

## Posthumous Reproduction and Palliative Care

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### Abstract

Posthumous reproduction is an issue fraught with legal, ethical, religious, and moral debate. The involvement of the hospice and palliative care community in this debate may be peripheral due to the fact that other health care professionals would be actually delivering the services. However, the hospice and palliative care community are more likely to treat patients considering posthumous reproduction as they near the end of their lives. This article provides the hospice and palliative care community with a review of the medical, ethical, and legal considerations associated with posthumous reproduction. Having knowledge of these issues, and a list of available resources, will be useful if hospice and palliative care staff find themselves facing a patient or family that is considering posthumous reproduction.

### Introduction

**J**IM IS A 28-YEAR-OLD MALE who has been diagnosed with stage IV non-Hodgkin's lymphoma. One year before Jim's diagnosis he proposed marriage to Leah, a woman with whom he had been in a 5-year relationship. Throughout their courtship and engagement, Jim and Leah had discussed their desire to someday have children and build a family. Once Jim's diagnosis was deemed terminal, the couple remained adamant about their desire to have a family. Jim asked hospice staff to help him determine how he and Leah could pursue his wishes. Hospice staff collaborated with a medical ethicist at the local hospital, a psychologist, a reproductive endocrinologist, and Jim's lawyer. As a result of the collaboration, Jim provided written informed consent for Leah to be granted legal ownership of sperm he had banked at the local reproductive clinic. Jim's parents, understanding the couple's desire to have children, supported his decision and agreed to pay for the costs to bank and store Jim's sperm. Jim died a few weeks later. On the 1-year anniversary of Jim's death, Leah underwent artificial insemination using assisted reproductive technology (ART). The third attempt was successful and she is currently raising her son with the help of Jim's parents. Leah's future plans include another attempt at ART when her son turns 1.

Mortal illness interrupts the most firmly committed of life plans. For patients at the end of life, the yearning for a family may still be a passion, one that is supported by family members who share that plan. Advances in ART, defined as *in vitro* fertilization, artificial insemination, sperm and egg donation,

surrogacy, and other forms of reproduction outside of intercourse,<sup>1</sup> can make such a yearning technically and medically feasible. Posthumous reproduction, a possibility that some patients may wish to consider, is fraught with ethical, religious, and moral questions, but it can be medically achieved by a variety of modalities. The European Society of Human Reproduction and Embryology (ESHRE) recognizes three categories of posthumous reproduction: (1) fertilization and pregnancy takes place before the death of a partner but birth of the child occurs after death, (2) fertilization and pregnancy take place after the death of one of the partners, and (3) fertilization and cryopreservation of embryos takes place before the death of the partner.<sup>2</sup>

### Medical Considerations

Understanding the advances in ART is important for the palliative care community. Posthumous ART can be done using frozen sperm, egg, embryos, or ovarian tissue. Sperm freezing is considered the most noninvasive method and is considered a standard medical procedure. Sperm can be banked easily through masturbation, surgical excision of the epididymis or vas deferens, or electro-ejaculation. Sperm can also be retrieved from a corpse, but time is of the essence to obtain a viable specimen.<sup>3</sup> Storage facilities for banked sperm are readily accessible throughout the United States and specimens can be delivered or picked up. Surprisingly, studies have found that few patients bank sperm. Schover et al.<sup>4</sup> found that of the 41% of male cancer patients who reported they were interested in sperm banking, only 24% did. Lack of

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information, already having children, and not wanting children in the future were cited as reasons for not banking sperm. A 2009 study corroborates that lack of information is problematic.<sup>5</sup> In a national sample of 613 oncologists only 47% routinely referred patients to a reproductive endocrinologist or infertility specialist. American Society of Clinical Oncology (ASCO) guidelines recommended that all patients of child-bearing age be given information about fertility preservation.<sup>6</sup>

