Cambridge University Press
0521852803 - Black Markets: The Supply and Demand of Body Parts
Michele Goodwin
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1 Introduction

A. A Tale of Two Cities

The politicians can have our organs, but they can't give us jobs.
(*Mr. Giles*)[1]

All week long, we've been trying to get someone to pay attention to this (beating), and nobody wanted to hear it . . . The police have not been cooperating with us. They haven't been investigating. All of a sudden, they want to speak.
(*Yvonne Lucas*)[2]

There is a book of rules that controls the placement of organs and the rules under which they're transferred from donors to recipients, and I said I want to be sure, and you've gotta assure me now, each one of you that those rules are gonna be followed to the letter, – and they were.
(*Robert Casey, former governor of Pennsylvania*)[3]

It was a Sunday night, June 6, 1993, when Mrs. Frances Lucas discovered her semiconscious son. William Michael Lucas, 34, had sustained an unmerciful beating.[4] Covered in a pool of blood, Michael had somehow managed to struggle from the front door to his mother's kitchen floor. Despite his urgent medical condition, police and ambulance were slow to respond.[5] One lone officer finally arrived, but would not call for an ambulance to the home.[6] So Mrs. Lucas dragged her son into her car, placing him as gently as she could in the backseat and drove off to the hospital.[7] One week later, two very different men would be fighting for their lives. Michael would lose, but the Governor, Robert Casey (Pennsylvania), would survive with a pair of new organs.[8]

Days after his brutal beating and shortly after being declared brain-dead, Michael's heart and liver were delicately inserted into the waiting caverns of Governor Casey who was dying from amyloidosis.[9] Michael was the "wrong guy" caught in a vicious cycle. Michael Lucas was a victim of mistaken identity, bludgeoned by a drug gang that "beat up the wrong man."[10] Local police described the attackers as a fleet of gang members from Pittsburgh who swarmed into this small Monessen town looking for trouble.[11] Beaten by life, unemployed, but searching for work, Michael was the second of two sons to die violently.[12] Most of his attackers were never found. Michael's forgotten contribution to the state of Pennsylvania was saving the life of Governor Casey. The story made headlines in part because of Michael's brutal death, poverty, and the toll of racism on a small town and local Black communities. The story also became newsworthy because transplant patients and their families were outraged that the governor skipped over hundreds of patients on liver and heart waitlists. A reporter from the *Washington Post* described Michael as a product from a dying steel town, "a man who had vowed to escape but never could."[13] The fated timing of Michael's death and the governor's dual organ placement on the waitlist illuminated uncomfortable realities about organ procurement and transplantation. The political, economic, and social ironies read like *A Tale of Two Cities*.[14]

Michael Lucas was yet another Black male statistic among many, demonstrating how he was not able to pull himself from the mire, but also how a state could not or did not resuscitate his dying community, ravaged by poverty, unemployment, drugs, and lacking healthcare to offer him an opportunity for success. Casey, on the other hand, a 61-year-old White male, would have another opportunity to live, contemplate running for president of the United States, and complete his term as governor. A social commentator characterized the irony of Michael's fall and the governor's rise: "so it was that a man marked by every scourge of his times – violence, drugs, joblessness, racism – saved the life of the governor of Pennsylvania."[15] The "tragic irony," he notes, "was that it was supposed to be the other way around."[16]

Keeping vigil over her son, even passing a birthday, turning 64 during her watch, Mrs. Lucas prayed as her son's condition worsened. The following Sunday, June 13, 1993, as soon as Michael was declared brain-dead, an organ procurement specialist approached his mother. Thinking that perhaps another life could be saved, she consented to his organ removal. Yet the contrasts between how Michael Lucas and Robert Casey were treated when both needed medical attention is instructive, reminding us that "[Michael Lucas] waged [a fight] against [the] odds"[17] and the quiet role his race and circumstance played outside of the Black community. Indeed, those outraged by the governor's immediate transplant were more concerned that he had not spent fair time on the waitlists, really ignoring the more subtle and complex issues of urban violence, racism, and disillusionment.

Michael Lucas, however, had a story like so many young Black boys whose visions for the future shattered. His story is full of false starts and tragedies piling and collapsing on each other. Michael's athletic prowess and hopes for college play were dashed by a hip and leg injury that left him in a body cast for over six months when he was 12. The next year, Michael's idol, an older brother, was shot in cold blood by a White tavern owner. His half brother described the options left to young people trying to live in Monessen: "there were three choices for anyone young who stayed, death, drugs, or jail."[18] Through a series of ups and downs, including unmarried fatherhood and dropping out of college training programs, in 1987 it appeared that he had landed on his feet. It was also the year Casey took office. That year, however, would end like many others, with compounding social hardships, compiling debt, and his introduction to drugs while living in the only neighborhood his sister said he could afford. Drugs devastated the small mill communities just as it did in the larger urban areas.[19]

