TPWKY - Special Episode - Carl Elliott

EW: [00:00:00] Hi, I'm Erin Welsh, and this is This Podcast Will Kill You. You're tuning in to the latest episode of the TPWKY Book Club, a series where I bring on authors of popular science and medicine books to chat about their latest work. Through this series, we've gotten to cover some fascinating and eye-opening topics, from animal senses to John Calhoun's rat experiments, the history of the pelvic exam, to the story of refrigeration. These episodes really run the gamut. To check out the full list of all the books we've covered on this series so far and to get a sneak peek for what's on the horizon, head over to our website, thispodcastwillkillyou.com, where you'll find a link to our bookshop.org affiliate page under the Extras tab. Once you're on Bookshop, you'll see a bunch of TPWKY related book lists, including one for this book club, as well as the kids' book club, put together by Erin Updyke and posted on our socials. So if you're not already following us on socials, what are you waiting for? As always, we love hearing from you all about these book club episodes, about our other episodes, your thoughts, your book or topic suggestions. We love it all. The best way to get in touch with us is through the Contact Us form or through the Submit Your Firsthand Account form. Both you can find on our website. Two final things before moving on to the book of the week, and that is to please rate, review, and subscribe. It really does help us out. And second, you can now find full video versions of most of our newer episodes on YouTube. Make sure that you're subscribed to the Exactly Right Media's YouTube channel so you never miss a new episode drop.

The Tuskegee Syphilis Study, the Willowbrook Hepatitis Study, medical experimentation at Holmesburg Prison. If you've ever taken a bioethics class or if you're a regular listener of the podcast, these cases are no doubt familiar to you as just a handful of the most infamous examples of unethical medical experimentation. We learn about these studies, the victims, the perpetrators, the circumstances that allowed them to happen, so as to prevent history from repeating itself. Like, this is why we have patient protections such as informed consent. This is why we have these rules and mechanisms such as institutional review boards. But often missing in the telling of these stories is the person or persons who fought to expose these wrongs and bring them into the light, the whistleblower. What does it take for someone to speak out, especially when speaking out can lead to tremendous professional and personal costs? In The Occasional Human Sacrifice: Medical Experimentation and the Price of Saying No, author and bioethicist at the University of Minnesota, Dr. Carl Elliott, explores the moral dimensions of whistleblowing and how the resulting fallout

leads to a long-term, almost existential crisis. For Dr. Elliott, this is a deeply personal topic, as he tried for years to uncover harms carried out in a study at his own university, harms that led to a patient losing their life. His experience serves as backdrop and crucial context for the other stories of whistleblowers that he shares throughout this book, at the heart of which is a question: Why do whistleblowers do what they do? It's tempting to imagine that if each of us were placed in a situation with unethical medical experimentation, we would stand up for what's right. But research shows that's rarely the case. Whistleblowing is a complex action guided by moral concepts such as shame and honor, and learning the stories of whistleblowers alongside the abuses they sought to expose adds tremendous value and insight into human nature itself. Through Dr. Elliott's compassionate storytelling and contemplative analysis of whistleblowing as a moral dilemma, The Occasional Human Sacrifice is truly a must-read, and it will stay with me for quite some time. [00:05:00] I do want to mention that this discussion includes descriptions of self-harm, so please listen with discretion. We'll take a short break here and then get started.

Dr. Elliott, thank you so much for taking the time to chat with me today.

CE: Well, thanks for having me. I appreciate it.

EW: In your book, The Occasional Human Sacrifice, you seek to answer how unethical experiments are carried out and why blowing the whistle is so difficult to do. And as you describe, this is a personal issue for you, with you having first-hand experience as a whistleblower. Would you mind sharing the impetus for writing this book and how it led you into a broader contemplation of whistleblowing in medical research?

CE: Failure is basically how it led me into the, into the book. So I guess for me, the, the story begins back in 2008 when I first learned about the suicide of a young man named Dan Markingson in a research study in our Department of Psychiatry here at the University of Minnesota. The circumstances of that were so gruesome and so horrific and so sort of blatantly exploitative and unethical that I felt as if it needed an external investigation, partly because of the, the circumstances of his death, but also to ensure that the same thing had not happened to others in our Department of Psychiatry And so I spent the better part of the next seven years basically trying to get that external investigation. So Dan Markinson was a, a young man in his 20s who had become psychotic and delusional and dangerous as a result of a psychotic episode in the summer of 2003.