Egg freezing is a more invasive procedure and considered experimental.<sup>7</sup> For females, the banking and storage of eggs should include directives about who may use the oocytes upon death, how the eggs will be fertilized, who will act as a surrogate, and how to dispose of unused or remaining eggs. Embryo freezing requires hormonal stimulation to remove a woman's eggs. Eggs are then fertilized with donor or partner sperm to create an embryo. While embryos can be implanted immediately, they are usually frozen until ready for use. Unfortunately, the harvesting process can take up to 6 weeks, which may limit availability to patients who need to begin treatment immediately. Many cancer therapies can damage the reproductive system rendering patients sterile or with impaired ability to produce viable sperm or eggs. Females undergoing treatment may experience premature ovarian failure or early menopause either at completion of treatment or within five years. Ovarian tissue and testicular tissue preservation are experimental and not yet widely available.

## Ethics

Posthumous reproduction raises serious ethical debates and such debates take place within a long history of social, legal, and religious responses to the yearning for children even after death. New technology expands these questions beyond the social reconstruction of families possible in earlier eras, and raises new questions about the ethical implications of the medical creation of a family. Embryos, created in the laboratory, are neither things nor persons, and this uncertain status is given meaning by history and moral location. Classically, ethicists turn to principles, narratives, and cases. Many ethical dilemmas in medical care begin with the conflict between the principle of autonomy, which would privilege a patient's personal wishes for her care and beneficence, in which others seek to do good or avoid harm.<sup>8</sup> In the complex cases of reproduction, there are competing moral appeals, from prospective parents, from future children and from all persons implicated in the process. Avoidance of harm in this situation is difficult to manage, for while IVF is becoming more medically common, it still is a complex process with uncertain outcomes and in its first generation of human use. The majority of studies conclude that babies born from IVF have rates of birth defects similar to those born through natural conception.<sup>9,10</sup> Beyond the medical risks, no studies have explored the physical or emotional outcomes of posthumous reproduction. Experts have expressed concern about children being raised in single-parent homes, the stigma of how the child was conceived, the child's difficulty in coming to terms with legitimacy, and the idea that the child may have been conceived as a replacement for the dead parent.<sup>2</sup>

There are other classic principles as well, such as, issues of justice in a time of scarce resources, as well as the larger moral meaning of parenting. Religious traditions have long struggled with the yearning for posthumous families and the

problem of legacy. Biblical texts stress the use of brothers to "carry the line" of widows after death. Other ethical concerns are related to the way societies think about human gametes as a special kind of human tissue. In the United Kingdom, every embryo is registered and stored for a maximum of 5 years. Bahadur<sup>11</sup> comments that posthumous reproduction is a way to prolong the relationship with the deceased partner. He points out that these feelings may fade and that of the 21 women seen in their clinic who requested that sperm be frozen from their partners, none had used the samples.<sup>11</sup> Kramer's study<sup>12</sup> also showed that over a 4-year period, no pregnancies resulted from the 13 requests of spouses to harvest sperm.

## Legality

Legality of posthumous reproduction hinges at the least on informed consent for all adults who are a part of the procedure, and may raise issues beyond, for the child created in this manner. There are a number of scenarios of consent for posthumous parenting including<sup>13</sup>: (1) patient provides consent to the doctor who will eventually do the tissue extraction, (2) patient provides consent to a doctor who will not be the one doing the extraction, (3) written consent is obtained, but this is given to a physician after death, (4) there is no written consent, but the spouse indicates that this is what the deceased wanted and this is confirmed by a consensus of family members and friends, (5) there is no written consent, but the spouse indicates that this is what the deceased wanted and there are no confirming parties, and (6) spouse indicated that although it was never formally discussed, this is what the deceased spouse would have wanted. As a result of these scenarios, there is no consensus on what should be included on an informed consent form. Crocchin<sup>14</sup> recommends that consent forms include a number of scenarios.

