

An Ethical Assessment of Fertility Preservation in Pediatric and Adolescent Patients

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ABSTRACT

Defining universal guidelines for fertility preservation in pediatric and adolescent patient would be too restrictive and potentially biased. As is the case with most ethical quandaries, it is most appropriate to meet with patients and their families to have an honest, open discussion about the patient's fears, wishes, and goals. The decision to pursue fertility preservation is not a simple one, nor are the impacts universal for every patient. A thorough ethics consultation can help to mitigate the decision-making process for the medical team, parents, and child and to come up with an ethical solution to such a complex situation.

Keywords: fertility issues, fertility preservation, pediatrics, adolescent patients, ethical assessment

INTRODUCTION

Pediatric cancer patients often undergo chemotherapy and radiation treatments which render their reproductive organs ineffective. Oncofertility expands the options of a reproductive future in these patients, even when their cancer strikes before puberty. Moreover, fertility preservation can be expanded to allow for a theoretically open future in post-pubertal female patients with early signs of gynecological diseases such as endometriosis and polycystic ovary syndrome. While a child's caregiver may have the best intentions in mind, there are a handful of critical ethical considerations surrounding the idea of preserving fertility in such patients which ought to be thoroughly assessed before beginning any procedures.

A. CANDIDACY

Addressing each patient on a case-by-case basis is important, as no patient's situation is the same. Weighing factors, including age, gender, and the stage of disease/proposed treatments are all important when having a thorough ethical consultation and discussing the decision of adopting or rejecting a plan for fertility preservation.

Inherently, a patient's age impacts whether their reproductive samples would still be viable by the point in life when they are hoping to start a family. Samples can become fragile and null as time goes on. That is to say, the technology would be put to better use in a patient who is 17 as opposed to one who is 7 years old at the time of treatment.

Gender also plays a role with regards to obtaining the sample. For males, obtaining a specimen in post-pubescent patients is simple enough for them to do on their own. If the patient is undergoing surgery and has not yet reached puberty, then a sample may be extracted at that point. For females, obtaining a sample is considered invasive -- whether or not the patient has hit puberty. Similarly, females carry a larger risk when it comes time to implant the tissue or eggs as they try to conceive. Additional surgeries come with the increased risk of surgical site infections. For cancer patients, infections can escalate quickly and affect the efficacy of the individual's treatment.¹

Lastly, the stage of the illness and the required treatment are of considerable importance. A patient who must undergo aggressive chemotherapy and radiation is believed to have long-term damage to their capacity for reproduction. Looping back to the gender issue, this is likely to be a heavier influence for females as opposed to males.

B. AUTONOMY

First and foremost, it is important to allow the patient to make their own treatment and fertility decisions, when applicable. When true patient autonomy is not possible, as is the case with younger patients, the child can be properly informed and involved in the discussion, providing assent for the proposed medical treatment when they agree with it.² This gets a little hazy, however, when the patient is very young and cannot maturely grasp the concept of being infertile ten years later. Young girls may be more inclined to be interested in fertility preservation as opposed to their male counterparts because of the social pressure for girls to become one day become mothers—a pressure that may stem even from their innocuous playtime activities. It is critical to thoroughly educate young patients on the fertility procedures, the longevity of the reproductive materials obtained, and the possibility that even with this technology, there is no guarantee of having a child of their own. Asking for the child's voice, respecting their opinion, and including them in the decision-making-process is a possibility when the proposed therapy is not mandatory, as would the treatment of the cancer or life-threatening illness.

A child or adolescent patient may be too embarrassed to talk about reproduction with their parents or doctors. Similarly, the patient may be completely resistant from any conversation about it due to their overwhelming diagnosis. Forcing a child to endure additional procedures strips them of any autonomy that they may have in the situation.

It is the role of clinicians to ensure that patients are not being coerced into undergoing additional, invasive, and painful procedures at the persuasion of their parents. Children are highly impressionable, and the last people that they want to let down are their parents. On the other hand, parents may not always want fertility preservation for their children and there may be a disagreement between the two parties. For example, religious perspectives may influence a decline from parents. Setting aside some time to meet with the family can help to establish an autonomous decision or agreement.

