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Embryos in Limbo

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Noah Markham was born in January 2007 to worldwide media notice. Like his Biblical namesake, this Noah had been saved from a flood. He had been one in a barrel of frozen embryos transported in a flat-bottomed boat from a flooded east New Orleans hospital in the days after Hurricane Katrina by the Louisiana State Police and Illinois Conservation Police. Interviewed at the time of Noah's birth, his mother, Rebekah Markham, said that she and her husband Glen were uncertain about whether they would use their remaining three frozen embryos to add to their family of Noah and his big brother Witt. Interviewed again on the occasion of Noah's first birthday, she said, "How can I not? I'm happy with two, but how can you not when you know what the possibility is? We almost lost Noah. I don't want to lose the others voluntarily."

Rebekah Markham's question is faced by thousands of couples who, like the Markhams, have embryos left from in vitro fertilization treatment. Many frozen embryos are used close to the time of their freezing either because the IVF cycle that produced them did not result in a successful pregnancy or because the parents will use them to add to their family. However, many others will not be used in a subsequent attempt at pregnancy; a 2008 study of patients with frozen embryos found that about three in ten patients were "very unlikely" or "somewhat unlikely" to use their frozen embryos to try to have another baby. Unlike British or Australian IVF patients whose embryos are destroyed after a fixed number of years, American patients have an unlimited amount of time to decide what should happen to these supernumerary embryos.

This so-called "disposition decision" confronts patients in the most intimate way with questions about the moral status of the embryo. The patient must decide if the embryos—*her* embryos—may be discarded, used up in research, or donated to another fertility patient and allowed to become the child of another mother. Some patients are able to make this decision fairly easily, but many patients find it so difficult that they are unable to resolve upon a course of action. An Australian study published in *Reproductive Technology* in 2000 found that 70 percent of patients with frozen embryos had not made a decision about what to do with them five

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years after the birth of their first child conceived by IVF; a 2005 study conducted in the United States found that 72 percent of patients with frozen embryos had neither disposed of their embryos nor made a plan to do so. Some patients keep their embryos in storage well past what would be the normal years of childbearing.

The accumulation of thousands of embryos in storage was not anticipated when fertility centers first began to freeze them in the early 1980s. At that time, fewer embryos were produced and more were transferred per IVF cycle than is typical today. Consequently, few embryos were frozen during a typical cycle. But more importantly, doctors seem to have thought that embryos would be used in efforts to become pregnant and that any "surplus" embryos would be thawed and discarded. Doctors did not anticipate that many patients would simply leave their embryos in storage after completing their families.

A 2003 survey of fertility clinics finding that perhaps 400,000 embryos had accumulated in storage in the United States shocked doctors and the public. This number far exceeded the previous estimates of 30,000 to 200,000 frozen embryos. Such a large and growing store of embryos was extremely problematic for any number of reasons. Doctors were alarmed by the prospect of finding themselves responsible for storing embryos indefinitely. Others were troubled by the ghoulishness of keeping embryos frozen for years on end. Some medical researchers viewed the store of frozen embryos as an untapped resource for embryonic stem cell research.

The 2003 survey spurred several studies by researchers eager to understand why patients are leaving their embryos in storage for so long, and to probe their willingness to donate surplus embryos to researchers or other infertile couples. Read together, these studies help us understand the intellectual and emotional terrain parents traverse when trying to resolve the fate of their embryos. Many patients agonize about this decision and find that the experience of having children through IVF causes them to revisit the directions they had given for the disposition of their embryos at the outset of IVF treatment. Many find themselves unable to reconcile their judgment about the moral status of the embryo with any of the available disposition options. When they are unable to choose an option that accords with their intuitions, many patients end up by default leaving their embryos in storage year after year.

The growing store of frozen embryos is a welcome testimony to the seriousness with which these patients regard the moral status of the embryos that they have caused to be created. On the other hand, the prospect of leaving embryos in storage indefinitely raises serious practical and ethical

questions. On practical grounds, it is very unlikely that doctors and clinics will continue to be willing to store patients' embryos for years on end. On ethical grounds, the situation is also highly problematic, both because of the limbo status of these tiniest of human organisms, and because of the generational puzzles these warehoused embryos open up. Several babies have come from embryos frozen for upwards of a decade; it now seems that embryos may be stored indefinitely without compromising their ability to develop once transferred. Thus we are entering a period in which it will be theoretically possible for a woman to gestate an embryo created by her parents many years previously and to give birth to her genetic sibling.