And his mother, after seeing him deteriorate over a period of months and seeing the kind of alarming things he had, called the police, and he was eventually brought to Fairview Hospital, which is the teaching hospital here at the University of Minnesota. And he was seen by the head of our schizophrenia program here, who thought he was psychotic, delusional, dangerous, admitted him to a locked ward, had him placed under a civil commitment order, and fairly soon began to recruit him into an industry-funded study of antipsychotic drugs that he was doing. His mother objected. She didn't want him in a study. She felt he could not consent to the study, that he was psychotic and, and incompetent, and that the circumstances, the civil commitment order, which essentially legally bound him to do whatever his psychiatrist was telling him to do, prohibited him from being enrolled ethically. And she objected, but she was told, "You know, sorry, he's an adult. He signed the consent form. He's in the study." She then spent the next four months trying desperately to get him out of the study. He had been discharged to a halfway house. She could see him getting worse, becoming increasingly agitated, and she was afraid violent. She called, she sent emails, she went to the Department of Psychiatry. She wrote to the chair of psychiatry again and again, expressing her worries. Eventually left a voicemail message for the study coordinator saying, "Does he have to kill himself or somebody else before anybody is gonna do anything?" And three weeks or so after she left that message, his body was found in the shower of a halfway house where he was staying, and, uh, next to his body was a note that said, "I went through this experience smiling

EW: When did you learn about this, and what happened after? Like, when did this become public knowledge? When did this become something that was a, a news story?

CE: Not for another four years. I read about it in the St. Paul Pioneer Press in, I believe, would've been May of 2008. I was actually on sabbatical at the time. I was in South Africa. A friend of mine, who was one of the reporters who did that, Paul Tosto, had sent me links [00:10:00] to it I found it so alarming that when I got home a few months after that, I started asking around and trying to find out what had, what had happened because it's actually my area of work. I mean, I work on research ethics. I work on psychiatric ethics. I had been on the institutional review board at the university for several years. I knew people in the Department of Psychiatry, and yet this grisly death, I had heard nothing about it. And when I started to ask around, it, it just felt as if no one was as alarmed by it as I was. Not people in the Department of Psychiatry, not people in the Bioethics Center, not administrators, and eventually it became clear to me that it was gonna take some kind of pressure from the outside to get the university to act. And so I got in touch with Mary Weiss, Dan Markingson's mom. She was not happy to hear from me, obviously. She had a lot of

suspicions of the university. She agreed to talk to me, and then after we talked, she agreed to let me have access to everything I wanted: court records, uh, medical records, Dan's diaries, anything that would be useful. And so I wound up writing about it in a sort of larger backdrop to it, which was a sort of scandal about research integrity involving the sponsor of the study, AstraZeneca, and eventually wrote about it in Mother Jones magazine, sort of hoping that having exposure in a national publication would shame the university into acting. But, um, that again, was a, was a complete failure. I mean, it, uh, it really accomplished nothing at all except to make the entire academic health center very angry with me.

EW: As you write, whistleblowing is incredibly isolating and disillusioning, and that kind of flies in the face of a lot of popular media representations or stereotypes about whistleblowers or stories that feature whistleblowers. They might be brave and bold or bitter and disgruntled, but they tend to follow this certain narrative arc which you describe or you, you label as, uh, Vonnegut's Man in a Hole narrative. Can you tell me more about this narrative, what it fails to capture, and what it's really like down in that hole?

CE: Kurt Vonnegut described the Man in a Hole story as somebody gets into trouble and gets out again, and he said, you know, we, we love this story. The Wizard of Oz, Dorothy s- kills the Wicked Witch and returns to Kansas. The Prodigal Son, Robinson Crusoe, David and Goliath The reason we like these stories is that they sort of reassure us that the world has a kind of moral sense to it, that the, the universe is a fair and just place. And if you watch, you know, whistleblower movies or TV shows about whistleblowers, they usually follow some version of that Man in the Hole story. The whistleblower takes down the corrupt organization. What I found when I started looking deeper into these stories, actual whistleblower stories, is that they usually don't follow that sort of narrative arc. I mean, they usually don't have happy endings, and the whistleblowers themselves usually come out of the experience with these sort of very deep moral wounds.

