

BOOK REVIEW*The Occasional Human Sacrifice: A testament to moral courage*

J WESLEY BOYD

Carl Elliott. *The Occasional Human Sacrifice: Medical Experimentation and the Price of Saying No*. WW Norton & Company, May 14, 2024. 368 pages. ISBN-10: 1324065508, ISBN-13: 978-1324065500

For most of the last decade, I have taught a course in the Master's degree programme in Bioethics at Harvard Medical School entitled "Bioethics Advocacy." In that course, I have had guest speakers who have been advocates for numerous causes — universal healthcare, ending the use of solitary confinement in carceral settings, and sane drug pricing, just to name a few.

Advocates can pay a price for their efforts. I have had guest speakers passed over for promotions or suffer public ridicule as a result of their advocacy efforts. They have found themselves at loggerheads with their institutions and been threatened with dismissal, or summarily dismissed from their positions. And to really put the icing on the cake, they often don't see any fruits of their advocacy efforts. For example, the US still doesn't guarantee access to needed healthcare, drug prices are still insanely high, and immigrants in civil detention are still being placed in solitary confinement.

Although advocacy in general can exact a toll, whistleblowers are a subset of advocates who all too frequently take the potential pain and suffering of advocacy to a whole different level.

Enter Carl Elliott's new book, *The Occasional Human Sacrifice: Medical Experimentation and the Price of Saying No*. Elliott is a bioethicist and a physician at the University of Minnesota and became a whistleblower after going public about abuses in research within his own institution. This was after the death by

suicide of a young mentally ill research subject when he was enrolled in a drug study over the objections of his mother. In *The Occasional Human Sacrifice*, Elliott narrates his own story of whistleblowing as well as that of a handful of other whistleblowers, including the stories of whistleblowers who exposed the abuses in the syphilis experiments at Tuskegee, the hepatitis study at the Willowbrook School, the synthetic trachea transplantations that occurred at the Karolinska Institute, and others. In each instance, Elliott interviewed the whistleblowers in those cases at length in order to not only hear their stories, but ultimately to see what the common threads — if any — are among whistleblowers.

Elliott opens *The Occasional Human Sacrifice* with a quote from one of the individuals whose story he recounts: "Every whistleblower is an amateur playing against professionals." As the reader moves through the book, we see over and over the extent to which this sentiment is all too true, with whistleblowers facing powerful and extensive obstacles imposed by those whose malfeasance they are trying to expose.

A central theme of Elliott's narrative is his portrayal of the inherent risks faced by whistleblowers, individuals driven not by fame or fortune but by an unwavering commitment to their moral compass. Far from being heralded as heroes, they are often met with scepticism, ridicule, and outright hostility. In Elliott's own case, he describes being patronised by multiple individuals around the University of Minnesota when he first began to inquire about the death of a research subject in a drug trial at his institution. But as things progressed, Elliott became increasingly ostracised and marginalised. He poignantly describes giving Grand Rounds in paediatrics and discussing the Markinson case in hopes that other faculty members would find the case as troubling as he did. But instead of being outraged at the malfeasance he described they became irate about his discussing it. And it wasn't just the paediatricians who rejected him. Elliott's own colleagues in the University's Center for Bioethics became hostile to him.

Over and over in *The Occasional Human Sacrifice* we see a similar fate befall whistleblowers. The individuals who exposed the corruption within the Karolinska Institute's deadly artificial trachea transplants, Oscar Simonson and some of his colleagues, suffered years of studied silence in the face of their efforts to expose the horrific, deadly results of a high-flying celebrity surgeon.

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Indeed, all of the whistleblowers whose stories Elliott recounts — including himself — in *The Occasional Human Sacrifice*, paid dearly for their advocacy efforts, save one. That individual is Peter Buxtun, the individual who for seven years tried to expose the decades-long Tuskegee experiments on poor Black men with syphilis, in which individuals with known syphilis infections were followed without being treated, in many instances for decades. As with all of the whistleblowers whose stories he tells, Elliott interviewed Buxtun at length decades after Tuskegee was exposed. Elliott highlights the fact that although Buxtun exposed perhaps the most notorious scandal in US history, few have heard of him and he is absent in many accounts of the Tuskegee experiments. Buxtun was a Public Health Service employee who began as early as 1965 to get officials to take notice about what he'd become aware of. Despite repeated failed efforts and silence, he eventually connected with a reporter whose organisation published a story in 1972 about what had been happening for decades at Tuskegee. The next day the *New York Times* reported the story, and ultimately the programme was shuttered.

