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0521852803 - Black Markets: The Supply and Demand of Body Parts

Michele Goodwin

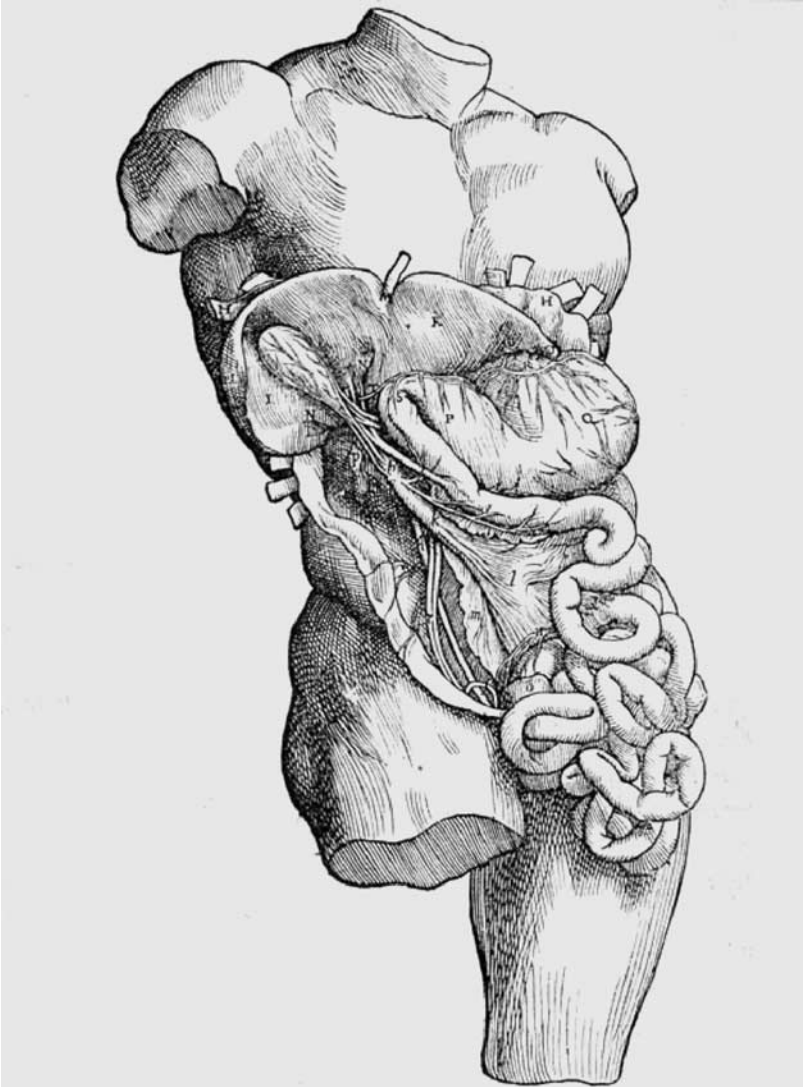
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BLACK MARKETS

In direct response to indefinite delays on the national transplantation wait-lists and an inadequate supply of organs, a growing number of terminally ill Americans are turning to international underground markets and coordinators or brokers for organs. Chinese inmates on death row and the economically disadvantaged in India and Brazil are the often compromised co-participants in the private negotiation process, which occurs outside of the legal process or in the shadows of the law. These individuals supply kidneys and other organs for Americans and other Westerners willing to shop and pay in the private process. This book contends that exclusive reliance on the present altruistic tissue and organ procurement processes in the United States is not only rife with problems, but also improvident. The author explores how the altruistic approach leads to a “black market” of organs being harvested from Third World individuals as well as compelled donations from children and incompetent persons.