It's almost as if it's a kind of existential disorientation because everything that they thought about how the world works is upended. I mean, they just assume, everybody just assumes if they've gotten to the point where they feel like they, there's nothing else to do, they assume that the rest of the world is gonna be as morally outraged by what they have found and what they're trying to reveal as they were when they found it out. And then when they blow the whistle, it turns out that that's not the case. They think the authorities are gonna do something, that they're gonna leap into action and rectify the injustice, and then that doesn't happen. And they think their friends are gonna stand by them, and then that

doesn't happen. Even if they have some measure of success, they very often come out of it with a kind of almost obsession with what they've been through, an inability to get over it and put it behind them because it's so disruptive to the way that they had always seen the world.

EW: Right. They're never truly free of that hole or of the, what the, the feeling of what it was like down in that hole.

CE: [00:15:00] Yeah. I mean, being in the hole is a very, is a very dark place, and it tends to turn people inward. And in the hole, you can't really think about anything other than yourself and what this is doing to you and how you get out of the hole. I mean, I can remember talking to the whistleblowers in Sweden in the Paolo Macchiarini scandal and hearing, you know, from them just how obsessed they became, you know. Because they could, they could see it. They were surgeons. They could see what was happening. They could see that, uh, that things were going very bad and that, and that people were dying, and no one would believe them. And so there's a kind of desperation to it, you know, this feeling that nothing else is as important as making people aware of this, and yet no one is paying attention.

EW: Let's take a quick break, and when we get back, there's still so much to discuss

Welcome back everyone. I've been chatting with Dr. Carl Elliott about his book, The Occasional Human Sacrifice: Medical Experimentation and the Price of Saying No. Let's get back into things. At the heart of your book is the question of why. Not why do these unethical medical experiments happen, but why does someone decide to blow the whistle in the first place? What did you discover in your quest to answer this question, and what roles do honor and shame play in this decision that people make?

CE: Part of it is that very often it doesn't really feel like a decision. It feels like there's no choice. I mean, people will say, "Really, I had no choice. I had to do it." Fred Alford, who wrote a terrific book on, uh, whistleblowers, said, "The question presents itself to whistleblowers not so much as what should I do, but how did it happen that I find myself in a position where there is nothing else for me to do but act?" I had initially just sort of expected that when I began to ask people to explain how it got to the point where they felt they had to act or to sort of justify themselves to me, that they would make a kind of moral argument, you know, that they would explain the situation, and it turned out that they didn't really do that. Nobody talked about, even the doctors, they didn't talk about the Hippocratic Oath, and they didn't talk about the Bible or some sort of

legal principle. They would, they would say things like, "If I kept quiet, how could I hold my head up?" Or, "If I kept quiet, how could I look at myself in the mirror?" So they, they sort of turn this moral question about the well-being of other people into a moral question about themselves. They always talked about how it would reflect on them if they said nothing. It seems really interesting to me, and almost unexpected or counterintuitive But the more I heard this story and tried to think about it, the more it seemed to me that they were speaking a kind of, uh, language of honor and shame. Because the honor ethic and what distinguishes the honor ethic from, uh, many other sort of ways of justifying actions morally is this idea of obligations to yourself, that honor is essentially about respect. It's about getting the respect of others, but it's also about self-respect and being able to respect yourself as a result of, of what you do and the necessity of avoiding shaming yourself in the eyes of other people and also in your own eyes. And so when people say things like, you know, "How could I hold my head up?" It's a, it's a very vivid sort of image of respect. How can I respect myself? That sort of explanatory frame runs through the book, and I have to say, it fits some of the whistleblowers that I talk to much more than it does others But almost everybody that I spoke to spoke of the choice as this sort of very personal, existential moment where they had to act in a way that they felt they could live with Right afterwards.

EW: Like you said, not, it's not even having a choice. It's this is what you are compelled to do because of who you are, even if there is no whistleblower-type personality.

CE: [00:20:00] Yes, exactly. Who you are.

EW: Mm-hmm.

CE: You know, you were, you were the kind of person who has to act in this, in this situation.

EW: A question that kept popping into my head as I was reading your book was, do we all have the capacity f- to go along with unethical medical experimentation and/or do we all have the capacity for whistleblowing? And I don't know if there's an answer to that, but it did make me think about what it is that allows someone to blow the whistle or requires them to blow the whistle.

