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Surrogate Pregnancy After Prenatal Diagnosis of Spina Bifida

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Some pregnancies today involve infertile individuals or couples who contract with a fertile woman to carry a pregnancy for them. The woman who carries the pregnancy is referred to as a “gestational carrier.” The use of such arrangements is increasing. Most of the time, these arrangements play out as planned; sometimes, however, problems arise. This article discusses a case in which a fetal diagnosis of spina bifida led the infertile couple to request that the gestational carrier terminate the pregnancy, and the gestational carrier did not wish to do so. Experts in the medical and legal issues surrounding surrogacy discuss the considerations that should go into resolving such a conflict.

abstract

The number of births that follow surrogacy arrangements involving a gestational carrier is at an all-time high in the United States.¹ Typically, in these cases, an infertile individual or couple makes an arrangement with a woman who is capable of carrying a pregnancy to bear a child and then turn that child over at birth to the infertile individual or couple. In some cases, the egg and sperm come from the contracting couple. In other cases, the egg comes from an oocyte donor or, less often, from the gestational carrier (an arrangement called traditional surrogacy). The parties to such arrangements sign legal contracts. Sometimes, money changes hands; in other cases, the surrogacy is altruistic. All such arrangements are fraught with potential conflicts. When such contracts arise, the courts may be called upon to resolve them. In this Ethics Rounds, we present a case of surrogacy in which the fetus was diagnosed with spina bifida (SB) and analyze the conflicts that followed.

THE CASE

A 32-year-old G3P2 female patient presented for a prenatal pediatric

consultation at 21 3/7 weeks' gestation. The pregnancy was the result of in vitro fertilization (IVF); the patient was a surrogate. The intended parents lived in Europe. Because surrogacy was illegal in their country, an American lawyer initiated the contract between the couple and the surrogate. After a few months of legal, psychological, and medical preparations, an egg from an anonymous donor was fertilized with the father's sperm, and the resultant embryo was implanted in the surrogate. The agreement was for the intended parents to take the child back to their country; the surrogate would have no future rights or contact with the child.

An ultrasound showed a male fetus with SB at the second sacral level. No hydrocephalus or other anomalies were noted. Shortly after the doctor introduced herself to the pregnant woman, she said that she was not the mother. She called herself “the toaster.” She suggested calling the intended parents to discuss SB. The father spoke some English; his wife did not. Over the course of 45 minutes,

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the doctor explained the expected challenges that their son may develop.

In general, the disabilities depend on the level of the lesion; the higher the defect, the more adverse the outcomes. Neurologically, most children with SB have an IQ in the normal range but many having learning difficulties. In this case, because of the low level and the absence of hydrocephalus, the need for a ventriculoperitoneal shunt was considered unlikely. However, because sacral nerves are needed for bladder and bowel function, the infant would be at risk for recurrent urinary tract infections and declining renal function. Daily intermittent bladder catheterizations and medications to prevent leaking might be needed. Sensory deficits in the genital area may require medications for future erectile dysfunction. In addition, constipation is a common problem and can lead to leaking of stool, recurrent urinary tract infections, pressure ulcers, and shunt malfunction. Orthopedically, the muscles innervated by the nerves below the defect will be weak. Children with sacral defects usually walk without assistive devices, but orthotic devices for ankle stability and protection of the feet will likely be needed. Sensory deficits place him at risk for pressure ulcers and fractures.²

After explaining these challenges, the couple stated that they did not want to raise a defective child. They preferred an abortion but would consider in utero correction. The surrogate objected to a termination and because of the low level of the lesion, she was not a surgical candidate.^{3,4}

Lynnette J. Mazur/Laura M. Rosas Comments

The first successful surrogate pregnancy (ie, the carrying of a pregnancy for other intended parents) occurred in 1985. Surrogacy

can be traditional or gestational. In traditional surrogacy (natural, partial, or straight surrogacy), the surrogate is impregnated naturally or artificially with the intended father's sperm, and the child is genetically related to both the surrogate and the father. In a gestational surrogacy (full, host, or IVF surrogacy), the embryo, resulting from the intended father's sperm and an egg donor, is implanted in the surrogate and is biologically unrelated to her. Either form can be commercial (the surrogate is compensated by the commissioner(s)) or altruistic (the surrogate has reasons other than financial gain). Our patient was a commercial surrogate.

