Selling Ourselves: The Slippery Slope of (Voluntary?) Human Body Part Sales

ABSTRACT

One of the greatest benefits of the world’s extraordinary technological advances over the last century is that we are now able to address and solve problems that once seemed insurmountable. This has been especially evident in the pharmaceutical and biomedical fields where technological advancements have been truly life changing. With the development of imaging technology like MRIs and CAT scans doctors can now detect diseases earlier and with greater accuracy. Coupled with the discovery of new medical treatments such as chemotherapy and more recently gene therapy, these technologies have greatly improved patient outcomes. Unfortunately, rapid societal advancements have also been fraught with examples of exploitation, where one or more groups reap a disproportionately small benefit from their contribution to the overall good. In this paper I discuss instances of inequality and exploitation in medical research and, more specifically, in the context of tissue procurement for said research. I consider the proposal to protect patient rights by granting them property rights over their bodies and establishing a new tissue market, concluding that such a solution is morally impermissible. While advocating for continued technological development and biomedical advancements, within the context of cell and tissue procurement I argue that we cannot ever let any of the power, wealth, fame, or even pure excitement of biotechnological innovation eclipse our duty to protect human dignity. We must ensure that our technological evolution is coupled by an equal progress in our ethical stance on how we use our new knowledge and how we treat all contributors. And the best way to do this, I argue, is by bolstering informed consent regulations for research involving human subjects and/or their biological materials.

A HISTORY OF EXPLOITATION

Perhaps one of the most infamous cases of exploitation in medical research is that of the Tuskegee Syphilis Study. From 1932-1972, researchers from the U.S. Public Health Service took advantage of hundreds of poor black men with syphilis, claiming to be treating the men for “bad blood” when, in actuality, the researchers were providing the men with placebos so that they could study the natural progression of the disease without the men’s consent (Brandt 21-29). The exposure of this study’s unethical methods had lasting
implications for medical research involving human subjects; as a result of the study, Congress established the National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research and later, in 1991, extended federal laws outlining the general rules for informed consent and requiring the operation of institutional review boards (IRBs) for studies involving human subjects (Emanuel and Menikoff 1145). Though these measures, known collectively as “the Common Rule,” significantly improved the nature of patient consent, they only scraped the surface of human subject protection.

Rebecca Skloot more recently brought this issue to public attention in 2010 when she published her best-selling biography *The Immortal Life of Henrietta Lacks*. The biography recounts the story of a woman whose malignant tumor cells were cultured without her permission after a biopsy in 1951. Ms. Lacks’ cells were made into the famous *HeLa* cell line that is used globally in research labs. More than 60,000 experiments have been conducted using *HeLa*, including those that led to the development of medical technologies and treatments including the polio vaccine, chemotherapy, and in vitro fertilization (Cohen). In her book, Skloot juxtaposes the success and wealth Henrietta’s cells brought to medical research with the struggles and poverty the Lacks family endures. Most ironically, Henrietta’s children are unable to afford their own much-needed healthcare. Thus, by sharing the Lacks family’s story, Skloot urges us to question the ethics of a medical system that allows for such disparity. She acknowledges that taking cells from patients without their consent was common practice during the 1950s: “In the 1950s when Henrietta’s cells grew, the concept of informed consent that we have today didn’t exist. People were routinely used in research without their knowledge…. Taking cells from patients was absolutely standard practice worldwide in the ’50s. In a lot of ways, it still is today” (Skloot, “FAQ”). In this sense, the researchers who developed and used the *HeLa* cell line are not necessarily at fault. Still, Skloot argues that the healthcare system failed Henrietta not only by allowing for removal of her tissue without her informed consent but also by preventing Henrietta’s own family from benefitting from her cells (Skloot,"FAQ").