Michele Goodwin, B.A., J.D., LL.M., is an Associate Professor of Law and Wicklander Fellow at DePaul University College of Law. She is the Director of the Health Law Institute and the Center for the Study of Race and Bioethics. In 2002 she was a visiting scholar at Berkeley School of Law in the Center for the Study of Law and Society. Her primary research interests are tort theory, property relationships in the body, bioethics, and biotechnology. Prior to joining DePaul, she was a postdoctoral fellow at Yale University, conducting research on the antebellum politics of sex and law. Her op-ed commentaries have appeared in the *Los Angeles Times*, *Houston Chronicle*, and *Chicago Sun Times*.



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Black Markets

THE SUPPLY AND DEMAND
OF BODY PARTS

MICHELE GOODWIN

Depaul University College of Law



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For Louise, Nina, Selena, and Theresa

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“Organ transactions today are a blend of altruism and commerce; of science, magic, and sorcery; of voluntarism and coercion; of gift, barter, and theft.”¹

Nancy Scheper-Hughes

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Chinese woman advertising her organs for sale. Chinese woman Liao Xiuyan begs with a sign reading "Sell my organs to save daughter" in Guangdong Province, China. Liao, 42, said that her 17-year-old daughter is suffering from leukemia and waits for marrow transplantation. The surgery, which costs almost RMB 500,000 (USD 61,652), is far beyond what Liao and her husband can afford. (Photo by China Photos/Getty Images)

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Preface

Organ poachers and distributors have developed international networks and some are more sophisticated than others. In October of 2005, police in Pakistan arrested a group of organ robbers from Afghanistan shortly after the devastating earthquake that killed more than 57,000 people and left more than half a million people homeless in that region.¹ The four men were caught carrying a cooler that contained 15 organs from victims who did not survive the devastation.² The victims' corpses were left in the rubble, emptied of the precious kidneys.

Americans live with the understanding that thousands will die each year because too few organs are donated in our present procurement system. Our demand for organs is soaring and the supply is very low. How we resolve this conundrum will reflect our values for autonomy, human dignity, and life-saving efforts.

The interrupted journeys of a few individuals who bravely fought (and later lost) their battles against treatable diseases helped to inform this book. Quite a few had been dropped from transplant waitlists or were misinformed about the benefits of transplantation versus dialysis. In particular, the willingness of some of these individuals to pay for organs to save their lives was a profound statement, particularly because they were African American.³ They presented an interesting juxtaposition to the race-based rationale for a ban on organ selling. For years, commentators based their opposition to markets in organs on the theory that organ selling resembled slavery. They predict that organ markets would hurt African Americans. Some scholars suggest that an open market in organs could result in familial homicides. They also argue that financial incentives could lead to economic irresponsibility (for the sellers). Some argue against financial incentives in organ procurement, opining that all financial transactions with the human body are coercive and could destroy the integrity of African American

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communities. Such fears have, in my opinion, limited the discourse and inquiry about how to increase organ supply. We may not know the impact on African Americans as participants in a market system, but statistics reveal how they have been disproportionately “hurt” by the current “altruistic” transplantation model.

In writing this book, I carried a number of stories with me. Some of these stories were more than mere interviews with patients about their experiences on dialysis; they were an oral history of people who influenced the lives of others and whose absences now reveal voids in their communities. Other stories were gleaned from legal cases, briefs filed by attorneys, and investigative reports. The personal experiences of dialysis patients interviewed as part of this project – Jerry, Tim, D. J., Emogene, and others – shed light on the racial dynamics of dialysis treatment, as well as organ transplantation and rationing. Their personal accounts helped to humanize an otherwise scholarly pursuit.

I found other stories equally interesting. These were the “after death” stories. Dead bodies do not speak; but their relatives can be quite expressive. Cadaver stories gripped my imagination, and led me on an interesting journey that included the review of hundreds of cases involving the mishandling, misappropriation, and unlawful burial of cadavers. In particular, the claims made by individuals who took legal action against companies for mishandling, moving, and otherwise disturbing their dead relatives presented unsettled nuances in the law as to property ownership in human bodies. The early legal history and analysis of body part appropriation and misappropriation seemed a logical extension of study and research on questions of institutional change in organ transplantation. Addressing system tolerance and institutional choice in procurement systems inevitably turns us toward the limits of our past engagement with body parts, how we value the deceased, and the level of our tolerance for institutional change.

