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Paying tissue donors: The legacy of Henrietta Lacks

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In “The Immortal Life of Henrietta Lacks,” Rebecca Skloot tells the moving story of the woman who was the source of the first immortal cell line (HeLa) (1). The cells were obtained at Johns Hopkins University in 1951 from biopsies performed during her treatment for cervical cancer. As was standard at the time, her physicians did not seek her consent before using her tissue for research, and it was not until many years after her death that Lacks's family learned about her singular contribution to medical progress.

For many, it seems an injustice that the Lacks family never received any financial benefits from the cell line, especially given that the family lived in poverty, unable to pay for even their own medical care. For example, Christoph Lengauer, Head of Oncology Drug Discovery at Sanofi-Aventis and Adjunct Associate Professor of Oncology at Johns Hopkins University, reportedly told Lacks's daughter that he thought Hopkins had “screwed up” by not sharing some of the proceeds from the HeLa cell line with the Lacks family (1). Although this sentiment resonates with a sense of fairness for many people, it requires critical examination before becoming accepted as precedent regarding payments to tissue donors.

We recently had an opportunity to consider these issues when a young man in his thirties was treated at Dana-Farber Cancer Institute for a NUT midline carcinoma, a rare, aggressive form of cancer. Shortly before he died, he was admitted to the hospital with increasing shortness of breath, requiring placement of a pleural drainage catheter. He signed an informed consent document that gave the institution permission to use “specimens removed for necessary diagnostic or therapeutic reasons... for research, educational purposes, or other activity, if in furtherance of the Hospital's missions.” With his knowledge and permission, the physician-investigators obtained discarded fluid from the catheter to obtain and isolate tumor cells. The cells were subsequently processed into a cell line that holds promise for basic science research and the development of therapeutics, and which may result in a revenue stream for the medical center as well as personal income for the physician-investigators.

After the patient died, the physician-investigators who cared for him were strongly motivated to see that his family receive some financial benefit from his contribution. They sought advice from the university's research ethics consult service, on which we serve.

Property Rights in Human Tissue

While the law is not entirely consistent on the question of people's property rights in their tissues (2), a sentinel case addressing this issue was Moore v. Regents of the University of California (3). John Moore had his spleen removed as part of his treatment for hairy cell leukemia. Several years later he learned that his physician at UCLA had developed a financially lucrative cell line from this tissue. In 1990, the California Supreme Court decided that Moore did not have a property interest in his cells, worrying that giving patients property rights would “hinder research by restricting access to the necessary raw materials” and might “destroy the economic incentive to conduct important medical research.”

While this view has become widely accepted, the court's concern that giving patients property rights to their tissues might hinder research is, in retrospect, somewhat ironic. Although the research community theoretically endorses the sharing of research, in reality sharing is commonly compromised by the aggressive pursuit and defense of patents and by the use of licensing fees that hinder collaboration and development (4-5). The court's decision in Moore has certainly facilitated the commercialization of tissues by researchers and academic institutions, but in the absence of any requirements for the research community to share its products and findings, it is not clear that this line of reasoning has prevented the problems that the court was hoping to avoid. Nevertheless, given the strong legal precedents in this area, it is doubtful that this patient could successfully claim a property right over the cells obtained from his pleural catheter.

Informed Consent and Tissue Removal

Even if patients lack property rights in their tissues, they do have a common law right against battery that would preclude investigators from removing tissue from their bodies and using it without their consent. Individuals may therefore demand payment for permission to remove their tissues, as in the current markets for blood, blood products, oocytes, and sperm (6-7). A striking case was that of Ted Slavin, a man with hemophilia who contracted hepatitis B and then developed extremely high titers of hepatitis B antibodies in his serum. When his physician informed him that his blood might be valuable to medical researchers, he was able to sell his serum for as much as \$10,000 per liter, providing himself with a source of revenue for the rest of his life (8).

Still, the rights of patients to obtain compensation before removal of their tissues are legally constrained. The markets in blood products and gametes both involve the selling of renewable tissues; American law currently prohibits individuals from selling non-renewable tissues such as kidneys or other vital organs, even after their death. Again, the asymmetry between the rights of patients and those of medical institutions is striking; although patients may not sell their cadaveric remains, hospitals may sell donated body parts to contractors

who process the bone, skin, heart valves, corneas, and other tissues into marketable products that bring thousands of dollars of profit to the hospitals and industry.

Despite inconsistencies in the law and the countervailing ethical considerations cited above, it is well settled that tissues may not be removed from patients' bodies without their consent. Therefore, we believe that when payment is permitted, it is in exchange for permission to remove the tissue, not as payment for the tissue itself.