Legal precedence on posthumous reproduction surrounds two issues: ownership of tissue, especially the unique and special sort of tissue that human gametes are, and inheritance. Other legal questions may be posed about the time frames when the tissue can be used and instructions on what will happen to the material at the end of the time frame. When tissue is not used, most courts defer to the original written consent documents.

Inheritance questions are related to legitimacy to ensure that a child born as a result of posthumous reproduction has the same rights as children born prior to the death of the parent. To date very little case law has been heard around inheritance. In 1984, a California judge ruled that a child born from posthumous parenting could receive an inheritance. While in a 2002 Massachusetts case the judge ruled that heirs born could not receive Social Security benefits from the deceased.<sup>15</sup>

Internationally, few countries have set legal precedents in cases about posthumous parenting. In the United Kingdom it is illegal to store reproductive tissue without the informed consent of the gamete donors, according to the HFE Act of 1990.<sup>16</sup> In a landmark case in the United Kingdom it was found that if the extracted sperm had been used immediately there would have been no violation of law but the fact that it was frozen violated HFE Act.<sup>17</sup> After eight court cases, Israel granted a wife permission to have sperm retrieved from her husband's corpse.<sup>11,18</sup> Israeli law does not allow the parents of

dead soldiers to retrieve sperm from their son's corpse to create grandchildren, thus requests for retrieval may only come from a spouse. Finally, a landmark court case in Tasmania ruled on the ownership of two embryos frozen by Mario and Elsa Rios.<sup>19</sup> The couple had a net worth more than \$8 million and died in an airplane crash. It was debated whether or not these embryos were inheritable, and whether it would be in the best interests of the children to bring them into existence without a mother and father. In this case, the final decision was to donate the frozen embryos to research.

### Palliative Care

What role can, or should, the palliative care community play? First, the palliative care community should be informed about the advances in science, the educational resources, and the financial resources available should a patient raise the questions about children after death. Second, while this article notes the new possibilities for advancing on this path, and offers resources for such a journey, it must be noted that when a patient raises this question, it may also be a way of asking about death and its finality. The palliative care community should be aware of the unique needs of patients and their families that are considering posthumous reproduction and the complex and contradictory sets of emotions it raises. Partners are mourning the loss of their loved one, but at the same time they are exploring the possibility of continuing their loved one's legacy through offspring, focusing not on their grief, but on a hope of picking up the pieces of a narrative that was shattered by death. ART and IVF are not facile or predictable processes, and they do not promise to result in a baby, much less in the restoration of the dream family imagined prior to the illness and death of the patient. If the observations of Kramer and Badahar are generalizable, and most partners do not utilize the banked tissue, then these issues may need to be addressed during the grieving process. A partner who decides that the enormity of raising a child on his or her own now outweighs the wishes of the deceased partner may have difficulty processing those feelings. Medical providers need to support families whose passions, promises, and yearnings for children may change throughout the dying process and beyond.

Finally, should the team need to direct families toward resources, resources can be found from The Oncofertility Consortium, Fertile Hope, ASRM, ASCO, Lance Armstrong Foundation, and the American Cancer Society.<sup>20–24</sup> Patients and their families can be given information on ways to reduce costs associated with banking. Sperm cryopreservation typically costs \$700–900 for the initial collection and \$200–400 per year for storage.<sup>25</sup> Embryo cryopreservation can cost up to \$5000 for stimulation of the ovaries, \$5000–10,000 for egg harvesting, and \$5000 for each embryo transfer attempt.<sup>25</sup> Fertile Hope and Livestrong have a Sharing Hope program that aims to arrange for discounted services and donations for eligible patients.<sup>26</sup>

### Conclusion

Regardless of whether or not the palliative care community believes that it should be involved in posthumous reproduction decisions, the likelihood of being approached with questions seems great. A better understanding of the medical, legal, religious, and ethical considerations will help to coordinate care or develop care plans that meet the reproductive needs of all patients.

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