Two civil cases intrigued me. The first case, *Moore v. Regents*,⁴ dealt with the question of conversion and more specifically whether Mr. Moore could sue his doctors for what amounted to his doctors misappropriating his cell line. Moore’s doctors made millions of dollars based on patents they developed from the nonconsensual use of Moore’s genetic material. The California Supreme Court answered in the negative; they argued that an individual has no ownership or property interest in his or her body! The second case, *Carney v. Knollwood Cemetery*,⁵ was more obscure. This was a Cleveland, Ohio, case that involved the mishandling of a deceased person. In this case, the Knollwood Cemetery instructed its employees to destroy a buried vault, including the casket within it, and to toss the remains in a trash heap behind the cemetery office to make room for a grave. Later, visitors reported

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seeing bones, a skull, and other body parts in the trash pile. News cameras captured footage of the macabre scene. In *Carney*, the court held that the plaintiffs (the sister and grandchildren of the late Mrs. Carney) had a viable cause of action against the cemetery for causing them emotional distress.

Yet another story intrigued me. This was slightly more personal, as it took me back to my childhood days visiting relatives in the South. My great-grandfather, a farmer wedded to southern soil, was nearly 100 years old at death. He was committed to the South and never left it except to bury his children in the North. As a little girl, I listened attentively to his fantastic stories, which as it turns out, often involved two subjects, the land and the dead. Within those two domains my cousins and I learned about harvests, moons, and tides. We also learned about “the value” of things buried: people and money. However, one story came back to me while I was in law school. It was a story he shared often about how Black graves were pillaged for body parts that were used for research and medical school anatomy classes. During summers in Mississippi, those stories seemed like interesting folklore. Only later, I researched his claims, and as shared in Chapter 8, you will see that his tales were true. The supply and demand challenge for body parts is not a new question.

It became clear to me that the law was not settled on body ownership questions. From state to state (and internationally), questions about property ownership in bodies and body parts were answered differently by courts. In some states, relatives were recognized to have “quasi-property right interests” in their deceased relatives’ bodies. Therefore, relatives could determine organ donation, burial location, disposition of the body (cremation, burial, whole body donation), and even instigate litigation for violation of their quasi-property rights. On the other hand, in even the most egregious cases of body parts misappropriation, including a hospital’s failure to return a prematurely born baby for burial,⁶ a two-headed fetus kept in a bottle on display at a circus,⁷ or nonconsensual removal of corneas for transplantation,⁸ the notion of property interests in human bodies was flat out rejected by some courts.

For me, the question of body ownership was relevant to the issue of organ transplantation. Body ownership was one way of looking at rights connected with the power to donate. Who has the power to donate? An individual may choose to donate her organs, but the state cannot force her to do so. The next of kin also possess a recognized legal interest in their deceased relatives’ bodies. They too can decide whether to donate a dead relative’s organs. But from where do their rights spring? The recognition of “quasi-property” right interests in bodies, specifically for purposes of body disposal dates back centuries in English common law. English courts initially applied this

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legal theory as an affirmative duty on relatives to properly bury and dispose of their kin. Early U.S. cases involved nuisance actions against relatives who improperly interred their relatives in stoves, fireplaces, and furnaces.⁹ However, “quasi-property rights” theory is inconsistently recognized and applied by courts. Some U.S. courts refer to it as a “legal fiction.” Indeed, as with all rights, there are also limits. In this book, I parse out these questions of ownership and how we might address an overburdened, underserving, organ procurement system.

Acknowledgments

My journey was aided by many. For more than a decade, John Paris has been a great mentor. He and Dean Hashimoto provided guidance and encouragement during the conceptual periods of this project, long before it was ever imagined as a book. John is an outstanding bioethicist and his willingness to respectfully challenge, inquire, and probe complex, nuanced medico-legal problems is inspiring. His spirited yet thoughtful engagement with sensitive issues taught me early on to courageously engage on bioethical terrain.

