

## REVIEW ARTICLE

## American death

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*Sharon Kaufman*, *And a time to die: How American hospitals shape the end of life*. New York: Scribner, 2004, 416 pp., ISBN 0-743-26476-2.

*Lesley A. A. Sharp*, *Strange harvest: Organ transplants, denatured bodies, and the transformed self*. Berkeley: University of California Press, 2006, 322 pp., ISBN 0-520-24786-8.

The central horrific revelation of *The Matrix* (1999) is a vision of nearly all humanity enclosed in pods, their vital energies serving as batteries fueling the artificial machine intelligence that dominates the world. Humans are plugged in through machine tubes connected through the backs of their skulls. While their bodies are cultivated and harvested for energy, their minds are occluded by the matrix, a program simulating late twentieth-century America. The hero, Neo, wants to be in control of his own life, and he always knew something was wrong. When he is finally unplugged by freedom fighters battling to save humanity from complete desubjectification, Neo's body and mind come back together in a relentlessly difficult, cold, drab, post-apocalyptic world. Neo is no longer a slave, but life free of the matrix is hard. Among the freedom fighters is the slithery traitor Cypher, who wants back into the comforts of the matrix. He is weak, precisely because he desires the plug of dependence.

Perhaps Neo and most of his companions would find solace in the residents of two old-

age homes in late twentieth-century Kolkata described by anthropologist Lawrence Cohen in his book *No Aging in India* (1998). The aged he found there were exemplars of independence. They planned their own meals, managed their own budgets, and controlled their own medications. They were unplugged, so to speak, from machines or relations of dependence. But for many of these residents, and most of the middle-class Calcuttans, that Cohen spoke with, this independence evinced great tragedy and pathos. Their autonomy and the abundance of their options and choices "invoked their absent or uncaring children; their institutionally intensified individuality signified abject solitude" (1998: 117). The weakness of these old women and men was their independence. They just were not plugged in enough.

There are all kinds of plugged in humans in late twentieth-century and early twenty-first century America. Some of the most unsettling of these hover on the borders of death, their biological existence fully dependent on machines and on the people who tend to these machines.

American debates about how this dependence is lived, and what it means are beautifully documented by Sharon Kaufman in *And a Time to Die: How American Hospitals Shape the End of Life* (2004) and Lesley Sharp in *Strange Harvest: Organ Transplants, Denatured Bodies, and the Transformed Self* (2006). Kaufman asks why in America, when “most people claim they want to die at home without invasive medical treatments, are they getting aggressive medical treatment in the hospital just before they die?” (97). Sharp illuminates the logics and materialities that make Americans available for organ harvest. Together these ethnographically rich accounts of the end of life and transplant, detail contemporary practices of death, newly congealed human conditions like persistent vegetative state (PVS) and brain death, and crucially, the tensions of autonomy and dependence that revolve around the mixture of persons with machines.

At first glance, *The Matrix*, a story about the horrors of dependence, seems to tell American death best. As Kaufman relates it, the epitome of the good death in America is a “natural” one; conscious, mind/body connected, not burdensome to others, and free of machines. And this essential connection of mind to personhood is, as Sharp shows, precisely one of the ways that transplant becomes possible. Once the mind is declared gone and machines take over, the unconscious living body becomes eligible for harvest. But as we read on in these two ethnographies, the Indian old age homes, described by Cohen, whose residents are horrified by their abject independence, take on more resonance. Kaufman repeatedly shows us the anguish of relatives as they struggle to care enough for their loved ones, which in American hospitals often means being hooked up to machines for a very long time. Similarly, Sharp writes how, despite the best efforts of transplant professionals to keep donor families and recipients separate, both groups persevere in their desire for entanglement with and dependence on each other. Of course there is nothing surprising about these desires for care and dependency. This is modernity after all, filled to the brim with simultane-

ous anxieties about both achieving autonomy and searching for the community and lost connection threatened by individuals in their separate iron cages.

The blame for all this separation is often heaped on Enlightenment thinkers like René Descartes, and certainly all of his preoccupations with the independence and dependence of minds and bodies are alive and well in both books (as well as in *The Matrix*). Although Descartes never argued that the mind and the body were completely disconnected, this is how many have since understood Cartesian dualism (Toulmin 1996). What Descartes did posit was mind, (*cogito*) and body as distinct entities that could *never* be separate from each other. The *cogito* lived in the body or else it would die. And there lay the great problem for Descartes—the composite nature of the two, their dependence on each other. As he wrote; “composition gives evidence of dependency,” and “dependency is manifestly an imperfection” (Descartes 1996: 23). Descartes’ frustration at the dependence of the mind on the body did not mean he abandoned the corporeal; in fact his work was a call to study the body. He argued that the more we know and can intervene on the mechanical functionality of the body, the less it will cloud our minds, leading to greater independence of thought. Descartes’ imperative was independence from things and people.

