Reproductive genetics: Conceiving new wrongs?

Genetic testing ought to make it easier for couples to make informed reproductive choices. But when mistakes occur, or communication falters, lawsuits soon follow.

Today's reproductive and genetic technologies offer prospective parents important genetic information about a future child. Parents may want to use this information to avoid having a child with a genetic abnormality. This rapidly evolving area of medicine, known as reproductive genetics, is creating new legal challenges and new legal concerns.

Until recently, genetic testing was performed through “carrier” testing of prospective parents or prenatal testing of fetal DNA. The development of in vitro technologies now makes it possible to obtain preimplantation genetic diagnosis (PGD) of embryos. Specialists remove one or two cells from an embryo, extract DNA from the cells, and perform genetic testing. Embryos found to be unaffected are then transferred to a woman's uterus, hopefully to result in a child who is free of the disorder the parents seek to avoid.

Mistakes in testing, failure to test, or failure to accurately convey test results are inevitable. Courts confronted with these newer technological mistakes are searching earnestly for ways to apply, extend, or redefine existing legal theories.

What can go “wrongful”

Theories of “wrongful birth,” “wrongful life,” and “wrongful conception” have all been applied to cases involving children whose births, or conditions discovered at birth, are unwanted and unwanted.

Wrongful birth usually involves a claim by parents that a child’s birth would never have occurred “but for” the actions or inactions of one or more medical professionals. In other words, if the parents had only been given certain information, such as the results of a key genetic test, they would never have conceived or would have aborted the pregnancy.

Wrongful life claims, in contrast, are brought on behalf of the child, and allege that but for the professionals’ actions or inactions, the child would not have been born.

Wrongful conception claims are less common—for the moment—but typically involve claims by parents that they would never have conceived but for a professional's negligent or intentional actions, such as a failed abortion, sterilization, or pregnancy diagnosis.

The majority of states now refuse to recognize wrongful life claims on the theory that any life is better than none, and that public policy frowns on assigning damages for a life. South Carolina's highest court is the most recent to reject a wrongful life claim. Wrongful birth or wrongful conception cases, however, are more frequently allowed on the theory that parents who face extraordinary costs in rearing a child with a medical condition they did not want or anticipate should be allowed to recover those costs. In most cases, only the costs over and above those of raising a normal child are allowed.

Recent court cases highlight some of the novel legal challenges created by these fast-moving technologies.
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The missed diagnosis
A child was born with cystic fibrosis after the parents were mistakenly assured that the tested embryo was not affected. The parents attempted to characterize their claim as a novel “preconception tort,” but the trial court ruled in favor of the doctor and clinic where the PGD was performed. The court interpreted the lawsuit as a standard wrongful life claim and disallowed it in accordance with Massachusetts law. The ruling pointed out that the genetic mutation, and not the physician or clinic, actually caused the child’s disease, thus the defendants could not be held liable for it.

Sperm and egg donation gone awry
A California sperm donor passed along a serious genetic condition, APKD (autosomal-dominant polycystic kidney disease) to a baby girl. The donor had noted on his intake form that he had a family history of kidney disease, but the sperm bank failed to act on that knowledge. In another case, a New York Assisted Reproductive Technology (ART) program failed to report that an egg donor had tested positive as a carrier for cystic fibrosis. The couple conceived a child with the disease, presumably because the male was a carrier.

In both cases, courts ruled that the gamete donor, and not the sperm bank or ART program, caused the genetic disease. The rulings rejected the child’s claims, which the courts characterized as based on wrongful life or wrongful conception. Meanwhile, the parents’ claims of malpractice (egg donor case) and fraud (sperm donor case) may yet proceed.

Failure to do the right test
As courts see more of these cases, plaintiffs will push to expand old legal theories to accommodate new fact patterns. A recent case from the Minnesota Supreme Court highlights some of these emerging issues. A couple sued three physicians who had either missed, mis-tested, or mis-communicated about the testing of an older child who was suspected of having Fragile X syndrome. The mother and her second husband wanted to avoid any possibility of having a child with the same problems they saw—but could not identify—in the woman’s older child. The older child was tested for a variety of conditions. Testing for Fragile X was contemplated and discussed but, through a series of errors, was never performed.

When the parents were assured the child did not test positive for any genetic abnormalities, they assumed Fragile X had been ruled out, when in fact it had never been tested for. Several years later, after a new child was born with Fragile X, the parents sued. Despite state laws prohibiting wrongful life and wrongful birth claims, the Minnesota Supreme Court allowed a claim based on wrongful conception.

The court found that a physician’s duty to warn extended beyond the patient to the biological parents and that the case was not barred by the state’s four-year statute of limitations for medical malpractice. The court noted that the injury did not and could not occur at the time of the missed diagnosis in the first child, but only upon the conception of the second child, something that could—and did—occur many years after the initial mistakes were made. This ruling, if accepted in other states, could have major implications for genetic testing and those who perform or order it, since liability for mistakes may not be uncovered for many years, or even generations, depending on the condition or defect.

What the future holds
Just as reproductive genetics is an evolving science, legal issues arising from new technologies will continue to emerge, and new and more nuanced legal rules are likely to follow. Claims resulting from failure to provide genetic counseling, failure to perform genetic tests, or failure to accurately report genetic test results may no longer be rejected out of hand as wrongful birth or life claims prohibited under prior court decisions. Instead, the courts may construe them as claims of wrongful conception or wrongful pre-conception counseling or otherwise expand their views of wrongful birth and professional negligence.

Similarly, the legal time limit for bringing claims after genetic abnormalities are discovered is likely to expand. The standard of care that courts will require in the performance of genetic testing services is likely to change as well. While old laws will continue to be relevant, new reproductive wrongs are likely to conceive new legal theories.

REFERENCES