Ethical Issues in Uterine Transplantation: Psychological Implications and Informed Consent

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ABSTRACT

Since 2000, 13 uterine transplantations (UTxs) have been performed in women with absolute uterine infertility factor (AUIF), from both living and deceased donors, in different transplantation centers worldwide. At present the birth of 4 children following UTx is documented by the literature, and a woman was having a second pregnancy in October 2015. Following these successes it is likely that the procedure will become part of normal healthcare practice, even though at the moment it is still experimental and, as such, requires careful attention. Because the emotional aspects that are tied to UTx may foster the “therapeutic misconception” of participants, which consists in an overestimation of the benefits and an underestimation of the risks, careful attention should be paid also to informed consent (IC), which must include the following: describing techniques, pointing out risks and possibility of failure, and informing about the treatments required after the intervention. Because the final aim of UTx is the birth of a healthy child, the IC document must include details not only of the transplantation itself, but also of the very particular pregnancy deriving from it, and the need to remove the uterus following delivery(ies) to avoid these risks. Here we suggest that the IC process includes counselling techniques, possibly involving the psychologist that is part of the transplantation team, to target the information and decision-making process to the specific situation of each couple.

The uterus is not a vital organ but its absence determines a definitive infertility. The Mayer-Rokitansky-Küster-Hauser (MRKH) syndrome is characterized by congenital aplasia of the uterus and the upper part of the vagina in women showing normal development of secondary sexual characteristics. The incidence is about 1 of 4,500 women [1]. Moreover, hysterectomy is the most common surgical procedure worldwide, with significant variations in incidence across countries [2].

Until recently, surrogacy and adoption were the only paths to motherhood for women with absolute uterine factor infertility (AUFI).

Since 2000, 13 uterine transplantations (UTxs) have been performed in women with MRHS or following hysterectomy, from both living and deceased donors, in different transplantation centers worldwide [3–10] (Table 1).

In September 2014, following a successful UTx, a healthy baby was born in Sweden, opening up the possibility to treat many more women affected by AUFI (6). This raised immense hopes but also clinical and ethical challenges. In particular, if UTx is possible, is it so far desirable and, if so, under what conditions? How much risk is justified in the face of an intervention that is aimed not at saving life, but at supporting the possibility to generate life [11–13]?

Some aspects make UTx desirable from both an individual and a social perspective in specific circumstances.

UTx provides a woman the opportunity for the experience of pregnancy that may be felt as a central expression of her womanhood, in certain cases (ie, in MRKH) after living a life that is marked by the absence of other experiences, such as the menstrual cycle, which also represents an
<table>
<thead>
<tr>
<th>Country and Year</th>
<th>No. of Patients</th>
<th>Age</th>
<th>Donor/s</th>
<th>Postoperative Framework</th>
<th>Outcome</th>
<th>Reference</th>
</tr>
</thead>
<tbody>
<tr>
<td>Saudi Arabia, 2000</td>
<td>1</td>
<td>26</td>
<td>Living, 46 y</td>
<td>Vascular occlusion in the anastomosed blood vessels 3 months after transplantation</td>
<td>Rejection and hysterectomy</td>
<td>Fageeh et al [3]</td>
</tr>
<tr>
<td>Turkey, 2011</td>
<td>1</td>
<td>21</td>
<td>Deceased, 22 y</td>
<td>First menstrual cycle after 20 d</td>
<td>Two pregnancies and abortion</td>
<td>Ozkan et al [4]</td>
</tr>
<tr>
<td>United States, 2016</td>
<td>1</td>
<td>26</td>
<td>Deceased, 30 y</td>
<td>Hysterectomy 12 d after transplantation for complications</td>
<td></td>
<td>Cleveland Clinic [9]</td>
</tr>
<tr>
<td>United States, 2016</td>
<td>2</td>
<td>20-35</td>
<td>Living (unrelated)</td>
<td></td>
<td>3 Removed</td>
<td>Baylor University Medical Center [10]</td>
</tr>
</tbody>
</table>
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