CE: I think there h- there has to be something to the circumstances in which people find themselves that makes it more or less likely that they can blow the whistle or that they will blow the whistle, and one of them, I think, if there is some sort of proximity, either as a, a caregiver, someone who's taking care of

patients, or personal knowledge, that makes it harder for people to stay quiet. I'm thinking, for example, of John Pesando, who was the oncologist at the Fred Hutch Cancer Center out in Seattle, uh, who blew the whistle on these lethal bone marrow transplant trials. This would have been '80s and '90s, and they eventually came to light in, uh, 2001. He learned about them by virtue of being on the IRB there. So he learned about them abstractly as a result of evaluating them to try to ensure that they're ethical, if the, if the IRB were, were working right, which it wasn't. And it was his specialty. He was an immunologist and oncologist, and so he understood the studies abstractly, but he also took care of subjects in the study on the wards, and that clearly was incredibly difficult for him, seeing two women in particular with lymphoma die as a result of being in these poorly designed, poorly thought out studies. And, you know, you could see the same thing in New Zealand with Ron Jones and the unfortunate experiment, the cervical cancer trials there, with the Willowbrook hepatitis studies at, um, on Staten Island. If you're up close rather than at a distance, and particularly if you identify with, in some way, the institution in which the studies are, are happening and you feel implicated, then that is a sort of predictor of whether or not you'll speak out

EW: In your book, you share the story of many different whistleblowers throughout the decades, and there was one in particular that was surprising for me to learn about. I grew up in Northern Kentucky. I went to undergrad at the University of Kentucky, did a master's at the University of Louisville, where I learned about medical ethics, you know, took a class on it, and still, your book was the first that I had heard of the radiation experiments at the University of Cincinnati, just up the road. Can you take me through the story of these experiments and the whistleblower, Martha Stevens? And I especially was re- really struck me the comparison of the memorial of whistleblowing and c- hidden behind a bush, in contrast- ... with the, you know, the, the lab that bears the name of the person responsible for these unethical trials.

CE: One thing I should s- say about that before I start, though, is that that's one of the few places that has, in recent years, started to try to make amends, uh, for the atrocities, not because of anything or anyone who had anything to do with them at the time, but a result of students largely who have, uh, who've learned about them and have essentially tried to shame the university into, uh, into trying to make this right. But anyway, I'm getting ahead of myself. So the radiation experiments were these Pentagon-funded studies done during the Vietnam War at the University of Cincinnati to try to figure out how American soldiers would respond to being irradiated from a nuclear weapon. And so to do that, they were exposing largely poor patients, about 60% of them Black, at the University of Cincinnati, these are patients with cancer, to total body irradiation, without telling them that, uh, it was for the military, without telling them that it

was not intended to cure their cancer, and without te- telling them how dangerous it was and that they might die as a result. These things were going [00:25:00] on in 19... I guess Martha must have found out about it in 1972, so they'd been happening for a decade or so at the University of Cincinnati when an English professor, a very young English professor at the time, Martha Stevens, found out about them. It was an article that was handed to her by someone in the political science department, and she got worked up about it and started trying to dig into it, was rebuffed at every turn by the dean of medicine. She was a very persistent woman. Eventually got ahold of those records and, despite having no medical background whatsoever, made her way through them Understood right away what was wrong with them, why they were unethical, and, uh, wrote it up in a kind of memorandum and held a press conference with her junior faculty association to make it public.

And there was a stringer for The Washington Post in town who happened to, to come to the press conference. And at the time, there were hearings being held, uh, by Senator Ted Kennedy at the time about unethical experiments, largely as a result of the exposure of the Tuskegee syphilis study at the time. And so Ted Kennedy read this piece, got interested in it, entered it into the congressional record, and then started looking into it. And as a result of that, it was shut down, but it was kept very quiet. It was not publicized in any way, and the victims of the study were not notified. The families of the victims were not notified that their family member had been in a research study or that it was funded by the Pentagon or anything else. They just shut it down very quietly. And that was a kind of partial success, I think, for Martha Stevens and, you know, her husband, Jerome, and the rest of the faculty members who were opposed to this thing, but not really a full victory. Um, and they had no way of finding out who the victims were or their families, and just sort of forgot about it. But then, 20 years later, the entire issue became a live one again when during the Clinton administration, it became evident as a result of some investigative wor-work by Eileen Welsome, a reporter in New Mexico, that there was a whole series of military-funded, government-funded radiation experiments happening at universities all over the country. And so there was an entire commission put forward to look into this, not just at Cincinnati, but all over the country. And that sort of gave new life to the story again. And as a result of that, she and a graduate student of hers began tracking down the victims and their families, notifying them and putting them in touch with a lawyer. And there was eventually a lawsuit, uh, against the University of, of Cincinnati as a result. Not a terribly successful lawsuit, but there was a settlement.