Skloot asserts that the donation-based system for procurement of biological materials takes advantage of patients by denying them the opportunity to profit from the use of their bodies in lucrative research. Skloot, a
so-called “tissue rights advocate,” questions the general attitude that individuals should donate their tissues to research since this research has the potential to lead to discoveries and developments that can help everyone. She argues that scientific research does not indeed help “everyone.” Rather, it benefits only those who are able to afford healthcare. Skloot criticizes the donation-based system, saying “there is an imbalance in this country, which means many of the medical advances coming from tissue research aren’t available to everyone, sometimes including those who provided raw materials for the research” (“FAQ”). Skloot is right to point out the disparity in the current healthcare system. Asking impoverished patients to contribute parts of their bodies to lucrative research, the results of which they are not even able to benefit from due to healthcare inaccessibility, certainly contributes to the gap between the wealthy and poor. This “imbalance” is an institutional problem within our healthcare system.

Given the recent rapid advancement of scientific research, it is ever more crucial that we protect the rights and interests of those who may be called upon to provide the actual biological materials needed to fuel such industries. However, in an article they published in The New England Journal of Medicine, Doctors Ezekiel J. Emanuel and Jerry Menikoff reveal that despite the substantial increase in volume of research involving human subjects, there has been almost no change in the Common Rule since 1991. Moreover, according to Emanuel and Menikoff, critics complain that the Common Law, “imposes a variety of burdensome bureaucratic procedures that do little to protect research participants, yet consume substantial resources” (1145). The doctors, therefore, propose that a reform of the regulations governing research with human subjects is desperately needed. I argue that this reform should be extended to research involving donated human biological material. We must make it our priority to uphold standards for the ethical procurement of biological materials to prevent patient exploitation, especially among the poor, who are perpetually vulnerable. Specifically, we must develop and enforce much better standards for educating these patients about their options and securing their truly informed consent when providing their own biological material for our general good.

THE TISSUE MARKET PROPOSAL
Many tissue rights advocates suggest that the best way to protect patients like Henrietta Lacks from exploitation is to allow them to sell their body parts through a new tissue market. Additionally, they assert that a tissue market could rectify the current economic gap between doctor-researchers and their patients. Lori B. Andrews, a professor of law at the IIT Chicago-Kent College of Law explains, “A market in body parts and products would require consent to all categories of research and ensure that patients are protected from coercion and given the chance to be paid fairly for their contributions” (Andrews 28). While well-intentioned, this solution is suspect; rather than protecting patients from coercion as Andrews suggests, a new tissue market is more likely to introduce coercion through its financial incentives. Giving individuals “the chance to be paid fairly for their contributions” will not shrink the economic gap between researchers and patients. Instead, I argue that it would further marginalize the poor. Those who are struggling financially may feel compelled to sell their bodies to support their families, whereas the rich will have the luxury to decide whether to sell, donate, or dispose of their cells. Furthermore, from an ethics standpoint, the sale of biological materials introduces difficult issues about commodification of the human body. The implementation and enforcement of informed consent practices for which Andrews advocates does not require the establishment of a tissue market; I argue instead that informed consent for tissue donation is the best approach. I acknowledge that improving informed consent will do nothing to decrease the economic gap. However, bolstering our informed consent regulations will allow patients to make their own decisions on how their bodies are used without the potentially coercive influence of financial compensation. And, when it comes to biomedical ethics, patient autonomy is of utmost concern.

While there has been strong support among medical and legal experts alike for increased patient control regarding the use of their tissue for research, few support patients gaining economic control of their bodies. When confronted with the concept of extending property rights to patients’ bodies, many dissenters have the same response as R. Alto Charo, a professor of law and bioethics at the University of Wisconsin Law School. She feels that a property-based approach to increasing patient control complicates the issue. Such an approach would introduce questions about who should profit from body parts. “A common bundle of rights associated
with ownership of property,” she explains, are “exclusive use, donation, sale, alteration, and destruction” (Charo 1519). Thus, she predicts, “if this pattern were extended to tissues, then selling organs might become a matter of right” (Charo 1519). If property rights are taken to mean economic control over one’s body, it could lead to a whole new industry in organ sale, something that is currently illegal in the United States (Prohibition of Organ Purchases).