I am also most deeply indebted to Dorothy Roberts and Dorothy Brown, both of whom have been incredibly generous with their time and guidance. I am fortunate to have both as mentors. Marc Galanter's contributions to this project are also appreciated, particularly his critiques in its early stages when he encouraged me to follow through with my then-developing theory on market systems and how they could relate to organ procurement. Research assistants are invaluable to all academic endeavors. This book is no exception. For this project, Tamara Hobbs provided outstanding research assistance and I am most grateful. She along with Rakeena Payne, Cora Smith, and Michael Bankhead helped me to reach the Black community of and throughout Chicago for comment on dialysis, organ transplants, and community health in general. Pamela Koszut provided invaluable research support for this project. Erin Crow, thank you for being an extra set of eyes and performing cite checking. Glen Weissenberger provided the research funding to help bring the project to its next step. Special thanks to John Berger, my editor at Cambridge University Press and his great team. Any and all flaws in this text are my own.

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Finally, there are the family members who make our journeys through life meaningful. I must express my deepest appreciation to Nancy for providing an underground railroad of sorts. Memories of those years will always bring gratitude and warmth to my heart. In the end, this was not possible without you. Ann, Vata, Julie, and Todd, thank you for being there. I owe much to Ingrid Hillinger and Margit Livingston. To my godfather, Daniel Kunene, thank you for inspiring such beautiful poetry and for supporting my endeavors. Lastly, my daughter and son, Sage and Brook, and husband, Greg, provide year-round inspiration and help to place life in perspective. Journeys are only as valuable as the homes to which we return.

– Michele Goodwin

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BLACK MARKETS

PITTSBURGH POST-GAZETTE ■ SUNDAY, JUNE 27, 1993

SUNDAY

PERSPECTIVES

A daughter waits

My daughter was placed on the list for a heart and double-lung transplant when she was 20 years old. She was born with a badly deformed heart, which ruined her lungs. It took one week after the evaluation for the transplant team to decide she was a candidate. We were told that it might take up to four years to have the surgery because she needed multiple organs and that she needed to "put in time on the list."

That was two years ago. Did Gov. Casey get preferential treatment? You bet he did!

Saying that his sudden death could occur was a copout. People are not placed on that list unless their condition is incompatible with life and nothing else can be done. My daughter has been in a dangerous cardiac arrhythmia for a year and her oxygen blood level is nearly incompatible with life. Still, she waits on the list, non-priority.

I'm not begrudging Gov. Casey a transplant, but I certainly think that he should have waited his turn. Yes, he's an important man, but there are thousands of people on that list who are under 30.

We've heard that people, angry over this incident, are tearing up their organ-donor cards. This will not punish the powers that be; it will only punish people like my daughter who desperately need transplants.

LINDA BURNS
 Harmony, Pa.

A family snubbed

I can't stand the umbrage I felt when I discovered that the members of William Michael Lucas' family, who so nobly donated their son's organs for transplantation into Gov. Casey, were denied forgiveness of their son's hospital and burial expenses.

Of the hundreds of thousands of dollars expended in this endeavor, I feel the Lucas family did not receive the consideration it deserved.



Gov. Casey
 Did he jump line?

Gov. Casey and Mayor Masloff were elected to oversee the community welfare. When public servants become recipients of the organs of violent-crime victims, one is left wondering, "To whom is protection being rendered?" Perhaps, murder in the streets has found its ultimate good. What a sad commentary!

ROLAND C. BARKSDALE-HALL
 Lincoln-Lemington

Let us sell before dying

Gov. Casey's recent heart and liver transplant, and the inordinately short waiting period he experienced, serves by contrast to emphasize the long waiting period ordinary folk endure.

Did Casey skip the line?