EW: Let's take a quick break here. We'll be back before you know it

Welcome back, everyone. I'm here chatting with Dr. Carl Elliott about his book, The Occasional Human Sacrifice. Let's get into some more questions. So I was wondering if you could describe to me your experience with going to the University of Cincinnati and visiting- The, the, the whistleblower memorial and what that was like.

CE: Well, so I, I learned that as a result of litigation against the University of Cincinnati, that the university had been forced to put up a memorial to the victims of the study. This was decades ago now. So I decided when I went to visit Martha Stevens that I should find the memorial. I didn't imagine that it was gonna be difficult to find, and so I just started walking around looking for it, and I couldn't find anything. So I went to the front desk and asked them, and they had no idea what I was talking about. Nobody, in fact, in the institution had any idea what I was talking about when I said, you know, the radiation studies, the Eugene Sanger's radiation studies. No idea. But they were very helpful, and they started calling around anything, anyone in the hospital that had anything to do with radiation. They eventually found someone in the radioisotope lab who knew what I was talking about. And [00:30:00] so she met me at the front desk and took me on this very long journey and We walked for what seemed like forever, and eventually emerged into this sort of courtyard next to heating equipment in a parking garage. You know, I'm looking around, and we're not seeing anything but a parking ramp and, you know, the heating equipment. And I said, "Where?" And she pointed to this big bush next to the hospital, and she said, "There." And I said, "That looks like shrubbery to me." And she goes, "No, no, no, no. Uh, I mean... Oh, I guess you can't see it. Um, it's behind that bush. And so if you kind of squeeze around behind it and put your back to the wall of the hospital, look outward." And so I did that, and there it was. It was like a two-foot by two-foot plaque with a bunch of names on it, and it said something like, "In Memoriam Radiation Study," whatever the dates were.

When I came back out from behind the bush, the woman said, "Would you like to see the, the Sanger Lab?" And I'm like, "What is the Sanger Lab?" She goes, "The Eugene Sanger, the... You know, the radioisotope lab." And I'm thinking, "Eugene Sanger? Like, the Eugene Sanger? The one, you know, the, the architect of the atrocities?" But I didn't say that out loud. And she, she said, "Yeah." And I was like, "Yeah, sure. Yeah, I definitely wanna see the Sanger Lab." And she took me, and there it i- there it was. His name is on the, on the door, and inside in the waiting room was this little, I mean, I don't know how to describe it. It's a, it's like a little shrine to Eugene Sanger. It had, like, pictures and honors and awards and a bunch of old, like, vintage medical instruments and so on. I, I thought to myself, "Yeah, th-this is, this is the way it usually works. To the architect of the atrocities, a shrine. To the victims of the atrocities, a plaque hidden in the shrubbery."

EW: God, it's, it's the perfect i- illustration. This, this encapsulates it all. And a lot of people might be able to recognize Tuskegee, right? It's probably the most infamous example of unethical medical experimentation. It's far from the only example, but even if someone has heard of Willowbrook or the Unfortunate Experiment or Protocol 126 or the Cincinnati Radiation Experiments, they might not know the name of Martha Stevens, for example. Can you contrast that with the recognition and honors that are bestowed upon many of the perpetrators of these unethical human experiments, like Saul Krugman or Albert Kligman?

CE: Yes. Uh, that was another striking thing to me. So the background story to this as a result, as a you know, as a consequence of my, uh, total and utter failure to accomplish anything at the University of Minnesota, despite getting a, a state investigation and, you know, being vindicated, I started to wonder how these things played out at other institutions. And so I started teaching this class on research scandals at the University of Minnesota, and the basic idea was, if we can get couple of dozen of the most egregious, the most exploitative research studies that I can find, the ones that I know about as a result of teaching bioethics, and put them side by side and examine them and compare them, maybe some patterns will emerge One pattern that emerged was that whistleblowers are rare. In most of these cases, there are no whistleblowers. If they become public, it's the result of family members or lawyers or investigative reporters or an investigation by some sort of external body, not as a result of whistleblowers. But the other thing I learned, to my shock, is that, um, or maybe I wasn't that shocked, pretty cynical, but the researchers behind the studies were, in general, not only not punished, not sanctioned by their institutions, they were rewarded. In case after case, you know, Albert Kligman with the Holmesburg prison studies, Saul Krugman with the Willowbrook hepatitis studies, Eugene Sanger with the Cincinnati radiation studies, you know, I could name a half dozen others. In every case, after the scandal, they were given honorary [00:35:00] degrees. They were made presidents of their medical subspecialty society. They were given awards. Lectureships were established in their name. It was almost as if the institutions of academic medicine were trying to fight back against any sort of accusation that something bad had happened here by elevating the people behind the scandals.