There are multiple institutions, ideologies, and infrastructures in *And a Time to Die* that promote independence, catching patients and their supporters in webs of decisions that they are staggeringly ill-equipped to make. Patients are given conflicting prognoses by doctors who must not be too directive (lest they appear to advocate death). Without any sense of the typical outcome of “heroic measures,” family and friends with a loved one in cardiac arrest or lung failure are made responsible to independently “choose” life or death. Kaufman calls this the “dark side of autonomy” (28). Ironically, by mandating that patients and their families make independent choices about the best way to exit life, patients frequently end up dependent on

machines in a “zone of indistinction” (277), for indeterminable lengths of time. When heroic measures are taken but fail to bring a person back to consciousness, their loved ones again have to make an impossible decision about what to do.

The climax chapter of Kaufman’s book presents the phantasmagorical outcome of hospital pathways to death, machine life, and independence imperatives. We visit the stand-alone institutions that house the outcomes. These institutions, with the wildly generic name of “Specialized Hospital Unit,” are designed for the long-term maintenance of vegetables. Unit residents are brought to this condition by heroic measures that kept them from death but did not return them to conscious life. The time for acute care has passed. Hospitals cannot keep them because they are not reimbursed for palliative care. It is time to move them along, but because these beings are plugged in, it is not necessarily their “time to die” either. Many unit residents inhabit persistent vegetative state, PVS, an ontology only thirty years old, made possible by medicine’s increased capacities to keep patients’ bodies alive. Those in PVS are wakeful but lack consciousness. They do not respond to human contact. Diagnosis is tricky because some PVS patients have more of a “spark” or “glow” than others (285), maybe like Neo did before his release. Kaufman takes us through the rows of these vegged out humans, maintained by attendants in a matrix of medicine, machines, and Medicare. Feared dependency is out in full force. As one nurse manager of a specialized unit told the author, patients arrive because someone along the way made the wrong decision. But once they are machine dependent, you “can’t pull the plug on all these patients” (275).

Kaufman gets us to this nonsensical outcome of extreme dependence, insisting that these outcomes have little to do with ideology, gender, race, class, or religion in the face of the powerful structural hospital pathways materially enacted through ventilators, hospital forms, insurance reimbursement codes, state legislation, and pain killers. She is convincing that most identities cannot predict how different people will react to

death in American hospitals. I wonder though if there is not more to be said about the conjunction of race and class. The good death, free of machines seems mightily specific. In the unequal world of U.S. medicine, the desire for care and dependence is surely differentially distributed. Throughout the book it is the more enfranchised who tend to want the “good death,” autonomous and machine free.<sup>1</sup> Never neglected, these people worried about “too much care” (36).

Patients and their families who wanted all the care possible for their loved ones, who welcomed their dependence, tended to be poorer, immigrants, or black; all people with some pretty good reasons to distrust any advice to pull the plug. Mrs. Vinh’s Vietnamese immigrant family was portrayed by hospital staff as obstructing her death because family members wanted her kept on machines. The hospital staff where Earl Morrison spent his last days sat in judgment of his large African American family’s decision to keep him on dialysis treatment and ventilator support. But for his family, pulling the plug would have been “murder” (243). The concerns of many of these families echoed the concerns of the Calcuttans Cohen interviewed, who were anxious to display their worthiness through the kind of dependent care they could receive from family or institutions. The desire to be worthy of care, especially care that requires intensive medical interventions is evident in unequal medical sites all over the world. It exists throughout Latin America, where poorer women in public maternity hospitals angle to get cesarean sections—a surgical birth in which an incision is made through a woman’s abdomen and uterus to deliver the baby. C-sections designate these woman as worthy of medical technology and infrastructure just like the upper-class women who get them routinely (Behague 2002; Roberts 2008). This desire is evident in how people in many poorer countries are desperate to participate in experimental pharmaceutical trials (Petryna 2009). These are the people usually denied care. They have nothing to gain from demonstrating their independence. In the United States these families can prove their love by mak-

ing sure their relatives get everything that hospitals can provide. They are more like Cypher than Neo. They want in to the matrix of care.

The “best death” that Kaufman records entwines stories of both dependence and independence. Walter Cole was forty-five and dying of advanced AIDS. He was white, educated, and had good health insurance. Everyone involved with his death tells Kaufman just how good it was because it was “self-determined.” Cole “took responsibility and expressed choice. But there were some other things that made Cole’s death so good. He got a month of life support in an ICU—all the best care money could buy—and beyond that, as one crying nurse commented “I only hope there will be that many people around my bedside when I die” (265). Within both scenarios, autonomous or cared for, Cole had a good death. Walter Cole was worthy of all sorts of resources and an outpouring of care. He was entangled with machines and people while maintaining his sense of independence until the very end.