For the hundreds of thousands of embryos in storage today to be in storage in a hundred years, or even thirty years from now, when even the youngest of today's fertility patients will be entering menopause, is not acceptable. Why *do* patients leave embryos in storage, and how did we end up with this large store of embryos being saved for no definite purpose?

The Moral Status of Embryos

When the authors of a study published in November 2008 in the leading journal *Fertility and Sterility* asked patients to describe the moral status of embryos on a one to seven scale that runs from "no moral status" to "maximum moral status," ten percent of respondents described the embryo as lacking moral status and eighteen percent described the embryo as enjoying "maximum moral status." While a one to seven scale gives only a crude insight, almost three-quarters of respondents indicated that the embryo has an intermediate status or that they were in too much doubt to give an answer.

Very few patients—only one in ten, according to this study—view the embryo as without moral significance. A 2005 study also published in *Fertility and Sterility* found that "some couples thought of their embryos as little more than biologic material." The same study found that some couples think of their embryos not as having moral worth in themselves but "as a kind of genetic or psychological insurance policy and considered the possibility that their embryos might provide some medical benefit to their living children.... Others even discussed the possibility of having them as potential replacements for their living children should they be lost through illness or accident." Presumably the disposition decision is easiest for these few patients who think of embryos as lacking moral worth, free of the weight of morally fraught deliberations at the conclusion of their IVF treatment.

But for the overwhelming majority of patients, who consider the embryo more than a clump of cells and have what one study called "strange feelings about discarding human life," the decision is a morally weighty one, as they must seek a disposition option that respects their embryos as more than biologic waste. The intensely personal nature of the disposition decision comes through in all the studies that relied on interviews in which many patients became emotional or wept, describing the decision in terms such as "very difficult" and even "agonizing."

Adding to this complexity is the necessity of confronting a change in their own views. During IVF treatment, patients are often so focused on achieving pregnancy that they lose sight of anything beyond that goal. Thus, the 2005 study found that patients initially regard frozen embryos not with a view to their moral status but to satisfying their own wishes for a baby: "While undergoing IVF treatment, couples are reassured by having large numbers of surplus embryos…when couples actually begin to confront the disposition decision, their reaction is frequently one of discomfort and uncertainty." This evolution of views is echoed in a 2005 Australian study that focused on patients who had reversed their decision to donate their surplus embryos to other infertile couples. During IVF treatment, "a healthy embryo represented a heightened possibility for becoming pregnant."

> Before becoming parents, embryos symbolized a successful endpoint of ovarian stimulation and an opportunity for pregnancy. But after conceptualizing the developmental continuum of embryo–live child, their embryos came to symbolize "virtual" children.

These changing views may account in part for the 2001 finding in the *New England Journal of Medicine* that 71 percent of patients at one U.S. clinic made a disposition decision at the end of their IVF treatment that was different from the one that they had selected on the consent forms they had signed at the outset of treatment. The fact that so many patients find themselves ultimately disposing of their embryos in a way other than the way they had selected at the outset of treatment attests to the powerful way in which the disposition decision challenges patients' previous moral views.

Virtual Children

An essential factor in this decision is that patients are not being asked about embryos in general, but about embryos that are—at least in conventional IVF therapy without donor eggs or sperm—"flesh of their flesh."

Many patients think of the embryos in terms of their existing families by referring to the embryos as their children, or "virtual children," and as siblings of their existing children. One woman described them as "an extended family you don't see but have to pay for." Another mentioned "mentally greeting her embryos every time she drove past the clinic where they were stored."

Like Rebekah Markham, many parents who would otherwise be "happy" with their family size decide that they cannot bear not to try for more children when they know "what the possibility is." The 2005 *Fertility and Sterility* study found that for some patients like the Markhams, "the embryo solution was to 'use them up' by having more children." A curious consequence is that these infertile women may end up with more children than they would have had without the experience of infertility.