EW: When you consider all of the ways that whistleblowing is disincentivized, you know, we talked about why people whistleblow, but there are many different reasons to not blow the whistle. Can you take me through some of those reasons to not blow the whistle, whether that's, that's from institutional punishment or social punishment or the reasons that were given directly, you know, quoted directly by people who were perpetrators or bystanders of these experiments?

CE: If you ask bystanders, not that I did this, but sociologists have done this, if you go into institutions where bad things have happened, institutions where there are corruptions or abuses of some sort, and you talk to the people who were there but just stayed quiet and asked them, "Why didn't you say anything?" You generally get one of three answers. One, "I would have been punished. There would have been retaliation against me." Two, "It wouldn't have accomplished anything anyway." And three, "I don't rat out my friends and colleagues."

EW: Hmm.

CE: You know, some, some version of loyalty to the institution. I think there's also another one that may be especially important in academic health centers that, that people don't mention, which is the kind of internalized subservience to authority that you get as a result of maybe any, any sort of hierarchical institution, but I think particularly in academic medicine, which is extraordinarily authority-driven, extraordinarily hierarchical, very rigid in the sense of what you should feel entitled to do. A lot of the doctor whistleblowers that I talked to mention some version of this, the almost sort of military-like hierarchy that you get in academic medical centers. And I think a lot of people just feel as if it's not my place to do this. There's a sort of reflexive obedience to authority that, you know, I think almost everybody has or is socialized into having, but it gets magnified in certain kinds of institutional settings

EW: Those institutional settings are everything to this. It's th- these environments where these things play out, and you opened your book with a quote that, "Every whistleblower is an amateur playing against professionals." And it got me wondering about those professionals. Who are they? What are they? What are they doing out there honing their skills? What are those skills? And they're learning from the past how to avoid getting caught or punished. You know, tell me more about those professionals that are defeating the amateur time after time after time.

CE: That quote came from John Pisando, the, the whistleblower in Seattle, and it came in the context of a conversation that we had. Uh, I think it was our very first conversation. And I think he was trying to express something about how little he knew when he began trying to expose the, uh, the abuses there. A lot of whistleblowers that I talk to only come to think of themselves as whistleblowers after the fact. It's not as if, many of them anyway, think of themselves as whistleblowers or know anything at all about blowing the whistle, or how to protect themselves, or what to do, or what they can expect, or anything at all about what they're trying to do. They're just ordinary people who have seen

something bad and are trying to figure out how to stop it or how to expose it. But what they very soon find, if they're in an institution, is that they might be amateurs, but the people at the institution, who run the institution, are not amateurs at all. They've been through this many times before, because any institution, at least any academic medical institution, will have seen a lot of bad things happen over the years. It's sort of the nature of the institution, and they know exactly what to do. And I'm talking here about the risk managers, the general counsel's office, the crisis managers, the communications team, the deans, the vice presidents, everybody who is there at the [00:40:00] institution who has been through this. And their mission is to protect the financial interests and the reputation of the institution. And job one is discredit the whistleblower. That happens almost as a matter of routine Because unless people think ahead, it can be a lone whistleblower against this entire institution. And if the institution can discredit the whistleblower, you know, "Oh, they have mental health problems. Oh, there's some sort of financial gain that they're going after. Oh, they've always been a problematic person. Oh, they're, they're carrying a grudge because their career is failing," some way of discrediting them and making their accusations sound hollow or empty or unbelievable in some way, then they have won, and that's something that, that it seems like every whistleblower has to learn for themselves for the first time.