Casey's first stop on the postcampaign trail was Monessen to make promises he surely hoped could be achieved, and to some degree progress was made.[20] Yet despite his laudable gubernatorial efforts, Casey's progress was overshadowed by double-digit unemployment, even then twice the national average. As Yvonne Lucas lamented, her brother was just as devastated and vulnerable when Casey visited in 1987 as he was six years later, writhing in pain on his mother's floor.[21] According to his job counselor at the job services center, "a Casey-Wofford initiative," Lucas applied for "easily 100 jobs" the year before his death, but came close to getting only one.[22]

The events immediately following Michael's beating illustrate the complex labyrinth of race, class, and medicine. Mrs. Lucas called the police twice before an officer appeared.[23] Mrs. Lucas, a medical receptionist, drove her son to Allegheny General Hospital "in her own car."[24] She donated his organs that Sunday after being informed that he would not come out of his coma and that he was officially brain-dead.

Governor Casey, on the other hand, son of an attorney, and well educated himself, was called on Sunday and told that "he would need a new heart as well as liver transplant to try to beat amyloidosis," an organ-destroying disease, and that both were waiting for him.[25] That day, he "was flown to Pittsburgh in a state plane and driven by state police car to the University of Pittsburgh Medical Center, where reporters waited to record every step in his treatment."[26]

Casey's doctors claimed that he did not receive special treatment because he was the governor, but because he "needed" two organs. However, tragedies mark many parts of the joined stories of Michael Lucas and Robert Casey; although Casey waited only one day for Lucas' organs, others continued to wait over 200 days for a heart and 67 days for a liver. Indeed, if the story were turned around, would Michael have received aggressive treatment? Because of procurement and allocation policies at the time, hundreds were passed over for the governor to obtain Michael's organs.[27] For the Lucas family, their tragedy played on as only two of the fifteen involved in his murder were convicted, and police called an end to the investigation, claiming that it was "stalled." Reverend Giles, a minister and cousin of Michael who performed the eulogy at Lucas' funeral, summed up the consternation of local Blacks: "They can come to our community and say how great things are, but they can't lift us up."[28]

And then there was J. D. . . .

J. D. was the first African American to chair the Fayette County School Board in Lexington, Kentucky. He took this role quite seriously, bringing about investigations into the proper treatment of children with disabilities, shutting down a school that had been a dumping ground for boys with behavior problems and replacing it with a model alternative school, and supporting what were considered "radical" efforts to eliminate sexual harassment at the professional and student levels in the district's schools. His exceptional accomplishments as the leader of the school board were considered milestones in a community where implementation of the mandates from *Brown v. Board of Education* was under federal watch as late as 1999, the year of his death.

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J. D., like thousands of other African Americans who preceded him, and many more since, died from complications arising from end-stage renal disease. Although placed on dialysis by his physicians, when I interviewed J. D. in 1998 and 1999, and asked whether he qualified for a kidney transplant, he thoughtfully expressed, "they never told me about transplantation."[29] J. D. was referring to his doctors. By the time of our conversations on organ transplantation, it was too late; his death was not an if only a when. J. D.'s death had a profound impact on his community; without him there were no other persons of color on the school board (the second largest district in the state). The African American community no longer had a voice on the school board. Another important community role model had died.

Although separated by miles, culture, education, and economic status, J. D. and Michael were Black men connected by end-of-life transplant stories. Neither story is unique. Ashwini Sehgal's illuminating study on organ transplantation in the United States revealed that Blacks were more likely to be organ donors whereas Whites were more likely to be recipients.[30] In the investigation, Sehgal, a nephrologist and director of the Center for Reducing Health Disparities at Case Western Reserve University, examined data from over 100,000 transplants performed in the United States during the period of 1996 to 2001.[31] The results confirmed long-suspected disparities. Blacks were more likely to be donors and Whites recipients for six of eight types of deceased donor transplants (kidney-pancreas, liver, lung, pancreas, intestine, and heart-lung).[32]

Commentators have long alleged inequitable treatment in the allocation and distribution of organs. Annual reports from the United Network for Organ Sharing (UNOS)[33] repeat the tale that has become all too predictable: *Blacks wait longer than all other ethnic groups for organs such as kidneys, and have the highest death rate (while on the list) of all populations in the United States.* The list does not share anything about those like J. D. who are not given information or presented options about transplantation. Those Blacks never make it onto the list, but spend their last months and years hooked to dialysis machines several days per week. They are the forgotten ones.