Surrogacy is especially complex because the interests of the intended parents, the surrogate, her spouse (if she has one), and the future child, may differ. Cases with international contracts have unique complexities. When unexpected fetal defects are encountered, both parties may face ethical, legal, medical, moral, and practical dilemmas. Given the time limitations on a postviability termination or a late-term abortion (after 20 weeks' gestation) and for fetal surgery (before 26 weeks' gestation), a timely legal settlement may not be possible.

How do the involved parties address these issues? By the nature of the agreement, both parties voluntarily accepted some restrictions on their autonomy. It follows that neither party should unilaterally change their mind after the start of the pregnancy. In addition, because the surrogate freely entered into the contract, she accepted other restrictions to her autonomy. She is expected to follow a healthy lifestyle and attend regular physician visits. Although she has a prima facie obligation to accept the advice of the obstetrician that will ensure the best outcome for herself and the child, she cannot be forced to accept a cesarean delivery (CD) for a child with SB. Also, given

the principle of autonomy, it is impossible either to prevent her or to force her to have an abortion.⁵ She retains the right to confidentiality and the right to determine what information about the pregnancy the health care providers can share with the commissioner(s).

In view of the fetus' birth defect, both parties questioned the agreement. Each wanted to do what was in their best interest, the principle of ethical egoism. The surrogate wanted to continue the pregnancy, and the couple did not want a child with SB. However, given their conflicting desires, who should make the decision? A termination may adversely affect the surrogate's health, her ability to care for her current children, or her future pregnancies. It may be against her beliefs or it may be too late in the pregnancy to perform. Accordingly, adoption would be an option; the surrogate could follow her conscience, and the couple would not have to raise the child. Payments and/or reimbursements for both the surrogate's and the infant's medical expenses would need to be determined.

Other important questions remain. For the surrogate's family, what are the psychological consequences for the surrogate's family of relinquishing their child/sibling? Our patient stated that her own children were confused about her pregnancy. One afternoon her daughter's kindergarten teacher asked for clarification of her daughter's statement "My mommy is pregnant but he is not our brother." What are the consequences if the surrogate keeps in contact with the resulting family? For the commissioning parents, what are the legal consequences of breaking the contract? What is the risk of rejection or risk of the child being the object of conflict between the parties? What information is shared with the child as he matures? For the egg donor,

is there a duty or a responsibility to find and inform her about her future risk for children with SB? This knowledge may lead her and her female relatives to receive folic acid supplementation before becoming pregnant in an effort to prevent SB. For the child with SB, what is his fate and who will pay his medical expenses? For the remaining embryos, what is their fate? For the health care provider counseling the surrogate and the commissioning parents, how does he or she maintain neutrality when presenting both parties with difficult choices?

Mary Kay Kisthardt Comments

This case raises complex ethical issues and even more complicated legal issues. I am a law professor and thus will focus primarily on the legal issues.

The development of the law related to enforcement of surrogacy contracts has had a tortured course.⁶ The complexity relates both to the complicated nature of the underlying issues but also to the fact that, in the United States, legal rules in this domain are made by the states and thus vary from state to state. Many states accept the notion of “intentional parenthood” and bestow rights to the legally recognized parents even if they are not the biological (or gestational) parents.⁷ However, parents do not always get the right to make decisions regarding their children, especially where the exercise of those rights conflicts with the rights of another adult who might be considered to be a parent or with somebody’s perception of what is in the best interest of the child.

There is an obvious legal deficiency here: the absence of any language in the contract regarding decisions during pregnancy. Most surrogacy contracts now contain clauses related to selective reduction in the case of a multifetal pregnancy or abortion in the event of a potential birth defect.⁸ Courts do not have the authority

to require a gestational surrogate to abort a fetus at the request of the biological parents. A contract with such a clause would thus be unenforceable.⁹ Contracts could raise the issue, however, to begin a discussion between the surrogate and the intended parents to gauge their ability to agree on a decision when a change of circumstances occurs. That is not to say that any pre-pregnancy consensus will necessarily continue once a pregnancy has begun (I believe that most women who have carried a child would agree that there is a fundamental difference between an imagined fetus and the one you are actually carrying in your womb), but it is a good starting point.