CONCERNS OF COMMODIFICATION

Beyond these legal complications that a tissue market poses, tissue sale is dangerously dehumanizing because it attaches a price to the body. Justice Arabian of the California Supreme Court, who ruled in the 1990 landmark Moore v. Regents of the University of California court case, strongly agrees. Similar to Henrietta Lacks, Moore was a patient being treated for cancer who had tissue samples collected from his body for medical research, including the development of a cell line similar to the HeLa cell line, without his informed consent. Moore sued his physician, claiming that his blood, tissues, and even the cell line were his personal property. However, the court ruled that Moore had no right to share in the profits earned from the commercialization of his cells. In the concurring opinion, Justice Arabian wrote, “[Moore] entreats us to regard the human vessel—the single most venerated and protected subject in any civilized society—as equal with the basest commercial commodity. He urges us to commingle the sacred with the profane” (Supreme Court of California 19). Justice Arabian fears that treating human tissue as “fungible articles of commerce” will devalue the person as a whole (Supreme Court of California 19).

Arabian’s reasoning draws from two widely-accepted Kantian ethics about proper human treatment. The first is the idea that “man is not a thing—not something to be used merely as a means: he must always in all his actions be regarded as an end in himself” (Kant, The Moral Law). That is, people should not merely be used for others’ benefit. Rather, each person should be unconditionally loved and valued. The second principle is that “in the kingdom of ends everything has either a value or a dignity. Whatever has a value can be replaced by something else as its equivalent; on the other hand, whatever is above value, and therefore admits of no equivalent, has a dignity” (Kant, “Transition from Popular Moral Philosophy”). In other words, as soon as
something is given monetary value, it loses its self importance. The idea is that an object with monetary value becomes fungible—it has no inherent worth and can be replaced with anything of similar nature. Justice Arabian believes that permitting patients to sell parts of their bodies has the potential to result in patient tissue vendors being treated solely as a means for procuring much-needed biological materials rather than as ends in themselves as people and patients. Moreover, he fears these patient-vendors will become commodities with value rather than dignity; for, it won’t matter who provides the tissues so long as they are provided.

Tissue advocates may express frustration with this reasoning, claiming that tissues and other biological materials are already being sold for profit by researchers. They argue that allowing patients to sell their body parts would not change anything, except for the fact that it would now allow patients to share in the profit derived from raw materials taken from their bodies. Charles Erin and John Harris, both ethicists at the University of Manchester, point out, “There is a lot of hypocrisy about the ethics of buying and selling organs and indeed other body products and services…. What it usually means is that everyone is paid but the donor” (137). In the case of organ donation, for example, “The surgeons and medical team are paid, the transplant coordinator does not go unremunerated, and the recipient receives an important benefit in kind. Only the unfortunate and heroic donor is supposed to put up with the insult of no reward, to add to the injury of the operation” (Erin and Harris 137). In light of this hypocrisy, some tissue rights advocates may even suggest that the current system is strategically designed so as to maximize the profits for healthcare and biomedical corporations and that the Kantian philosophical argument is an attempt to cover up researchers’ greed for profits with a pretense of concern for their patients’ well-being.

However, there is a legitimate philosophical difference between selling raw biological materials and selling altered or engineered goods. To illustrate this, Margaret Swain and Randall Marusyk, both lawyers in biotechnology law, have proposed a three tier construct to differentiate between cells within the person, in their natural form outside of the body, and in a new, altered form outside the body. They argue that cells within the body constitute a part of the human persona and, given the aforementioned Kantian principles, shall not be sold. Cells temporarily removed from the body (such as those being transplanted into another body), they claim, shall
be deemed *res nullius* while outside the body—they belong to no one because they are no longer within the context of a persona. Thirdly, certain cells permanently removed from the body (such as biopsied tissue) can be deemed *res communes omnium*, common property of humankind. If these cells are combined with high technology, researchers can alter them to generate property rights over the transformed product (Swain and Marusyk 13-14).