To a person, all of the whistleblowers in *The Occasional Human Sacrifice* other than Buxtun suffered tremendously for their efforts. Indeed, their battles are not merely against corrupt institutions but against a culture that prioritises silence over dissent. Yet, despite the overwhelming odds stacked against them, they persist, driven by a sense of duty that transcends personal gain, driven by various motivations and personal sensibilities that Elliott explores over the course of the book.

As one reads Elliott's tract, one asks: Where were the Institutional Review Board (IRB) committees and bioethicists who ought to have been speaking out and taking action in these instances? In general, they remained silent. Elliott writes that instead of being watchdogs, bioethicists often act more like show dogs, having the appearance of ensuring basic ethical principles are being upheld; but, in fact, looking the other way and not speaking out.

Why is that? Elliott's argument throughout *The Occasional Human Sacrifice*, an argument that resonates strongly with me, is that as bioethics has become increasingly integrated into academic institutions and healthcare systems, bioethicists have become beholden to the interests of those institutions. As such, the rise of bioethics as a specialised field has created a cadre of experts whose allegiance may lie more with their academic or professional affiliations than with ethical principles. Alas, this alignment with institutional interests can lead to a culture of silence or even complicity in the face of wrongdoing.

In the end, Elliott's position underscores the irony that bioethicists, who are supposed to serve as moral guides and advocates for ethical behaviour, may themselves become complicit in unethical practices due to their integration into institutional power structures. And given this sad reality, having bioethicists serve on IRBs or prominently placed elsewhere in one's institution, can provide cover for

malfeasance instead of exposing and correcting malfeasance, which is exactly what Elliott saw in his own institution.

No matter the costs, Elliott makes clear over and over in *The Occasional Human Sacrifice* that whistleblowers often feel like they have no choice but to do what they have done. As he writes, "Whistleblowers feel morally obligated to speak out, yet they often feel bad about doing it. Many of them understand they are embarking on a professional suicide mission, yet they feel as if they have no choice but to do it anyway." The extent of the potential emotional toll cannot be understated. Elliott writes: "For many whistleblowers, their life is divided into two parts: before and after the event. Whistleblowing changes their lives in an elemental, almost primitive way. Why this is true for those who have suffered brutal retaliation is no mystery. Many whistleblowers lose everything. Their careers end in ruins. They are forced into bankruptcy. Their spouses abandon them. It is as if they awoke one day to find themselves living out the Book of Job."

Elliott's work is a sobering reminder of the sacrifices made in the name of truth, the toll exacted not only on the individual but on their families and loved ones. Yet, even in the face of such adversity, for whatever their particular set of psychological reasons, whistleblowers are compelled to go forward and persist.

Not surprisingly, Elliott notes that many whistleblowers start out as idealists. Indeed, that idealism is at the core of what drove them to blow the whistle in the first place. But in the end, whistleblowers can end up with their idealism in tatters: "(Whistleblowers) talk about disillusionment, loneliness, and anger, about their struggles with guilt and shame, about a sense of betrayal and crushed idealism."

Given this reality, by the end of *The Occasional Human Sacrifice*, we see that its title refers not just to the research subjects who have died at the hands of researchers, but also to the whistleblowers themselves, who are compelled to proceed even while hurling themselves towards their own demise.

At its heart, *The Occasional Human Sacrifice* is a testament to the enduring power of the human spirit, a reminder that even in the darkest of times, there are some who refuse to be silenced, and it serves as a clarion call for ethical accountability in an age where the pursuit of scientific advancement, personal aggrandisement, and greed often eclipses the upholding of basic moral principles.

In conclusion, *The Occasional Human Sacrifice* is a must read for everyone who cares about principles and doing right, but especially for bioethicists, IRB committee members, and others interested in human experimentation gone awry, and the price some pay to shed light on the malfeasance and injustices therein.