However, in this case, we are left with the need to make a decision when those conversations have not taken place. The key question is how to facilitate those conversations now that the parties are facing significant time pressure as well as possible language and cultural barriers. The intended parents’ desire to consider a “correction” may indicate that there may be room for further consideration, especially in light of the fact that the surrogate will retain the right to carry the pregnancy to term. If we start with that assumption, the focus can then shift away from the immediate decision to the long-term consequences of it. If the child is carried to term, who will be responsible for his care? Does the gestational mother intend to raise him? Most gestational surrogates are without the resources to raise another child. If she does, the courts will undoubtedly require financial support from the intended parents. What if she wishes to raise him but the intended parents wish to place him for adoption, thereby terminating both their rights and their duty to support? As the legal parents of the child, they are presumptively entitled to do so. These questions should all be part

of the discussion because they help to inform the decision. I do not think that there is a single right answer to these questions. Instead, I think there is a need for open, honest discussion that will, as its goal, help the parties involved come to a mutually agreeable plan.

To me, this case is ideal for a mediation process (again revealing my professional bias) because these implications can only be fully explored through conversation. As a mediator, I would hope to not only allow the parties to consider the legal implications but to begin to turn the discussion to a common goal of advancing the best interest of the child. How do the intended parents view a child with health issues? Is their desire to terminate based on a concern about their ability to meet his needs both financially and otherwise? Is their sense of disappointment in not having a “normal” long-desired child influencing their judgment? Is the gestational surrogate’s objection to the abortion a religious one? A moral one? How does she feel about raising the child? How will she feel if she carries the child to term and then is unable to keep him?

The implications of the decision will no doubt have lasting effects on all the parties involved. At a minimum, they deserve the opportunity to engage in a meaningful conversation about them.

Helen H. Kim Comments

In 2012, I experienced “15 minutes of fame” when I helped “Grandma to give birth to her grandchild (as reported by the Today Show).”¹⁰ The intended parent had a hysterectomy for the treatment of cancer. Her 52-year-old mother carried the pregnancy. This case was the story of an altruistic woman who served as a gestational carrier out of love and delivered a healthy infant after an uncomplicated pregnancy.

In contrast to that heartwarming story, the present case is heartbreaking. After birth, it is possible that the infant will have no parents. The parties were strangers who met via a lawyer. They did not have a preexisting relationship and most likely never developed a relationship. They live in different countries and do not speak the same language. When an unexpected pregnancy complication developed, they disagreed on the best course of action. After learning that the fetus has SB, the intended parents no longer want the infant; they prefer that the pregnancy be terminated. The gestational carrier, however, objects to pregnancy termination, an invasive procedure, and thus does not give her consent.

A little history might put this case in context. In 1978, the birth of Louise Brown, the first human infant born after IVF, proved that viable embryos could be generated in the laboratory.¹¹ Although IVF was initially developed to treat tubal infertility, the ability to generate embryos outside the body allowed for third-party reproduction, using oocyte donors and gestational carriers. By synchronizing the uterine lining with the development of the embryo, embryos generated with eggs from 1 woman could be implanted in the uterus of another. The first pregnancy using donor oocyte was reported in 1984,¹² followed in the next year by the first pregnancy in a gestational carrier.¹³

Between 1999 and 2013, there were 1 664 844 cycles of assisted reproduction in the United States that resulted in embryo transfer, of which 30 927 (1.9%) used a gestational carrier.¹⁴ Now, with gestational surrogacy, patients who are unable to carry a pregnancy are able to have genetic children. Indications for gestational surrogacy include lack of normal uterus (due to hysterectomy, uterine abnormality, or lack of female partner) or the presence of a serious

medical condition that would be a contraindication to pregnancy. In addition, because gestational surrogacy is illegal in some countries, an increasing number of patients are seeking this service in the United States. In 2013, 18.5% of US gestational carrier cycles were performed for non-US residents (in contrast to 9.5% in 1999).