Swain and Marusyk’s second category, *res nullius*, includes the raw biological materials that tissue advocates claim patients should be able to sell. But, because of the *res nullius* classification, these tissues would be disqualified from sale for profit. Why, then, is it that patients cannot make any money from their *res nullius* tissue, but corporations can make billions on *res communes omnium* materials? Swain and Marusyk clarify by saying, “A key distinction between matter deemed *res communes omnium* and *res nullius* is that the latter need not be transformed in any way to be useful to humankind: it functions in much its original form” (45). This differentiation reflects reasoning according to the Lockean labor theory. Considering a man who man who nourishes himself with acorns picked from a tree, Locke claims that the action of picking the acorns from the tree defines the moment when the acorns are no longer a part of nature, and instead now belong to the man: “That labour put a distinction between them and common: that added something to them more than nature, the common mother of all, had done; and so they became his private right” (Locke sec. 28). In other words, since labor is viewed as belonging to a person and raw materials as belonging to all of humankind, once a person combines his labor with raw materials he has created a new product that belongs to him alone. In this way it is possible to ascribe property rights to cells that previously legally belonged to no one. Thus, it is not philosophically inconsistent to prohibit patients from selling their raw biological materials but to allow researchers to benefit from the sale of goods derived from those same materials. Since researchers put in the work to fundamentally change the biological materials, they should have the right to profit from the cell lines and other technologies they develop.

WIDENING THE ECONOMIC GAP
Philosophical considerations aside, the patient-as-vendor approach is not the solution. Despite tissue advocates’ claims that the patient-as-vendor approach will help re-appropriate costs and benefits more equally in favor of patients, research suggests otherwise. In 2003 *The International Journal of Economics* published a study conducted by Heather Kolnsberg at the Lahey Clinic in Burlington, Massachusetts that suggests that even if patients were permitted to sell their body parts, they would not actually gain a significant financial benefit. According to the report, “the economic models demonstrate the probable outcome of falling organ-selling prices” (Kolnsberg 1066). Though this study looks specifically at the sale of organs, the same logic can be applied to the sale of other biological materials; as the supply of biological materials increases due to financial incentive, the demand for those materials will fall. Consequently, the price of the materials will also decrease, providing patient-vendors with little profit. Thus, an open tissue market would fail to resolve the economic inequality between patients and researchers.

To the contrary, the study suggests that introducing a new tissue market would likely increase the existing economic gap. According to the 2003 report, “The contention is that it is unethical to put human beings and their organs up for sale, a situation that could easily create a class of exploited poor. The poor would sell for the benefit of cash, but never gain enough cash to impact their poverty. Also, the poor might never be able to afford to purchase an organ if in need at some future time” (Kolnsberg 1050). Though patients would earn some money from the sale of their tissues, the report predicts that in the long run the profitability of a tissue market would fall not to the patients, but instead to third parties. These third parties would include tissue brokers, coordinators, and transplant facilities, and they would have the ability to influence the supply, distribution, and price of tissues. Were a patient allowed to sell her cells, she would have to go to a transplant or other surgical facility to have her cells removed. Following the procedure, she would sell her cells to a broker or coordinator who would, in turn, sell her biological materials to those researchers or doctors that desired them. Serving as the middlemen, the third parties would be able to alter prices—they could lower the price they paid the patient and/or increase that which they charged customers—to ensure their own profitability. Furthermore, while the profit the patient stood to make would be limited by the volume of cells that her body produced, the third parties
would be able to draw from a large pool of patient-vendors, making their opportunity for profit relatively unlimited (Kolnsberg 1061-1062). Third parties’ profits would clearly outweigh those of patients’, defeating tissue advocates’ purpose in creating this new tissue market in the first place.

In addition to increasing the economic gap, allowing patients to sell their tissues would also socially marginalize the poor. Some might argue that any compensation is better than none. But for the poor, a small remuneration has greater potential for coercive effect than it does for lasting compensatory effect. Kolnsberg explains, “In the long run, only the poorest and most destitute would be willing to sell [a body part] for depressed selling prices” (Kolnsberg 1066). The poor, given their financial disadvantage, are willing to accept lower standards to acquire income. In the case of tissue sale, the poor may tolerate lower prices for their biological material, though they may not feel it is fair compensation. Furthermore, impoverished individuals who see the sale of their body as the loss of their dignity may nevertheless feel compelled to sell their tissue so they can support their families. While, in theory, the rich and the poor would have equal autonomy in an open tissue market, in practice, the poor would experience less freedom in deciding whether to sell their body parts given their lack of other viable options for acquiring income.

