Technology and Kinship

LBST 2213 Lecture 4

This lesson

In this lesson and for the rest of the week, we'll ask the following questions:

- How does technology influence users' notions of ***kinship***, or family relatedness?
  - How does DNA testing influence notions of kinship and social identity?
  - How do Assisted Reproductive Technologies (ARTs) influence notions of kinship?
  - How do genome editing techniques, such as CRISPR, influence notions of kinship?
- What are some ethical concerns surrounding technologies that influence notions of kinship?

DNA Testing

Commercial DNA testing services, such as Ancestry.com and 23andme, have been on the rise. Since 2017, more than half a million people have taken commercial DNA tests. But what can these tests really tell us?

DNA Testing

First of all, when we take commercial DNA tests, it's important to consume with caution. These tests aren't an exact science. Full siblings - even identical twins - have gotten widely differing reports on where their ancestors were from. One man took nine different DNA tests and got six different ancestry reports. Another submitted DNA from a dog, and the company was none the wiser - it came back with a list of likely human relatives.

DNA Testing

There's only about 0.1% of the human genome that differs from other parts of the human genome. The places where the DNA of one human differs from the DNA of another human are called **Single Nucleotide Polymorphisms** (or **SNPs** for short). DNA tests compare your SNPs to the SNPs of other people who have taken the test. Therefore, DNA tests can tell you the parts of the world where other people have the same SNPs you do. They can't tell you for sure where your ancestors lived.

DNA Testing

Nonetheless, the things we learn from our commercial DNA testing results can change the way we see ourselves. In some cases, people who take DNA tests take on a new ethnic identity. This may not be the same ethnic identity the test-taker was raised with.

https://www.ispot.tv/ad/wKqV/ancestrydna-kim

DNA Testing

Traditionally, the definition of *ethnicity* refers to the culture in which a person was raised. Ethnicity doesn't always match up with ancestry. Someone may have African ancestry, but identify as being ethnically Scottish if they grew up in Scotland. In this example, a test taker finds out that her ancestors were, in her words, "from the Bantu people." However, she wasn't raised ethnically Bantu.

With the advent of DNA testing, the definition of ethnicity has shifted, with some people beginning to practice a culture they weren't raised in on the basis of a DNA test result.

DNA Testing

What are the implications of claiming and ethnic identity based on a DNA profile alone? According to Kim TallBear, a professor of Native American studies and author of *Native American DNA,* claiming indigenous identity on the basis of DNA test results alone conflicts with traditional ways of knowing when it comes to what makes someone indigenous. Does someone who does not know their Native American ancestors, but claims a Native American ethnic identity on the basis of a DNA test result, really Native American? Not everyone agrees on the answer to this question. However, many anthropologists have pointed out that it's problematic to claim an identity on the basis of a DNA test alone.

DNA Testing

And ethnicity isn't the only new identity that emerges from commercial DNA testing. Some people find out that they are genetically predisposed to get a chronic or terminal illness later in life. This creates an identity category that anthropologist Margaret Lock calls "presymptomatically ill" (2007).

DNA Testing

Scholars and consumers alike have raised ethical questions surrounding DNA testing for the predisposition to medical conditions. Is it right for commercial DNA testing companies to disclose medically-sensitive information without a doctor's order? Is it ethical for consumers to use this information to decide whether or not to reproduce?

DNA Testing

In one case, a man named Patrick Burleigh considers whether or not to do genetic testing on embryos he and his wife conceived through IVF. During IVF, embryos are fertilized outside of the body before being implanted into the uterus. Burleigh and his wife had the option to do PGD (preimplantation genetic diagnosis) on their embryos, and implant only embryos that had no genetic mutations.

DNA Testing

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Was it ethical to select against an embryo because of its genetic difference? Here is what Burleigh decided to do.

"I didn't know, when we were going through the process of thinking about having a child, I didn't know that it would be possible to test for this. It didn't occur to me. My wife and I ended up doing in vitro fertilization, and we ended up with fertilized embryos, and my wife happens to be an endocrinologist, and so we found out that we could test the embryos for the LHCGR mutation. And so ... I was faced suddenly with this decision, whether or not to select out for this mutation.

"It feels like an obvious decision, right? Like, why would I ever wish the challenges that I endured on my own child? But it ended up being a lot more complex than that, because this mutation — for all of those struggles — it ... has defined me. Certainly it defined my childhood, and had a profound and lasting kind of impact on how I think about myself and probably the path that I've taken. The same is true for my father and my grandfather and great-grandfather. And so selecting out for that mutation, eliminating it from my lineage, in a way it felt like eliminating this essential part of myself. And that was a feeling that ... surprised me. But it was present."

DNA Testing

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What would you have done in Burleigh's situation? What about if you knew you were carrying a gene for a disease that would significantly shorten your future child's lifespan, such as Tay-Sachs or Cystic Fibrosis?

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We'll discuss this topic in depth after watching the videos for this week.

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Finding out that the person you grew up thinking your dad isn't really your dad, or that you have a long-lost half-sibling, is sensitive information. Should DNA testing companies have the power to disclose this information? This is another ethical question raised as commercial DNA testing rapidly expands.

Assisted Reproductive Technologies

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These technologies are designed to treat impairments that cause infertility. Worldwide, about fifteen percent of couples experience infertility, which is defined as the inability to conceive without technological or medical intervention for a period of 12 or more months of unprotected intercourse.