Some commentators allege that inequitable distribution of organs is caused by racial profiling and "cultural incompetence" that impedes the

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fair distribution of organs.[34] African Americans have a greater need for kidneys, where the acute shortage is felt most. As of July 12, 2005, the Organ Procurement Transplantation Network (OPTN), which gathers data on transplantation, reported that there were over 66,000 Americans waiting for kidneys and African Americans comprised over one-third of that list.[35] Currently, there are 23,042 African Americans waiting for kidneys, making them the largest per-capita ethnic group on this list.[36] Yet how many of these waitlist candidates will ever receive an organ? How many more will be passed over because the matching criteria is too restrictive? What is the solution? I have come to the conclusion that the altruistic procurement process is inadequate, creating problems for all those who seek organs because it simply does not generate an adequate supply. The current altruistic procurement system that supplies organs is problematic for Whites too. Even if organs were equitably distributed, there is still a dramatic shortage in the number of organs available for transplantation.

The stories of Michael and J. D. speak to the significance of status and the troubling nuances of contemporary organ procurement and allocation. From whom will we capture organs and to whom will they go? Biotechnology provides methods to increase life span. However, biotechnology cannot (at least at this time) address the supply and demand of human resources. We are at a crossroad where institutional sufficiency must be measured and tough choices are to be made. If we continue with the present altruism-based procurement strategy, one thing can be predicted with certainty; thousands will die annually.[37] Disproportionately, morbidity will be greatest among people of color.[38] In particular, African Americans will wait longer than other ethnic groups and suffer the highest rates of death.[39] Such predictions are alarming, but not surprising; they are based on current practices and trends.[40] Each death will have an impact on a family and local community.[41] Those who can avoid America's transplantation system will do so. They will bypass the American waitlist process for greater access abroad, even if that choice involves paying a destitute living donor and violating the law.

B. Black Markets: Altruism's Limits

In this book, I contend 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 death toll resulting from organ failure is high – it is not declining – yet more people are added to the organ waitlists each day. Let us examine what this means in real terms. Each day, 18 persons on the UNOS waitlists die before ever receiving the anticipated organ.[42] They are replaced by another 110 persons who will enter that list by the end of the day.[43] This number rises each year.[44] The dramatics of who enters and exits would be far less onerous if there were equilibrium between who enters and exits. If we consider the demand only for kidneys, notice the number of candidates added to waitlists each year between 2001 and 2003, respectively: 64,280 (2001); 68,333 (2002); 72,132 (2003).[45] One person becomes a waitlist candidate every 13 minutes. These figures help to place in context the gravity of our organ demand.

The crisis in U.S. organ transplantation is only partially addressed by the actual organ shortage. The balance of the equation requires us to honestly consider the limitations of our procurement system and strategy. Rationales once used to justify the prohibitions on incentives in organ donation may be less persuasive in an era where demand for transplantable organs is exponentially higher than nearly 40 years ago when the Uniform Anatomical Gift Act (UAGA)[46] was originally drafted and in 1984 when the National Organ Transplantation Act (NOTA)[47] was enacted. At the time of the U.S. ban on organ sales, transplantation was slightly better than an implausible reality. Transplants were episodic as relatively few transplantations occurred in the 1970s and 1980s. In 1984, a transplantation system based purely on altruism was compatible with our medical capacity and social trust of biotechnology. Moreover, the medical technology to sustain transplants, cyclosporine, and other drugs were yet to be developed. Thus, the collective concerns of urgency, biotechnology, and social confidence in transplantation are far different today than 20 years ago.

In addition, we have learned in considerable measure that the market pitfalls predicted by Richard Titmuss in his seminal study, *The Gift Relationship*,[48] were overstated and wrong. A generation ago, Titmuss suggested that market systems in human blood would attract "skid row" participants who would infect the blood supplies of Europe and the United States. In particular, Titmuss noted that many of these skid row types were "negro" because the commercial banks "are better placed" in "Negro and Ghetto areas."[49] His concern about the disproportionality of "Negro" involvement in the blood supply reverberates in contemporary debates about financial incentives in organ supply. *The Gift Relationship* is concomitantly laudable and troubling; it develops a thesis praising the value of human relationships developed through altruistic gestures. On the other hand, Titmuss equates racial and economic status with diseases that would infect a blood supply pool from which Whites would draw. Titmuss forewarned the Western world that blood commodification would lead to insalubrious plasma entering the supply and incapacitating the blood procurement system. He pointed out, for example, how one commercial blood bank in Newark, New Jersey, collected 12,680 donations in 1968, but that "85 percent of its donors were male, Negro . . . part-time workers."[50] The significance of this fact was not lost on legislators and readers of the early 1970s. The United States was highly segregated at the time and the reality of integating blood supplies in a nation resistant to school and housing integration must surely have caused concern. Titmuss highlighted such donation scenarios as dangerous for the blood supply and an incongruent redistribution of blood (i.e., from poor to rich supply).[51] And what was the solution? Should Blacks have stopped donating? One way to read Titmuss' warning about "bad" donors is that Black males are less ideal donors only when compensated. It is difficult to know whether Titmuss was leery of poor donors or poor "Negro" donors. In other words, Titmuss might have believed that all poor donors potentially placed blood supplies at risk. If so, his solution to forbid payments to poor donors addressed only one aspect of the tragedy he predicted, because poor donors were not excluded from altruistic blood donations. What Titmuss does make clear in his writings is that Negroes were potential polluters of the American blood supply. Ironically, Titmuss assumed that blood would flow *only* from Blacks to Whites. Did Titmuss forget that Blacks needed blood too?

