

Navigating Tubal Ligation Decisions for Manuela, a Person with Down Syndrome.

CLINICAL CASE

Manuela, a 42-year-old woman with Down syndrome, visits the gynecology office accompanied by her sisters, requesting a tubal ligation. Her sisters express concerns about the high risk of Manuela becoming pregnant. Manuela, who lost both parents two years ago, is under the care of her sisters. She is sexually active and has a steady partner. When questioned by the gynecologist, Dr. Martin, Manuela states she does not want children and that her sisters advised the procedure, arguing she would be unable to care for them. Dr. Martin explains the tubal ligation procedure to Manuela but is uncertain if she fully comprehends its implications. Manuela mentions using the withdrawal method for contraception, while her sisters assert she has been on oral contraceptives for years, although they are unsure of her adherence. They fear a potential pregnancy, insisting on tubal ligation as they cannot care for a child and believe Manuela cannot either. One sister, who is Manuela's legal guardian, provides a court ruling on the matter, indicating attempts to prevent her from engaging in sexual activity have failed due to her relationship with a boyfriend at the occupational center. Dr. Martin, after consultations with Manuela and her sisters, doubts Manuela's capacity to make an informed and voluntary decision. While she seems to understand the basic aspects of the procedure and its primary consequence (inability to have children), Dr. Martin is unsure if this level of understanding is sufficient. He also believes surgery is not the only option, as other contraceptive alternatives exist.

Should Dr. Martin perform the tubal ligation?

ETHICAL ANALYSIS OF THE CASE

In this case, the autonomy of Manuela's sisters and Manuela herself (albeit limited) conflicts with her (Manuela's) health care, as a surgical intervention with inherent risks is being considered, despite the availability of alternatives.

When making health care decisions, it is essential that consent is given freely and voluntarily, with the patient fully understanding the information provided by the physician to make an informed decision that aligns with their values. If patients lack the competence (i.e., sufficient skills to make these decisions), proxy consent is required. For individuals with disability support measures, such as Manuela, legal rulings can specify how health decisions should be made. Nevertheless, it is crucial to consider the opinion of the person with the disability whenever possible.

When a proxy decision is clearly beneficial to the patient, such as in the case of surgery for cancer, it should be followed. However, challenges arise with elective procedures or surgeries, like tubal ligation, that are not clearly indicated and rely on the patient's autonomous choice. In these instances, proxy decision-making becomes more complex, as it involves determining the best course of action for the patient. Consequently, in recent years, the sterilization of individuals with Down syndrome without their explicit consent has been prohibited through legal action, as it is considered a violation of their personal dignity.

In the case under discussion, two key issues must be assessed: Manuela's autonomy (competence) and the potential benefits of the procedure. Specifically, if Manuela is not competent, is tubal ligation proportional (beneficial) in relation to the potential risks and harms to her? To determine this, it is essential to consider whether less aggressive alternatives exist that can achieve the same or a very similar result.

POSSIBLE COURSES OF ACTION

- Perform the surgery taking into account the wishes of the sisters, since they are her legal guardians.
- Interview Manuela alone, without the sisters, and assess her competence in making this decision.
- If the gynecologist, who is in charge of assessing Manuela's competence, does not know how to do so, ask for help (ethics committee, psychiatry) to assess competence.
- Discuss other contraceptive alternatives that are safe, such as contraceptive implants, IUDs, or patches.
- Refuse to perform the intervention on the grounds that it violates the dignity of persons with disabilities.
- Inform the Court, so that the correct authority may determine, with the advice of a forensic doctor, what action is most appropriate according to Manuela's competence.

RECOMMENDED COURSES OF ACTION

- Whenever possible, a consensus decision should be reached among the medical team, Manuela, and her sisters.
- A thorough explanation of the information process with Manuela and her sisters is essential, ensuring they understand the procedure and possible alternatives (contraceptive implants,

IUDs, or patches). While her sister is the legal guardian, it is crucial to include Manuela in the decision-making process.

- Dr. Martin, as the gynecologist in charge, should assess Manuela's competence and respect her decision if she is competent. If he does not know how to assess competence, he should seek help in doing so.
- In the event that Manuela's competence is in question or there are doubts about it, and she and her sisters still insist on the tubal ligation, the case must be taken to court for a judicial decision on what is best for Manuela. If she is deemed incompetent, the tubal ligation is likely to be denied, as it is an elective procedure and there are highly effective, less invasive contraceptive alternatives available.

DISCUSSION

Currently, the sterilization of persons with a disability does not require judicial authorization. Judicial approval should be a last resort and reserved for exceptional cases. This situation is not urgent, allowing for sufficient time to inform the patient and her sisters thoroughly and consider various courses of action. To make an informed decision, comprehensive information about the procedure is crucial. This includes not only the explanation of the technique used and its potential complications but also presenting alternatives and explaining thoroughly how they function. It is ideal to adhere to the principle of proportionality, utilizing alternative contraceptive methods to ensure optimal adherence. The information provided should be tailored to the disabled patient's level of understanding and also consider the comprehension level of the sisters.

If the patient is competent, she must make the decision independently and willingly, without any influence from her sisters. If she is deemed incompetent, it's imperative to still involve her in the decision-making process, but the case should be escalated to the courts due to the elective nature and potential risks of the surgery. While judicial involvement in healthcare is generally undesirable, as it can be intrusive and disrupt the clinical relationship, in this case, it might become necessary.

Sgd.: ASISA-Lavinia Bioethics and Health Law Committee
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