The use of gestational carriers has always been controversial due to concerns regarding commodification of the body or infant selling, but for many, gestational surrogacy is the only option for genetic parenthood. Generally, gestational carrier cycles are very successful. As reported by Perkins et al,¹⁴ among US clinics reporting to the Centers for Disease Control and Prevention (CDC) between 2009 and 2013, gestational carrier cycles had higher rates of live births (41.5%) than nongestational carrier IVF cycles (36.5%). Consequently, the use of gestational carriers is becoming more common and more widespread. The number of gestational carrier cycles reported to the CDC increased from 727 cycles in 1999 to 3432 cycles in 2013. During the same time period, the number of clinics performing gestational surrogacy increased from 167 in 1999 to 324 in 2013. By 2013, 85% of the clinics reporting to CDC offered gestational carrier treatment.

With the increased prevalence of gestational surrogacy, efforts are needed to avoid heartbreaking situations such as the one described in the present case. The American Society for Reproductive Medicine (ASRM) practice committee has recommendations for practices utilizing gestational carriers.¹⁵ These include psychosocial consultation for both gestational carriers and intended parents. Recommended counseling topics include pregnancy scenarios, such as multifetal pregnancy reduction, prenatal diagnostic testing, and elective termination. Discussions between

the intended parents and gestational carrier should occur before embryo transfer to confirm that their values are aligned. Although the human response to a particular situation is never completely predictable, it is hoped that adequate pre-pregnancy counseling and discussion would allow intended parents and gestational carriers to prepare for various pregnancy outcomes and develop matching expectations. Unfortunately, such preventive measures do not always work.

So, how should the present case be resolved? Because abortion is illegal after 24 weeks' gestation, a decision to terminate the pregnancy would have to be made quickly. Pragmatically, if an agreement is not reached, the infant will be born.

Deciding to terminate a (previously) desired and planned pregnancy is always difficult—and is even more difficult with a third party. When multiple parties, from different backgrounds, are involved in 1 pregnancy, there is great potential for conflict. The best outcome would be for the couple and the gestational carrier to come to an agreement, but it will be difficult for them to build rapport and have a meaningful discussion when they are not in the same room and do not speak the same language, a scenario which is not uncommon.

Even if the gestational carrier had previously agreed to pregnancy termination, she may feel differently now. Her refusal to have an abortion may be a breach of the surrogacy agreement with financial implications, but she cannot be forced to undergo an invasive medical procedure without her consent. Both the American Congress of Obstetricians and Gynecologists¹⁶ and the ASRM¹⁷ support the gestational carrier's right to "autonomous decision-making." The ASRM ethics committee opinion states "the carrier has the ultimate authority about any procedures on

her body and cannot be compelled to submit to a procedure regardless of the contract.”¹⁵

Thus, although this case is complex, the right answer is clear. The pregnancy should not be terminated without the consent of the gestational carrier. If the contracting couple will not take the infant, the infant will need to be put up for adoption.

RESOLUTION OF THE CASE

This case had a happy ending. The surrogate agreed to give birth to the infant via cesarean delivery, and the intended parents decided to keep the infant. The defect was surgically repaired shortly after birth.

In general, surrogacy agreements are binding for the commissioning parents in cases of birth defects or a multiple pregnancy. Regardless of what was stipulated in the agreement, the child or children born are their responsibility. However, timely enforcement and legal arguments may leave the child without permanent placement while awaiting resolution.

In 2013, ~67 000 infants were born in the United States through IVF. About 2% of those (ie, >1300 births) were through surrogacy arrangements. Even if 99% of cases go well, there will still be many cases that raise legal and ethical controversies. Health care providers need to know not just the medical issues associated with such pregnancies but the legal and ethical ones as well.^{18,19}

JOHN D. LANTOS COMMENTS

Surrogacy arrangements involving gestational carriers have shed a new light on an old dilemma about the responsibilities that go along with bringing a child into the world. There is no licensing agency for parenthood. For anybody with the natural ability to have a child, they can have one

whether they are capable of raising a child or whether they truly desire to have one. With surrogacy, as with adoption, the law is called upon to attempt to define the responsibilities that parenthood entails. But the law is a blunt instrument. It is not surprising that dilemmas sometimes arise in these complicated gestational arrangements. It is, perhaps, more surprising that they do not arise more often.

ABBREVIATIONS

ASRM: American Society for Reproductive Medicine
CDC: Centers for Disease Control and Prevention
IVF: in vitro fertilization
SB: spina bifida

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