

The occasional human sacrifice: Medical experimentation and the price of saying no

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The Occasional Human Sacrifice provides a vivid description of a number of instances of medical research misconduct and the people who blew the whistle on the relevant researchers. Its author, Carl Elliott, claims that in popular culture there are generally two paradigms associated with whistleblowers: (1) "... the brave, conscience-driven hero who risks everything to expose corruption and injustice..." and (2) "...the aggrieved, disgruntled malcontent who snitches on the organization to settle a grudge" (p. 5).

Elliott believes that these paradigms are limiting and generally inaccurate, though they do help to explain something: why whistleblowing does not typically end with any real justice or attempts at compensation for victims or their families, and rarely even results in admissions of fault or all that much moral or emotional relief for whistleblowers themselves. Elliott claims that the moral values that drive people to blow the whistle are rooted in a sense of honor, which he characterizes as the antithesis of shame. For him, "shame is what happens when an honorable person fails to measure up to the honor code," (p. 41) the code of a community that one would have been loyal to had they not put others in harm's way. After whistleblowing, even if others experience the moral outrage that is appropriate to the situation, whistleblowers are often left alienated from their professional community. And since one can't undo the past and avoid the harm to research subjects, whistleblowers themselves rarely feel that they've made a "simple moral choice" (p. 45)—sometimes because they feel complicit in the wrongdoing, and sometimes because there are significant social and professional costs to whistleblowers that are their own source of shame. How novel this moral framework seems will depend on one's typical moral starting point, but it is nice to see Elliott's effort to explain the complexity of the emotions bound up in whistleblowing, whether or not it has obvious professional or social costs for those who chose to engage in it.

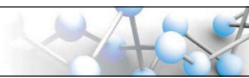
Elliott begins by laying out, as he puts it, his "credentials as a coward" (p. 1): instances in medical school where he ought to have stood up to authority to avoid harm to patients but failed to do so. He

worried that medical training was making him "harder, meaner, and more entitled" (pp. 4–5) and so went on to study philosophy, becoming a faculty member in the Center for Bioethics at the University of Minnesota.

He then elaborates on his experience whistleblowing with respect to a clinical trial for the drug Seroquel after an especially vulnerable patient was coerced into participating and killed himself. His mother had tried to prevent him from being enrolled in the study while he was floridly psychotic and under a civil commitment that required him to obey the recommendations of his psychiatrist. After his suicide, she sued the University of Minnesota, but was unsuccessful, and in fact the judge in charge of the case wanted her to compensate the university for its legal fees. Elliott's advocacy helped to get some additional public attention and oversight on psychiatric drug studies at his university, but he was disappointed at how major structural features of the Department of Psychiatry and the ethics board did not change, and he felt alienated from his colleagues after having advocated for such change. This led him to further investigate medical research scandals and whistleblowing, and to further develop his viewpoint about how social and ethical values are often intertwined in complex ways in medical research.

This book has many strengths: it explains medical research and its shortcomings with a level of detail and clarity that makes it accessible to a general audience. It also makes a substantive philosophical argument about the sorts of values at stake in whistleblowing and why it may feel like a lose-lose situation even in cases where whistleblowing has clearly had some positive moral impact. Most of all, Elliott has a talent for finding aspects of these studies that make the humanity, vulnerability, and abuse of research subjects clear and memorable. Like it or not, I doubt I will ever be able to forget that disabled children at Willowbrook were deliberately infected with hepatitis via chocolate milkshakes contaminated with other children's feces.

That being said, it is sometimes unclear why Elliott includes and leaves out the details that he does. For example, he seems to assume



that his audience knows a significant amount about Watergate. While Watergate obviously involves a famous example of whistleblowing, it may not be quite as famous to all his readers as Elliott seems to assume. In contrast, Elliott goes into a fair amount of detail about the Presbyterian upbringing he shared with the whistleblowers he spoke with in New Zealand about “the unfortunate experiment.” This “experiment” was essentially created by one obstetrician-gynecologist, Herb Green, who aimed to demonstrate his false and unorthodox view that cervical carcinoma in situ (CIS) would not progress to cervical cancer by allowing CIS to go untreated in patients without their knowledge or consent. While it is an interesting coincidence that Elliott and the whistleblowers in this New Zealand medical practice shared a similar religious upbringing, its significance was not as clear as some of the other facts brought out to illustrate what led various people towards whistleblowing and the significance those acts had for their moral and social outlooks.

Elliott also wants to make clear that the existence of Institutional Review Boards, consent forms, and other institutional structures ostensibly put in place to protect research subjects, as well as the fact that bioethics courses teach about Tuskegee and Willowbrook, does not erase the power differential between medical researchers and subjects that is a significant cause of medical research misconduct. In fact, these structures can be used to protect institutions more than anything else, and he provides some clear examples of that as well.

It is very important to pay attention to the power differentials Elliott is pointing to, and it is something that anyone aiming either to understand whistleblowing or to conduct ethical medical research should be mindful of—for example, when thinking about experimental design and how subjects should be addressed and compensated for their efforts. It may also be true that IRBs are part of institutions and

will often stand by institutions in the face of evidence of misconduct. But it is likewise true that IRBs have an interest in not approving research that will land the institution in hot water and can make things difficult for researchers hoping to conduct studies that pose significant risks to subjects. Sometimes, there are obvious reasons why those studies should never be conducted, even when subjects are adequately informed of the risks. But it is difficult to say that across the board, especially given the current United States political environment where there is significant skepticism about the value of medical research and even of clinical practice.

Conducting ethical medical research may be deeply challenging, and important ethical concerns may have been notoriously elided when researchers were more focused on their own reputations than the wellbeing of their subjects. This book contains plenty of important and vivid reminders that unethical medical research has not all been conducted either by supervillains or in the distant past. It is nonetheless worth noting that not all medical research is unethical, or as unethical as practicing medicine without research about how medical interventions impact human subjects or avoiding medical care altogether in situations where people could really benefit from it. While one would hope that medicine is not always brought to us via the occasional human sacrifice, one must also remember that clinical medicine is supported by research, and that IRBs are not entirely useless, even though we should also be aware of and responsive to their limitations. While Elliott is not overtly advocating for a global skepticism about medical research, he is nonetheless illustrating many reasons for skepticism without any counterweights, which are important to keep in mind when considering the overall significance of the book.