Technological advances in IVF treatment over the last decade have changed the stakes somewhat. In the early years of IVF, the medium in which embryos were grown could only support embryo growth for a day or two, and embryos of four or eight cells were frozen, each of which had only a very small chance of resulting in a successful pregnancy. Sometimes very many embryos would be frozen in a single IVF cycle and patients would accumulate them in storage; the 2005 study included one patient with twenty-eight frozen embryos. Now embryologists at the most advanced clinics are able to let embryos grow as long as six or seven days. During this period, most will fail naturally and only a few will be left to freeze, but these will be blastocysts of perhaps a couple hundred cells and, if thawed and transferred to the patient's uterus, have perhaps as great as a one in three chance of resulting in a successful pregnancy.

Few ethicists would distinguish a three-day-old eight-cell embryo and a week-old two-hundred-cell embryo in moral worth; in both cases, the embryo has passed the point of fertilization and has yet to reach the point of implantation. However, the recent technological advances may affect how patients are able to imagine incorporating additional children into their families. It seems very difficult to imagine accommodating a brood of twenty-eight embryos into one's family. "Oh my God, what am I going to do with the embryos?" one woman agonized in a 2000 study published in *Reproductive Technology*. "If there were just one or two I would have them transferred. So then I could think, I tried and it wasn't meant to be. As there are eight I can't do that. I'm clearly not going to have eight more children!"

More recent patients may have only a couple week-old embryos that each have a good prospect of becoming a baby; perhaps the smaller

number of embryos and their greater prospects for resulting in successful pregnancies will make these embryos tug at the imagination of some patients even more intensely.

But in the end, many decide not to try for another baby. During the original IVF cycle, the patients placed great hope in every embryo. Thus when they decide not to use the embryos to try to have another baby, this indicates a reversal of attitude toward the embryos. The frozen embryos that they were so glad to have as assurance that their efforts to have a baby would succeed are now "surplus" embryos unwanted for their original purpose. Whatever the reason for not wishing to have another baby, many patients feel guilt and grief about this change of heart toward the embryo, and this makes it very difficult for them to think about what to do instead.

A Change of Universe

For patients who do not wish to use their embryos to have a baby, an alternative is to donate the embryos to other infertile patients. The 2008 *Fertility and Sterility* study found that 62 percent of couples who do not want another baby were "very unlikely" or "somewhat unlikely" to choose to donate their embryos to another couple, while only 16 percent were "very likely" to do so. However, several studies suggest that even this 16 percent is an overstatement—many patients who indicate that they wish to donate their surplus embryos to another couple find that they cannot in the end relinquish them. Frequently, the obstacle is their strong sense that the embryos were "their own" and they could not entrust them to another couple to raise. "I just couldn't bear the thought that it was ours," one woman explained, in a 2005 study in *Human Reproduction* about patients who revoked their decision to donate their embryos. "It had everything about us in it."

Many begin the IVF process with every intention of donating. A sense of sympathy with other infertile couples and desire to do something altruistic made it seem like the obvious choice. "Life in the making seemed so precious," as one mother explained, and when the creation of healthy embryos was the focus of intense attention, it seemed only natural to want to share that joy with the less fortunate. No one had thought through what it would mean to share "an actual, biological child" with some other family.

The experience of parenthood is, as one father put it, a "change of universe." One woman who *did* donate, described in the 2000 *Reproductive Technology* study, did so at the outset of treatment, even before conceiving

her own children, "out of the superstitious belief that this altruistic act would improve her own chances of success on the program. She subsequently had two boys, and frequently wondered whether 'the other one' was the girl she so much wanted." Parents making this decision with children already in their lives are more able to imagine the situation that this woman faces every day: the knowledge that their genetic child is (or could be) out there somewhere, unknown to them, uncannily similar to and just as lovely as their legal children. (In one deeply regrettable example, a woman decided not to donate because her existing child had been diagnosed with attention deficit disorder, and on that basis she thought those "from the same batch" should not be brought to birth.)

