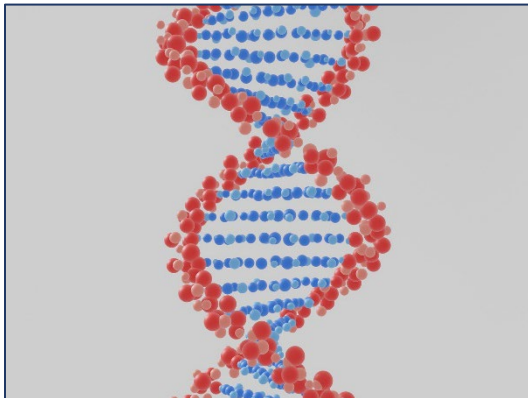


Case Study – Genetic Material: To Whom Does It Belong?



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Bioethics case study on genetic material.

Who we are is a fundamental question that is extremely difficult to answer.

A major topic in philosophy is the question of, what does it mean for a person to be them? Who are we? Are we our bodies? Or our history and experience? Or are we our genetic codes?

It seems that we are all of these things, but also each does not tell the whole story of identity by itself. Our DNA, our genetics, is often seen as the true measure of who a person is. But is that enough? And also, if that is a person, then does the person own their own genetic material? Does a person own their own genetic material? And following that, can someone own someone else's genetics? These are very difficult questions that do not have an easy answer but were brought up in a recent clinical ethics consultation request.

Fetal Tissue

The patient had recently had a difficult pregnancy. The fetus was diagnosed with a genetic condition that was non-compatible with life. Mom was admitted to the hospital due to complications but wanted to have her pregnancy naturally. Labor soon began and the fetus was delivered at 14 weeks gestation. Mom and Dad understood and were incredibly saddened by everything. But they would become more distressed later.

They soon informed the hospital that they found out that “not all of her baby was at the funeral home.” This made the family extremely distraught, and they wanted to know more and, most importantly, why? They felt that they had already gone through a terrible situation and now they cannot be at peace because they cannot even bury all of their baby.

Policy Dilemma

Of course, the hospital looked into the situation and found that, per pathology, they keep samples of tissue for 10 years, in case more tests are needed. They do a histology on all <20 week fetal losses. The mom said they did not get her consent to take part of her baby and she wants them back as soon as possible. There currently is no consent for pathology that we are aware of.

This touches into a larger policy it which states, "If any tissue, part, limb, or organ is removed during the operation or procedure, the medical facility will handle it in accordance with the medical facility's policies." Similarly, I consulted on a scenario where a patient's surgery remains were being sold to a "bio-bank" without their knowledge. The hospital was selling genetic remains, and genetic codes, to those who might be able to profit off them, without patient consent.

Questions

If you were the ethicist for this case, what would you do?

- Does the family have cause to feel their baby is not buried complete?
- Do patients have a right to their own genetic materials?
- If patients do not own their own genetics, who does?
- If others are profiting from someone's DNA, does that person have a right to the profits?
- And, finally, as technology marches forward, where do we go from here?

These are challenging questions that healthcare professionals do not come across often, but another situation that could benefit from clinical ethics support.