C. BENEFICENCE

Albeit perhaps optimistic depending on the scenario, fertility preservation can “open doors” for patients who otherwise have had them shut in their faces. Rather than promising the capacity to reproduce with this technology, it ought to be cautioned that it is more so the opportunity to try to reproduce.

Offering this potential service to patients and their families who have questioned what they will do when they try to start a family after aggressive chemotherapy and radiation treatment can be a large advantage, allowing them to focus instead on beating cancer or treating the underlying issue.

D. NON-MALEFICENCE

This principle converges with the tenant of autonomy. Without guiding a biased decision, it is important to make sure that the longevity, or the lack thereof, of the samples is made clear to the patient and his or her caregivers.

Is it realistic that the individual will use the samples before they begin to deteriorate and are no longer viable? Is opting for preservation then a bad thing, as it will likely contribute to psychological pressure and mental turmoil several years later?

We certainly do not want to make a patient feel as though they have to rush through deeply personal experiences and decisions before a timer runs out, nor do we want them to feel as though they are forced into a commitment.

Alternatively, some cancers respond to the presence of estrogen by growing exponentially—a patient who has one of these tumors would clearly not be a good candidate for undergoing the ovarian stimulation necessary in order to obtain a sample.³

In an attempt to offer a patient the same reproductive abilities as their “healthy” peers, opting for preservation may require a delay of starting life-saving cancer treatment in order to harvest reproductive materials. For some patients more than others, time is of the essence, and any delay can be considered too critical of an impediment to treatment. This too is an example of a patient who may be precluded from utilizing fertility preservation tactics.

The long-term effects of fertility preservation are unknown due to the newness of the technology. Does introducing hormonal therapy for ovarian stimulation have any negative impacts on a patient who does not have an estrogen-sensitive cancer? Is it possible that doing this will disrupt the patient’s hormones and result in a secondary (or more) medical conditions due to a hormonal imbalance? Although impossible to predict, precautions need to be taken in order to prevent negatively impacting a patient’s endocrine system by flooding it with hormones which can adversely control their blood pressure and metabolism.

Some instances allow for preservation tactics to begin during and after treatment has already begun. Is there enough research on the long-term effects of pregnancy and lactation in a woman who had cancer (and rigorous treatment) as a child?

E. JUSTICE

While there are often institutional, public, and private financial aid programs to assist families to completely cover or partially offset the financial burden of fertility preservation, not all who want the technology will be able to afford it. Preservation fertilities are also not always child-friendly, nor willing to preserve materials of those beneath the age of 18.

Should we offer this technology to young patients with who are “too sick” with highly aggressive cancers and diseases, even in the face of statistics which illustrate poor outcomes? What if they go on to participate in novel clinical trials which yield remission or cures?

What happens to the genetic, reproductive material in the event that the patient passes? What happens if the patient ends up getting cancer again and cannot make use of the materials—are they simply destroyed, or are they put to some scientific use?

For non-cancer patients, we need to make sure that the trajectory of their illness is on par with undergoing fertility treatment. For example, offering preservation assistance to a high-school-aged student who has had one ovarian cyst is likely a misuse of the technology. This would be an instance of providing extraordinary measures in an inappropriate setting.

CONCLUSION

Defining universal guidelines for fertility preservation in pediatric and adolescent patient would be too restrictive and potentially biased. As is the case with most ethical quandaries, it is most appropriate to meet with patients and their families to have an honest, open discussion about the patient’s fears, wishes, and goals. The decision to pursue fertility preservation is not a simple one, nor are the impacts universal for every patient.

A thorough ethics consultation can help to mitigate the decision-making process for the medical team, parents, and child and to come up with an ethical solution to such a complex situation.

¹ Loren AW, et al. Fertility preservation for patients with cancer: American Society of Clinical Oncology clinical practice guideline update. *J Clin Oncol.* 2013; 31: 2500-10

² Klass, Perri. "When Should Children Take Part in Medical Decisions?" *NYTimes*, September 20, 2016. Accessed June 7, 2017.

³ Fallat, Mary. Hutter, John. Preservation of Fertility in Pediatric and Adolescent Patients With Cancer *Pediatrics* May 2008, 121 (5) e1461-e1469; DOI: 10.1542/peds.2008-0593