Many parents envisioned scenarios in which their children might unwittingly fall in love with a full sibling, or complications would arise in the distribution of inheritance, or they would answer the doorbell one day "to face an angry teenager demanding an explanation about why he was given away." But these concrete concerns are perhaps not as powerful as the sense that someone in their family is hauntingly absent.

Thus they arrive at the torturous decision: because the future child is so precious that the parents cannot countenance relinquishing him to anybody else, they must instead consider the destruction of the embryo altogether. Many of the participants in the 2005 *Human Reproduction* study broke down weeping during the interview. One woman described feeling "hit" when she finally signed the disposal form. "To actually say like I'm going to destroy this embryo that had taken so long to get there, that is still a child to me?" But, she said, and repeated, "I didn't feel I could donate it."

Even for the few patients who are willing to countenance embryo donation to another couple, U.S. laws about testing the man and woman whose gametes were used to create the embryo for infectious diseases puts great obstacles to carrying out the intention of donating the embryos, and some who would choose this option find that they cannot do so. As of 2003, the waiting list for a donated embryo was three years long.

Donation for Research

Another option, donating unimplanted embryos for research purposes, appeals to some patients, who describe it as a way of salvaging something good from their embryos—not allowing them to be "wasted." The 2008 *Fertility and Sterility* study found that 66 percent of patients who do not want another baby were "somewhat likely" or "very likely" to choose to

donate embryos for research; this decision was correlated with ascribing a lower moral status to the embryo and with "altruistic concerns." Other studies have reported lower numbers of patients willing to donate embryos for research. The purpose of the research often makes a difference: a 2004 Danish study in *Human Reproduction* found that among patients who were willing to donate their embryos for research, fewer would agree to donate their embryos for stem cell research (57 percent) than would agree to donate their embryos for infertility research (60 percent), and, interestingly, fewer still would donate their embryos for approved stem cell *treatments* (49 percent).

What's more, there are daunting logistical obstacles to donation for research. Many embryos are unsuitable because they are not of sufficiently high quality or could not be shipped at an acceptable cost from a clinic to a research site. In her 2007 book, *Everything Conceivable*, Liza Mundy describes an IVF patient who is unable to donate her embryos for stem cell research in spite of diligent efforts to find a researcher who would accept them. And even if researchers are interested, there are complicated provisions for informed consent that must be met.

Discarding the Embryo and Compassionate Transfer

The simplest way of disposing of surplus embryos, and the only way offered at some clinics, is to allow the embryos to be thawed and discarded. However, the 2008 *Fertility and Sterility* study found that, among patients who do not want another baby, 43 percent are "very unlikely" and another 11 percent are "somewhat unlikely" to choose this option; only 6 percent of all patients included in this study were "very likely" to want their embryos to be thawed and discarded. It is unsurprising that the number of frozen embryos continues to increase when nearly half of patients who do not want additional children are "very unlikely" to choose the only way offered by many clinics to dispose of surplus embryos.

While many studies have focused on patients' decision to donate their embryos to other infertile couples or to research, there is not much information about how patients think about the process of destroying their embryos and what meaning they ascribe to the act. One possible meaning is suggested by Leon Kass, who writes in *Toward a More Natural Science* (1985):

> The demise of the unimplanted embryos would be analogous to the loss of numerous embryos wasted in the normal *in vivo* attempts to generate a child. It is estimated that over 50 percent of eggs successfully

> fertilized during unprotected sexual intercourse fail to implant, or do not remain implanted, in the uterine wall, and are shed soon thereafter, before a diagnosis of pregnancy could be made.

Of course, when embryos generated *in vitro* are discarded, what is invisible and natural becomes visible and chosen. Thus, another possible meaning for the disposal of embryos would focus on the element of choice and analogize the disposal of embryos to abortion.