Gifts for Tissue Donation

We have argued that patients have the right to decline, for any reason, consent for procedures that procure tissue from their bodies. Implicit in this claim is that patients have the right to demand payment in exchange for consent. The next question is whether investigators should provide such payment, or whether they should only accept tissue when the patient offers it as a gift. Policy considerations favor the latter approach.

Three models for paying research subjects have been proposed: the market model, the wage-payment model, and the reimbursement model (9). With regard to tissue donors, the latter two models are of little relevance, since the patient is not doing any “work” in donating the tissue, and reimbursable “expenses” are nil.

The market model is reasonable in situations where it is possible to estimate prospectively the value of the tissues. This would apply to donation of blood and gametes, as well as less common scenarios such as that of Ted Slavin. But for the vast majority of tissue donations, this is not the case. In most situations, the true market value of the tissue – if any – may not be fully known until years after the actual donation. Furthermore, most specimens currently in biobanks have no value in isolation – their value comes instead from being part of the larger collection.

While it might be theoretically possible to keep track of donors and offer them some percentage of the financial proceeds that develop over time, the practical difficulties of such a scheme are formidable. More to the point, very few tissue donors will contribute cells that become financial blockbusters. Should we reward patients for “winning the lottery,” or instead for their willingness to be a donor in the first place? If the latter, then it would be fairer to pool the revenue from all such cell lines and divide it equally among donors. Under this scheme, however, the payment per donor would likely be quite modest. Such token payments might undermine the willingness to donate by cheapening altruistic motivations.

Even if there is no legal or ethical obligation to pay donors for their tissues, the physician-investigators in this case were strongly motivated to share the potential financial gains with the patient's surviving family. Much like Christoph Lengauer, their intuition was that, if the cell lines proved lucrative, the patient or surviving family should receive some financial recognition of his contribution. Would it be permissible for them to give the family a monetary gift? By definition, such a gift would not be something that the investigators “owed” the patient or something the patient “deserved,” but rather would serve as an expression of the investigators' gratitude.

While we do not believe that the investigators should be prohibited from offering gifts in these circumstances, we believe the practice should be strongly discouraged. First, it has the potential to be unfair, with investigators preferentially giving gifts to patients and families with whom they have become emotionally bonded, and not to patients and families who were equally generous but with whom personal relationships were absent. Second, it would tend to create expectations among donors that monetary gifts should be forthcoming. In the absence of enforceable standards about the size of such gifts, donors could feel angry or insulted if their expectations were not met.

Although the Moore court argued that paying patients for their tissues would impede medical progress, we believe that measures are required to ensure that patients not bear all of the altruistic burden of promoting medical research. At present, virtually all of the financial reward goes to those who modify the cell lines and use them in ways that give them scientific value. The knowledge, techniques, and processes involved in cell line development and modification, however, rest upon a large foundation of work developed by the scientific community, much of it publicly funded. It is unfair that the individuals who contribute only the last link in this long chain of scientific development should be the only ones to reap the financial rewards. Without denying their right to be compensated, more needs to be done to assure that the benefits of the research are more widely shared.

Some practical solutions for addressing this injustice might be for investigators and institutions to share the altruism of tissue donors by agreeing to license the cell lines to other academic investigators at cost, consistent with a suggestion by Mitchell and colleagues (10). Legislation that required these kinds of sharing incentives, or even that prohibited the patenting of cell lines altogether, could relieve the pressure on investigators and academic institutions to voluntarily implement these measures. However, such legislation would inevitably lead to windfalls by commercial institutions (e.g., pharmaceutical companies) that develop products based on these cell lines. In response, the legislation could further require that 5% of the revenues earned from products developed from the cell lines be reinvested into the institutions and investigators who engage in publicly financed basic science research.

Conclusion

While Rebecca Skloot's book is moving and compelling, we urge caution in drawing too close an analogy to present-day research ethics. Henrietta Lacks never gave informed consent for the research use of her tissue, and the tissue was obtained in a medical context that was even more prejudiced than today's against the rights of economically and socially disadvantaged patients (11). While the intuition that tissue donors should be financially compensated for their donation is commendable, as a policy matter this approach is ethically and practically problematic. Except in those situations where the tissue's market value can be estimated beforehand, investigators should adopt a practice of accepting tissue donations only when patients have freely agreed to give the donation as a gift, without expectation of monetary compensation. However, the altruism of patients to donate tissue to medical research must be met by similar generosity on the part of investigators and institutions. This could be accomplished through legislative mandates that promote the sharing of research

findings and products with other scientists, or by voluntary efforts of investigators and institutions to do the same.

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