Mayer-Rokitansky-Küster-Hauser syndrome (MRKH), the most common group of women with absolute uterine factor infertility undergoing uterus transplantation to date (1). Most prior research regarding patient opinions on this procedure has focused on the question of preference for uterus transplantation versus gestational surrogacy or other alternatives for childbearing. Yet, the conversations surrounding uterus transplantation are much more complex, and research that delves further into the human experiences surrounding absolute uterine factor infertility and uterus transplantation is lagging.

A related previous publication focused on a small cohort of women already enrolled in a trial of uterus transplantation. It examined the intersection between the medical/surgical, social, and ethical aspects of uterus transplantation. The result was a deeper understanding of how the diagnosis of absolute uterine factor infertility frames and influences the decision to pursue uterus transplantation, specifically the motivations for pursuing uterus transplantation and the conceptualization of associated risks (2). Fischer et al. (1) have identified a scarcity of research surrounding the attitudes, beliefs, and considerations of individuals with MRKH specifically, despite the predominance of this population of women with absolute uterine factor infertility among recipients of uterus transplants. The authors responded to this need with a well-designed study, which makes an important contribution to the literature and to the active conversations about the motivations of women who seek this evolving procedure in pursuit of gestational motherhood.

The Fischer et al. study (1) provides an analysis of multiple factors: baseline knowledge, source of knowledge, personal and ethical considerations, family planning considerations, financial considerations, and emotional/social support for people with MRKH. They reinforced previous findings that individuals with absolute uterine factor infertility, and MRKH specifically, are keenly interested in uterus transplantation. Additionally, they found that most women with MRKH believe the procedure to be ethical and should be covered by insurance, a belief previously demonstrated among the general public and health care professionals but not specifically in the MRKH population (3). The study is also the first to provide an educational tool, through which they found that those with MRKH tended to be well informed regarding uterus transplantation while still demonstrating a significant improvement in their knowl-

edge after the use of the educational tool. This is a significant finding, as most study participants cited the news and media as their primary source of information, sources often known to be problematic with respect to the accuracy and context of the information provided. As uterus transplantation becomes increasingly available, and as advancements in the field continue, it is vital that those who are considering the procedure have access to reliable, evidence-based information.

The Fischer et al. study (1) also suggests that women with MRKH who desire uterus transplantation are willing to make a substantial financial investment and tolerate significant personal risks in pursuit of their goals, making them a patient population in need of accurate and unbiased information about their family-building options. This is important to understand because prior studies have shown that a significant proportion of individuals with absolute uterine factor infertility would choose uterus transplantation over surrogacy and adoption despite knowing that the alternative two options would pose fewer physical risks to themselves and potentially the infant (4). This study delves deeper into the perspectives surrounding risks of uterus transplantation, revealing that one fifth of the MRKH individuals surveyed considered the risk to themselves as least important, while more than one third listed the risk to the fetus as most important. This serves as a critical reminder that understanding the human experience of those with absolute uterine factor infertility as they navigate through their reproductive journey, with all its financial and psychosocial consequences, is just as important as understanding the medical and surgical aspects when discussing or performing uterus transplantation. Keeping this perspective in clear sight will reduce harm to this patient population, which faces several life-long challenges to family building.

While the study's findings are notable and thorough, the use of social media and only one online MRKH community, limits the generalizability of their elicited perspectives. As with any survey-based study, there is likely inherent sampling, and response bias as those who chose to complete the survey may have either an overly enthusiastic or pessimistic view of uterus transplantation. Additionally, MRKH and absolute uterine factor infertility affect many diverse populations of women; a limitation of this study is that it represents the views of a subset of women who have higher health literacy levels and may have greater levels of knowledge or comfort with using social media. As mentioned in the discussion, respondents were primarily white, educated, employed, and with health insurance. This may not reflect populations of women with absolute uterine factor infertility or MRKH in the general public and/or the views of the overall population of women seeking enrollment into clinical trials of uterus transplantation. In addition, the authors do not describe a process of validating or testing a newly developed survey instrument prior to field use. The novel nature of this survey, coupled with a low response rate, raises further questions about the generalizability of the study findings.

Due to the increase in uptake of uterus transplantation, it is also important to consider the possibility that women who

are active and vocal within these online communities may have had uterus transplants or been candidates for participation in a uterus transplantation trial themselves. In a recent review from April 2020, there were noted to be a total of 52 women who have undergone uterus transplantation (5). It is not unreasonable to believe that these first-hand experiences could influence the results of the survey (e.g., those who used living donors are likely to have stated a preference for living donors in the survey). However, the survey did not include questions to identify the participants who have had uterus transplants or applied for clinical trials, another significant limitation to consider.

In summary, this study contributes to the body of literature and to active dialogues surrounding uterus transplantation. This paper extends and deepens the conversation about the many human factors that play into patients' understanding and perspective of uterus transplantation, focusing on the MRKH community in both the United States and internationally. As we continue to push ahead with numerous scientific innovations surrounding uterus transplantation, this study is a valuable reminder of the individuals and families that are ultimately the most affected by the procedure. We must continue to place their perspectives at the forefront of our discussions as we move into the next phases of uterus transplantation.

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