



***The Occasional Human Sacrifice: Medical Experimentation and the Price of Saying No*, by Carl Elliott. New York: W.W. Norton & Company, 2024**

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Reading Carl Elliott's *The Occasional Human Sacrifice: Medical Experimentation and the Price of Saying No* is a bit like looking at a black and white figure-ground image. In the “foreground” are detailed stories about “whistleblowers”—people who have called out medical research misconduct in specific times and places. With a different focus, though, the “background” comes into clear view: a disquieting reflection on our innovation-driven culture and society at large. Although both these perspectives are gripping, neither offers comfort to the reader. This narrative nonfiction book is disturbing because it reveals upsetting truths about human behavior. Elliott needed to write it, and medical researchers, journalists, and ethicists should read it. Since wrongdoing and whistleblowing are not limited to any one field, the issues explored are important and relevant to everyone.

A trained medical doctor with a doctorate in philosophy, Dr. Elliott is a professor and bioethicist. He has published articles in academic journals, mainstream publications such as the *Atlantic Monthly* and the *New Yorker*, and two other books. He sparked national, not to mention local, attention for going public with concerns about a research study at his academic institution, the University of Minnesota. Dan Markingson, a 27-year-old man, committed a gruesome suicide while in a pharmaceutical company-sponsored study, which compared the safety and effectiveness of different antipsychotic medications. Before his death, Markingson's mother was concerned about his stability and well-being and repeatedly tried to try to get him off the study, but she was ignored. After her son's death, she sued the university. The lawsuit was dismissed on technical grounds, and pouring salt on her wounds, the university demanded that she pay its legal expenses (this demand was dropped when she gave up her right to appeal).

After learning about the lawsuit and serious problems with the study, Elliott worked for years to procure accountability and change at the University of Minnesota, but he was rebuffed by researchers and administrators. He was vindicated when the Office of the State

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Legislative Auditor reviewed the study and concluded that the “case raises serious ethical issues and numerous conflicts of interest, which University leaders have been consistently unwilling to acknowledge” (Office of the Legislative Auditor, State of Minnesota 2015, 2). As an academic bioethicist, I have assigned Elliot’s *Mother Jones* article about the Dan Markingson case as a discussion reading when I teach research ethics (Elliott 2010). Arguably, many things went wrong with the study, so it is an effective, albeit sad, way to review ethical requirements in research—including obtaining informed consent (which should be voluntary and uncoerced), involving surrogates when there is any doubt research participants can advocate for themselves, respecting the welfare of research participants and their right to withdraw, and managing conflicts of interest (Emanuel, Wendler and Grady 2000; U.S. Department of Health and Human Services, Office for Human Research Protections 2004).

During my own bioethics training, I was dismayed to learn that whistleblowers can face significant personal, professional, and financial hardships. At the time, it felt an odd message for aspiring ethicists—a caveat emptor about doing what’s right. *The Occasional Human Sacrifice* confirms that whistleblowing is indeed a risky endeavor. Elliott embarked on the research, which includes deep investigation of the experiences of other medical research whistleblowers, to reflect on his journey and as a means for meaning-making and self-healing. In the book, he shares why he chose to go public, what sustained his advocacy, how people responded, the highs and lows of what happened, and how he has made sense—or not—of his experience. Why did he speak out and persist for so long? For Elliott, the question was not so much about saying something, it was living with himself if he did not. Through his research, he learns that this motivation is not unusual among whistleblowers: “the decision to blow the whistle is a choice about the sort of person they are and the one they want to be... It is about the personal stakes of keeping quiet. More often than not, what torments whistleblowers is what their decision will reveal about them. They are worried about the state of their soul” (40).

Elliott chronicles six other incidents involving medical research misconduct in different chapters. It’s fascinating and upsetting to learn new details about these cases, which demonstrate the hazards of speaking truth to power. For example, Elliott interviews Peter Buxton, who expressed concerns about the Tuskegee Study for years before the Associated Press published the infamous story. When Buxton met with the study researchers, he first felt reprimanded for asking questions, but when he quoted from their reports, “everyone in the room began to look nervous” (74). John Pesando, a medical doctor and Institutional Review Board member who raised concerns about a cancer study at the Fred Hutchinson Cancer Research Center, had a similar experience. The senior researcher asked him, “Who the hell are you to question what we do around here?” (144).

There is intense material here for readers—in book clubs or research ethics classes—to process and discuss. Weaved throughout these stories are considerations of societal-level issues that lead to problems in medical research in the first place, and the often-problematic reactions to accusations of concern. One theme, perhaps slightly underdeveloped, is that loyalty, a strongly held societal norm, can have a dark side: it prevents people from speaking up about serious organizational problems.

I was particularly intrigued by Elliott’s discussion of Judas, the disloyal disciple who betrayed Jesus by identifying him to the authorities with a kiss. Curiously, Elliott compares himself to Judas, a character who does not do the right thing in the story and is universally disliked. Elliott shares that he doesn’t identify as a traitor, as Judas is often portrayed, but that he relates to an alternative, fictional description of Judas, as someone who had a “quiet reluctance to conform to the demands of the group” (29). This reflection reveals Elliott’s

misgivings about groupthink as well as the isolation he has faced. Interestingly, although Elliott notes that Jesus “chased the money changers out of the Temple and called out the Pharisees as parasites and hypocrites” (29), he does not explicitly consider Jesus a whistleblower. In my estimation, publicly challenging the ethics of the leaders of your religious group would likely meet the definition. Furthering this argument, like other whistleblowers, Jesus did not have an easy time.

The stories in *The Occasional Sacrifice*, which has a title with more than one possible meaning, will convince readers that people can go down on very problematic paths. Once these roads are chosen, it is difficult for humans to turn back or admit fault, even when challenged by sincere others. The book does provide reassuring evidence that good, brave folks do exist, but sadly, when people stand up against authority to do what is right, they often feel very alone. Elliott’s book is not a light read, but it is thought-provoking and worthwhile.

Declarations

Conflict of Interest Dr. Chapman works at the Multi-Regional Clinical Trials Center of Brigham and Women’s Hospital and Harvard (MRCT Center), a research and policy center based in an academic, non-profit setting. The MRCT Center receives financial support from foundations, corporations, international organizations, academic institutions, and government entities. For additional information, please see <https://mrctcenter.org/about/funding-support-policies/>.

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