We see both stories of horrific dependence and abject independence at work in Sharp’s book as well. The structures and machines that produce a new kind of dependent humans, who could veg out forever, are similar to the structures and machines that make another new kind of human, the brain dead. One could argue though that unlike PVS humans, brain dead humans are actually good for something. They do not suck up resources for long, because the classification exists only to allow their organs to be harvested. Their bodies become worthy resources, and the increasingly acute sense of organ shortage has made more and more kinds of people worthy to give. As in Kaufman’s book, class and race politics are simmering just below the surface but Sharp does not do much with them. Surely, when a mother says of her gang member son “my son did nothing to help anybody when he was alive, but I’m going to make damn sure he does something now that he’s dead!” (97), Sharp could have pointed to the multiple elided structures that shaped the violent course of his life. By donating his organs his mother made his individual failings worthy of

redemption, but no one redeems the failings and neglect of American health care, education, and social welfare to him or to his mother. It all remains personal. This woman’s son was never worthy of care by anyone besides his mother. And by donating his organs his mother makes him give back more than anyone else ever gave him.

What Sharp does so well is elucidate the Cartesian-infused tussles that take place between the transplant professionals and donor kin about personhood and death. Transplant professionals need brain death to do their work. Like PVS, brain death requires machine dependence but because these patients are potentially destined for harvest the emphasis is on the severance of the patient’s subjectivity from his/her body. To paraphrase Descartes, a body without a mind is no human at all. The transplant professionals are told their loved ones on the table are just corporeal husks. Patients’ kin do and do not go along with this version of death. They allow the donation but, for many, their loved one is not dead until they are actually harvested. After all, the surgeons use anesthesia during these procedures as if the patients were still alive.

At the same time, donor kin “are encouraged by procurement professionals to imagine their lost loved ones as living on in others, their life essence persisting in the bodies of strangers” (114), a very uncartesian assertion. Many donor kin vehemently reject the transplant professional’s arguments about the transfer of the donor’s essence in order to assert their own understanding of their loved one’s demise. One father described his brain dead daughter’s donation in the following terms, “As far as I am concerned she died on the operating table during the procurement of her organs” (82). The harvest ended her life whereas brain death did not. Sharp is terrific when analyzing how in all these situations donor kin complicate the narratives told by transplant experts, refusing and incorporating some of the imagery they offer about personhood in the face of brain death.

Despite the fact that so many donor kin refuse the story of their loved one’s essence moving with their organs, donor kin still seek connec-

tion to organ recipients. Shape excels in her description of these connections (mostly chapters two and three). Transplant professionals have worked for years to prevent relationships between donor kin and recipients, calling the need for connection pathological because they “anticipate so readily the emotional dangers of social intimacy” (190). Sharp does not find pathology in these “subversive” relationships between donor kin and recipients, although many are extremely intimate and involve multiple forms of care between the living. Sally Duster and Larry Merrill knew each other for years before realizing that Larry had Sally’s son, Charlie’s, heart inside of him. After this revelation Larry came to call Sally “mom” even though he is twelve years older than her. When Sally’s husband died, Larry, as well as Paul who received Sally’s son’s kidney, stood in for Charlie at the funeral. Larry and his wife spend holidays with Sally; He helps her out around the house and she visits and keeps him company especially when he is not feeling well. Charlie’s heart passed between them making them both a kind of recipient, both worthy of care from each other. The heart, as Sharp points out, is the most highly charged transplant organ. When donor kin and heart recipients meet for the first time, “donor kin may long to hear the sound of the beating heart, and some ask permission to press their ear to the recipient’s chest, hoping to sense their loved one at work inside another’s body” (74).

The movement of heart does not mean that the heart itself conveys the donor’s essence. The care relationships formed between donor kin and recipients can involve the self-determination of the donor, sometimes even from beyond the grave. During her research Sharp collected several ghost stories, some that will curl your toes, like Cindy Hartley’s. When her husband Brian, a firefighter, collapsed from a cerebral hemorrhage Cindy agreed to donate his heart. For Cindy, Brian’s heart was inanimate. His essence did not live on inside his recipient. Instead it was Brian himself, all of him, who determined who his heart recipient would be. Brian’s heart recipient was Ryan, and when Cindy finally met

with Ryan he already knew a fair amount about Brian. Ryan explained to Cindy that when he was in the hospital near death’s door, awaiting a heart, a man came to him with dark curly hair, a mustache, and a big grin. When Ryan told him he was afraid of dying the man reassured him “It’s OK I’m a firefighter.” After four days of spectral bedside visitations, the fireman said goodbye and Ryan lost consciousness. It was that same day that Brian died, surrounded by Cindy and his firefighting crew on a trip in the Rockies. Ryan received his heart from Brian and eventually he, his wife, and Cindy all became close. Although Brian does not dwell in Ryan’s body, his independent, out-of-body actions set in motion a new series of relations and dependencies between Cindy and Ryan and their children.

Both of these books, about extremely dramatic and painful death, are American stories to be sure, but they are more compelling than any single narrative of cold individualism, rugged independence, or fierce dualism could be. Kaufman and Sharp document new kinds of humans inhabiting PVS or brain death that might look like extras from *The Matrix* who should be sprung from machine enslavement. But it is not so clear that everyone wants the plug pulled, especially when machines so often mean the production of new relationships and dependencies with other people, institutions, and things. Because really, who, in the end, does not want to be worthy of care?

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### Note

1. Similar to how in America the “good birth,” free of drugs and machines is classed (Morton and Hsu 2007).

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