EW: When you learn about these situations, you learn about these unethical experiments and whistleblowers, and it's tempting to think that if we were faced with a similar scenario, if each one of us was faced with the scenario, we would object, and we would refuse to go along with things, and maybe that's true for someone, and maybe it's not. In your book, you talk about a couple of experiments and how that reflects on, uh, roles of obedience and social dynamics and power dynamics, specifically Milgram's 1960s obedience experiments and then the 2012 Amsterdam whistleblowing experiment. What do those show us about the difficulty in blowing the whistle and what people actually will do or some of the, the barriers in place to prevent them from blowing the whistle?

CE: Well, what it shows is that most of us are self-deceived about our ability to, uh , to resist the demands of obedience. The Amsterdam study, the 2012 study, was modeled on the Milgram studies, the M- the Milgram studies being those, uh, Yale studies done by Stanley Milgram in the early '60s, in which nearly 65% of subjects were willing to obey the commands of a man in a white coat, who was an actor, but they thought was a legitimate scientist, to give what they thought were lethal, potentially lethal electrical shocks to an innocent, uh, victim The new version was trying to figure out how many people would blow the whistle on a study that was clearly unethical and dangerous, given the chance. And so what they did was, this was a study, they did it, it was university

students, Dutch university students. And the setup was there was a distinguished scientist, and they were introduced to him, actually a man in a white coat who's just an actor. And he explained to them, "I need some help recruiting subjects into a sensory deprivation experiment that I'm doing, and I'd like your help." And so he said, "Here's what we do. We, we take these subjects, we put them in a, in a sort of sensory deprivation chamber, a kind of pod where they can't hear anything and they can't see anything, and then we just keep them there and measure their brain activity and see what happens." And he says, "You know, we, we did this once. We had a, we had a pilot s- study and, um, it was a little disturbing. It didn't go well. You know, they started to become psychotic and delusional and they panicked and, you know, they were begging, 'Please let me out. Please let me out.' But we couldn't let them out, of course, because that would've ruined the study. But, you know, we've, we've made some adjustments and we're gonna try it again, and we'd like your help. And all we'll need for you to do is write an email to at least four friends and acquaintances telling them about this study using words like amazing, incredible, superb." So the idea was how many people would do this and how many would blow the whistle, and so they gave them the opportunity to blow the whistle. They actually gave them every opportunity to resist. The man in the white coat left the room so they weren't face to face with any sort of authority figure. They were given a form that could be delivered to the university ethics committee. They said the ethics committee hadn't, hadn't approved this yet. You know, so if you have any concerns about this study whatsoever, just write them down here anonymously. They'll be delivered to the ethics committee and there'll be no way to trace it back to you. And they had two groups. In the first group, they presented them with this scenario purely in [00:45:00] theory.

If you were in this situation, what would you do? And in that situation almost every one of them, something like 96% said, "You know, I would, I would, uh, resist or I would blow the whistle or both." But in the actual study, when they were actually confronted with this fake scientist, 77% of them complied with the experiment. Wow. And only 9% blew the whistle. So like 96% said they would blow the whistle, and only 9% did blow the whistle. For me, the interesting thing about this is that if you go back to that, those sociological studies that I mentioned before, where people go in and ask bystanders who said nothing, "Why did you say nothing?" And they say, "Well, I would've been punished. It would've been futile. I don't rat out my own group." In this case, there was no punishment that it would not have been futile, and there was no group to rat out, and still almost nobody blew the whistle. The lesson that those researchers drew from this is that it's all about obedience. It's all about obedience to authority. My conclusion looking at that one and looking what people say is that people who don't blow the whistle are, in a lot of ways, self-deceived about why they don't blow the whistle They think it's because they

would be punished. In fact, even if there were, uh, no chance of punishment, then most people would not.

EW: I mean, that is... It's grim. It is a little bit crushing, but it is also the reality, and it kind of begs the question of, like, well, h- how can we make things better? And there have been occasions where whistleblowing has led to reform, but it seems, I think, naive, especially considering these experiments, to think that unethical experimentation is a thing of the past. What do you think are some of the biggest weaknesses in this system that could be modified or improved to at least protect from these harms or support whistleblowers?