Most common causes of infertility in the US (CDC data):

In male bodies:

- Variocele- a testicular circulation problem (17% of US cases)
- Azoospermia, or the absence of sperm in ejaculate (10-15% of US cases): diabetes and other endocrine disorders, history of drug/medication use or chemotherapy
- History of urogenital infections (up to 10% of US cases)
- Retrograde ejaculation (up to 2% of US cases)

In female bodies:

- Polycystic Ovarian Syndrome and other ovulation problems (40% of US cases)
- Endometriosis and pelvic adhesions (20-30% of US cases)
- Structural abnormalities (12-15% of US cases)

Differences in Sexual Development *or* **DSDs** (where someone's body is neither fully male nor female) can also lead to infertility.

What are the implications of being infertile around the world?

- The couple may separate and if the woman is the infertile partner, she may not be able to remarry
- The couple may be childless, meaning they cannot advance an age class or that they may have no one to care for them in their old age
- The couple may be expected to spend significant sums of money on ARTs (Assisted Reproductive Technologies)

Infertile Women among the Lusi Kailai

South Pacific - Kandoka Village in Papua New Guinea

Infertile women are moved into the age class of *mate*- translated as “dying” or “ruined”

(Counts & Counts 1985)

Image 1: map showing the Lusi homeland on the Island of New Britain, Papua New Guinea.

(Dorothy and David Counts)

Image 2: a group of Lusi

Assisted Reproductive Technologies

Let’s start by taking a look at some of the most common ARTs.

Assisted Reproductive Technologies

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Inhorn and Birenbaum-Carmeli, 2012

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Cryopreservation: long-term freezing of sperm, embryos, and ova, as well as human ovaries for later use in postmenopausal women and cancer survivors

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Assisted Reproductive Technologies

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Preimplantation genetic diagnosis (PGD): a technique used to screen IVF embryos for genetic defects, sex selection, and, potentially, certain "designer" traits

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Only sixteen US states require any type of fertility treatment to be covered by insurance, so most people pay out of pocket for these treatments. This includes low-income groups, and disproportionately people of color. Anthropologist Elizabeth F. S. Roberts once called assisted reproduction “assisted whiteness” (2012), because the vast majority of those who used these technologies were (and still are) White, upper-class Americans. Additionally, White sperm and egg donors are more likely to be chosen than those of color.

Assisted Reproductive Technologies

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Let's see why:

Assisted Reproductive Technologies

	TYPICAL COST	INSURANCE COVERAGE	TAX CREDIT
Sperm	$300	Varies by state	0
Eggs	$4,500	Varies by state	0
IVF	$12,400 per cycle	Varies by state	0
Surrogacy	$59,000	None	0
PGD	$3,500	None	0
Cloning	Unknown	None	0
Adoption	$2,500 (foster child) $15,000 (domestic infant) $25,000 (international)	Does not apply	$10,000 (federal)

Table 1: average costs of ARTs in the US, 2012

Country	Costs per IVF/ICSI cycle (USD)
Australia	$5,645 (ICSI additional $469)[91]
Brazil	$3,000[9]
Canada	$8,500 (ICSI additional $1,172)[91]
Germany	$4,148–$4,977[*,6]
India	$600–$1,000[92]
Japan	$3,956 (ICSI additional $860)[91]
Scandinavian countries	$5,549 (ICSI additional $614)[91]
South Africa	
IVF	$4,500±$796 (mean ± standard deviation)[*,93]
ICSI	$4,565±$864 (mean ± standard deviation)[*,93]
United Kingdom	$5,244[*,1,2]
United States	$12,513 (ICSI additional $1,626)[91]

Table 2: average costs of IVF in ten countries, 2012

Source: Harvard Business Review

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- When parents pass away or no longer want to preserve their frozen embryos, what should be done with them? Some people think it's okay to dispose of fertilized embryos, while others think that the embryos must be adopted and carried to term.

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- Female-bodied people who have healthy eggs but cannot carry a pregnancy to term may choose to use a surrogate mother to carry her child. A US-based surrogate could cost as much as $100,000. For this reason, many people hire surrogates from India and China, where surrogacy is much less expensive.

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- Some countries, like Japan, Australia, Taiwan, and Kuwait, have outlawed surrogacy on the basis that this type of body modification is exploitative.
- On the other hand, surrogacy allows single women in India and China a unique chance to make a living (Pande 2016).

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- Sometimes, this genetic abnormality will cause a deadly disease such as Tay-Sachs, which causes extreme pain and usually kills the child by age 2-4.
- Other times, the genetic abnormality will cause no significant hindrance to the child's quality of life. Examples could include Down syndrome, dwarfism, or differences in sexual development (formerly known as intersex).

Assisted Reproductive Technologies

What do you think? Should surrogacy be legal? Should gamete donors be promised anonymity? Should mothers be allowed to abort babies on the basis of non-life-threatening genetic abnormalities, such as those causing dwarfism or Down syndrome? Should it be legal to dispose of fertilized embryos once the parent stops paying to freeze them? These moral and legal gray areas are still being debated as we enter into the world of assisted reproduction.

We'll discuss these ideas, as well as the possibility of actually editing the genes of living people and embryos, during this week. When humans are created, manipulated, and edited using technology, they enter our realm of inquiry into all things technical.