Some evidence in the studies indicates that many patients are indeed going to considerable lengths to analogize the action of thawing and disposal to the natural failure of many embryos to implant that Kass suggests. The 2008 *Fertility and Sterility* study noted "the importance to patients of the actual process of thawing and discarding embryos." The study's authors inquired after patients' willingness to choose disposition options that would make the disposal of the embryos visible to them. One of these, known as "compassionate transfer," has the embryos transferred to the patient's uterus at a time in her monthly cycle when she is very unlikely to become pregnant. This process is essentially an effort to make embryo disposal as closely analogous as possible to the natural *in vivo* failure of embryos Kass describes. Of those who do not want another baby, 18 percent were "somewhat likely" or "very likely" to choose compassionate transfer.

Absent compassionate transfer, many patients seek a way of disposing of their embryos more respectfully than simply throwing them out with lab waste. Asked whether they would choose an opportunity to be present during a small ceremony when the embryos were thawed, 24 percent of patients were "somewhat likely" or "very likely" to choose to be present. The invisibility to patients of the disposal process may make it difficult for them to discard their embryos without more assurance than they feel is offered by doctors' promises that they will be "respectfully" disposed of as nonviable biologic tissue.

Fewer than 5 percent of U.S. clinics now offer either compassionate transfer or disposal ceremonies. Many clinics implicitly take the position that if an embryo is thawed and discarded, it doesn't matter whether that event happens in a glass vial or in a woman's uterus, or whether it is accompanied by a ceremony or prayer or nothing at all. Nevertheless, the interest in services suggests a willingness to allow embryos to be discarded if patients' morals concerns could be satisfied, and suggests that one reason that patients fail to discard their embryos is that they have doubts about the actual process.

No Good Choices

The unattractiveness of the various disposition options, combined with the inability of patients who would choose embryo donation to another infertile couple or to researchers to act upon that wish, means that many patients end up choosing by default to leave their embryos in storage. Left without what seems to them to be a morally coherent option, patients become stuck in indecision—and as a society we are confronted with the problems of a growing store of embryos being saved for no clear purpose. The 2008 *Fertility and Sterility* study found that 20 percent of patients with frozen embryos who do not want another baby are "somewhat likely" or "very likely" to keep their embryos "frozen forever."

The continued growth of the store of frozen embryos in the United States is an urgent social problem. This situation is unlikely to be tolerated by the doctors and clinics who have unwillingly found themselves with so many embryos in their trust. It also confronts us with the prospect of new ethical problems, such as ever more confused family lineages if embryos are used long after their creation. Introducing fixed storage limits such as those in the United Kingdom and Australia would help to alleviate some, although not all, of these problems. But this is unlikely to be easily achieved in the United States, where IVF practices stand for the most part outside government regulation.

The growing number of frozen embryos also reveals the complexity of individuals' experience of fertility treatments. For many patients, the true joy of taking home a baby after IVF treatment is tinged with a nagging anxiety about how to resolve the fate of their frozen embryos. Some of them find that the incongruity of their inability or unwillingness to accommodate all nascent life created in the course of their fertility treatment with their former passionate desire for new life is heartbreaking; for these patients, the grief of infertility has been replaced with anxiety about the nascent life they have caused to be created. The modern technological project which has brought relief from one sorrow does not enable them to elude a new and sometimes lasting sadness.

The authors of the 2008 *Fertility and Sterility* study concluded that "restructuring and standardizing the informed consent process and ensuring availability of all disposition options may benefit patients." Revising the "informed consent" process, however, does not reach the heart of the question these parents face. In their conventional role as mothers and fathers, determining their children's destiny is precisely what they *do not* do: recognizing that the full scope of the lives they brought into being

will not and should not be in their control, they devote themselves to their well-being, and (barring tragic circumstances) in the natural order, precede them out of this world. The standard disposition options do not reflect this inborn sense of relationship and purpose. The thousands of people with indefinitely stored embryos are acting upon the sense that they are called upon to be responsible for a choice that violates their intuitions about the moral status of human embryos and their care for their own offspring. Rather than empowering themselves with clarified terms of consent, it seems that many wish to *decrease* their direction of the outcome: those women who express interest in compassionate transfer want some way to let fate take the reins again, to see their embryos out of existence not because they were deliberately destroyed but because "it wasn't meant to be." This small act of abnegation, however, does not fully answer, even in the narrow minority of cases where it is available and appealing.

But though there is no clear way forward, ultimately some decision will have to be made.