The Gift Relationship garnered significant praise and recognition, but its racial undertones have largely been ignored. Titmuss described the worst aspects of a market – and in that he was not incorrect. There are harmful downsides to unregulated market – based approaches, including coercion of unwitting participants, the incapacity of markets to respond adequately to certain social dynamics, and the potential for disparate class relationships to emerge.[52] What Titmuss did not predict nor account for was acquired immunodeficiency syndrome (AIDS) and the very generous donation patterns of gay men unaware of their human immunodeficiency virus (HIV) status, which threatened the American and Western blood supplies in the 1980s.[53] A crippled blood supply had nothing to do with the wealth of those who donated, but rather their health. The correlation between wealth and health in that context is far too narrow. Moreover, Titmuss erroneously assumed that altruistic behavior positively corresponds to physical and psychological health. In this, only unhealthy people engage with markets; healthy people avoid markets and are more altruistic. Altruism does not respond to status in the manner in which Titmuss predicted. The health emphasis in any procurement system is better placed on screening, testing, and documenting social histories. Reliance on the gift relationship model ignores biological shortages and unhealthy gifts from very generous people.

Recent health crises involving organ donation further demonstrate the unreliable correlation between altruism and health. On October 6, 2005, the Centers for Disease Control (CDC) in the United States announced that three individuals who received organ transplants from a single donor were infected with West Nile virus. Two of the patients were comatose at the time of the CDC announcement. The New York City donor was declared brain dead on August 26, 2005, after suffering a traumatic head injury, and within two days, his liver, kidneys, and one lung were harvested for transplantation. However, this was not the first incident in which West Nile, a flu-like virus, was transmitted through transplantation. The first instance involved a donor contracting the virus through a blood transfusion, and later after his donation, four recipients of his organs contracted the disease. The infected donors in these instances were not "skid row" menaces to society, focused only on financial reward. Rather these altruists were among the very classes Titmuss suggested would be infection free and safe. Ultimately, it is not a matter of class that determines whether the donor's organs or blood are safe, but rather effective tests.

Altruism may be the noblest form of giving, especially in the context of organ donation, but how many people need die before we rethink our procurement strategy? A Gallup poll indicates that whereas 85% of Americans support organ donations, only 20% carry donor cards. Americans are very generous people, but they refuse to volunteer their organs at a rate that accommodates national demand. Their generosity must be placed in context with what they are willing to "give" and to whom they are willing to provide it. Despite aggressive public service campaigns and more than a billion dollars spent over the past decade to promote organ donation, Americans are unmoved. As the death toll mounts, demand for organs continually outpaces the supply, resulting in rationing that at times could be considered arbitrary and capricious.

The most noticeable flaw in the altruistic procurement process is system incompetence. By this, I am suggesting that if altruistic procurement is designed to meet the overwhelming need for organs, it is a numerical failure. In this way it closely resembles a sophisticated lottery system rather than a reliable supply system. I am not suggesting that altruism should be abandoned. That would be foolish; we don't wish for the supply pool to drop. Nor am I suggesting that the dedicated procurement specialists at organ procurement organizations (OPOs) or the regulatory staff at the United Network for Organ Sharing (UNOS) are failing in their responsibilities. To the contrary, they have been very innovative in their efforts to increase supply within a limited framework.[54] What I suggest, however, is that exclusive reliance on altruistic procurement will perpetuate organ shortages and an avoidably high death rate for patients.

The altruistic procurement system veils other pitfalls and problems. Biotechnological developments, such as organ transplants, fetal transplants, cloning, and tissue transplants, outpace legislative regulation and judicial inquiry, and thereby create gaps in the rule and role of the law. Where such gaps exist, secondary and alternative systems can develop, undermining public awareness and affecting health, safety, and public trust. The law has yet to catch up with subsystems that exact a harmful toll on vulnerable populations. Often, subsystems develop in response to incompetent primary systems.[55] Let's consider some of the system by-products of our current organ procurement model.

1. The Black Market

Consider first that altruism veils the existence of thriving black markets. In direct response to indefinite delays on the national transplantation