ENHANCING AND ENFORCING INFORMED CONSENT

Because the proposed tissue market falls short of increasing patient rights (and economic status), I propose that stricter regulation and enforcement of informed consent would be more effective at minimizing patient exploitation. The best way to increase patient control is to allow patients to make more enlightened decisions about whether to donate biological materials removed from their bodies. These decisions should be made while the materials are still within the body (i.e. before they acquire res nullius status), and they should be informed by full disclosure and driven by medical, spiritual, and cultural considerations. Money should never be a reason. Increased financial profit does not increase a person’s ability to make reasoned decisions about his or her body; knowledge, on the other hand, gives patients power by helping them to understand their choices and choose what is best for them. Thus, doctors should be required to have a discussion with their patients prior to surgery about their options regarding the legacy of their cells. He or she should explain the implications of cell
donation to the patient in a way that the patient can understand. How exactly to ensure patient understanding, is a topic worthy of its own discussion, as “understanding” may have different meanings depending on each patient and his education and upbringing. The idea is, though, that doctors must take the time to discuss the process of cell donation in terms accessible to an average patient, yet in enough detail that the patient feels confident making a decision about the future of his biological material. Furthermore, the doctor should be required to reveal any stake, economic or otherwise, she or he has in the research that the donated cells may be used in. This way, if patients feel that their doctor has a conflict of interest, they can seek out a second opinion. These efforts to increase transparency in the medical process will help ensure that consent to donate is truly informed.

Having acknowledged the utmost importance of involving the patient-tissue-donor in the decision to provide biological material(s) for research, to what extent should the patients be allowed to dictate the future of their cells? Should a donor be allowed to indicate which types of research their cells are used for? Proponents of what is termed “specific consent” argue the affirmative. Though researchers point out that it can be difficult to know what future experiments might be conducted using donated biomaterial, Dr. Robert Sade asserts, “There should be no doubt about what is at stake in developing policy for the use of stored samples: the fundamental right to decide whether and how one's body and its parts will be used in research” (Sade 1440). I disagree. While allowing patients to choose specifically how their cells are used would grant them even greater control over their bodies, it is impractical to implement such a practice in the research world. The science community is a collaborative one. Scientists share ideas and materials, working together to make important advancements in their field. Though a patient may entrust his or her cells to one researcher, it is quite possible that their cells could end up, as Henrietta Lacks’ cells did, in labs across the globe. Giving patients the right to decide what types of research their cells are used for could prohibit this natural flow of ideas and restrict scientific advancement. Furthermore, when actual research participants’ opinions were considered, it was revealed that this specific consent is not something most people demand. An investigation conducted by a group of doctors at the National Institute of Health (NIH) on research participants’ preferences regarding consent revealed that in
actuality, “Most research participants [greater than 85%] authorize the unlimited future research use of their biological samples when given the opportunity to do so” leading the researchers to conclude that, “providing research participants with a simple binary choice to authorize or refuse all future research might allow individuals to control use of their samples, simplify consent forms, and allow important research to proceed” (Chen et al. 652). Therefore, I maintain that allowing patients to decide strictly whether or not their cells can be used for research is sufficient. And, if patients are concerned about the types of research their cells will potentially be used for, they can simply opt for their cells’ disposal as medical waste.

CONCLUSION

The proposed tissue market, though well-intentioned, is an unethical approach to tissue procurement. At first glance, it appears to maximize patient control by granting patients property rights over their bodies which, in turn, allow patients not only to control what is done with their tissues but also to profit from those tissues. This idea is tempting because it gives the illusion of being able to reconcile a financial disparity between researchers and patients. However, in practice, a sale-for-profit model would introduce monetary coercion and draw even more people into an even more exploitive situation. The best thing we can do for patients is maintain and enforce informed consent regulations so that all patients can be empowered to make their own best decisions about their bodies, protect their own interests, and preserve their own inherent human dignity. Furthermore, the implementation of enhanced informed consent practices should not stifle medical research. That way, scientists will be able to continue to advance the medical field and tackle those major problems that now seem insurmountable but will one day be conquered.
Works Cited