CE: One of the big problems that's, that's specific to blowing the whistle on unethical research that could be fixed is that it's not clear to whistleblowers who they should blow the whistle to. So the oversight system in this country is extraordinarily porous and is extraordinarily opaque. And so if someone sees something bad happening in a research study and they want to blow the whistle, typically where they would go would be the IRB at their institution or whatever IRB has approved the study. That's where complaints are supposed to go. But what you find if you actually try to do this is that the IRB has approved the study, they may even know about the abuses, and they are complicit in some way. So blowing the whistle to them does no good. They've already approved the study. They have a stake in the study, you know, going ahead as it is, and so very often they'll do nothing And then the question is, well, who is overseeing the IRBs? And that's a very complicated bureaucratic question, but let me just... The upshot is there is very little oversight of IRBs and very little place to go outside of the IRB if you're getting nowhere with them. The other difficulty is that any kind of IRB decision proceedings is secret, and so just getting access to what the IRB has found or what their decisions are is extraordinarily difficult. It is easier at public institutions, like a public state-funded medical school, but it's almost impossible at private universities and in any university or research institution that's contracted with a for-profit IRB to review their trials.

EW: For-profit IRBs, that's, that-

CE: Yeah.

EW: Uh, not, not great, not great at all. I'm curious about your thoughts on the role of whistleblowers in this administration. You know, you, you write that whistleblowers need to believe that other people will stand up for what's right, but the Trump administration has shown repeatedly that that's not the case, that whistleblowing is consistently quashed even more and more, and that standing up for what's right doesn't, doesn't seem to mean much these days. Do you

anticipate fewer whistleblowers because there's less or no hope of the [00:50:00] information changing anything, or do you expect there to be any impact on the rate of whistleblowing?

CE: The fate of whistleblowers in this administration is very dark. I mean, really dark. I mean, it's, it's interesting. If you go back and look at, for example, the, one of the earliest books on whistleblowing from the early '70s by Taylor Branch and Charles Peters, this was the era in which the term whistleblowing was being coined, and it was a new phenomenon. You had people like, uh, Daniel Ellsberg and Frank Serpico at the time, but it was kind of new, and they were trying to figure out some way of putting a positive moral valence on, on the language because there didn't seem to be any sort of morally praiseworthy term for someone who did this. There were terms like traitor and J- Judas- and rat and snitch, but, uh, nothing that, that gave it a sort of positive spin. And one of the things they wondered was whether in the future there would come a time when there would be so many whistleblowers that it would do no good. I mean, the whole idea, the whole hope for the whistleblower is that someone's gonna listen to the whistle But if you have many, many whistleblowers blowing the whistle every day, it's almost impossible to pay any attention to any single one of them, and it feels like that is what we have now. We've got a lot of whistleblowers and also an, an administration that is intent on absolutely making their lives miserable in every way. So I think in this sort of, uh, environment, it would take an extraordinary amount of courage to speak out.

EW: Yeah, and to trust that someone will hear that whistle being blown and do something about it. I kinda wanna, to circle back to how we started off this conversation, which was your personal experience with whistleblowing, and this whole book seems like it must be, it must have been very deeply personal to write. And I'm curious, what was that experience like for you? You know, did you find it to be painful, therapeutic, educational, discouraging? I mean, all of the above. I'm, I'm wondering about your journey, your personal journey in writing this book.

CE: Some of the easiest interviews I've ever done. I felt like I had something in common with every one of these people. I felt a kind of sense of solidarity with them, you know, to be honest. I wished, you know, I wished that they had been able to meet one another. Some of the whistleblowers, by the time that I talked to them, were in their 80s. Some of them have died at this point, so Peter Buxtun, the Tuskegee whistleblower, uh, died two years ago, and Ron Jones, the last of the Unfortunate Experiments whistleblowers, died last year. And Jerome Stevens, uh, Martha Stevens' husband, died a couple of years ago. And it sort of saddens me that it, it was impossible not to get them all in a room

together somehow, because I feel as if it would've been useful for them and therapeutic and that they would've found some sort of sense of solidarity by getting to know other people who have been through similar experiences. The other thing that came of working on the book, I think, is, I mean, everybody, I think, who goes through these sorts of experiences needs to come up with some sort of story to tell themselves to explain the episode to them in order to be able to put it behind them. I think what's very often troubling for people and why it becomes such a, you know, such a deep wound is that there is no good publicly available story that their experience fits into.

It all seems sort of unsatisfactory in some way. And, uh, it doesn't fit into the David and Goliath narrative because very often they feel like they've lost. They haven't slain Goliath. It's very easy, I think, to, if, if you've really accomplished very little, to come away from the experience feeling really demoralized, as if you were duped in some way, that you're the chump, right? Everybody else understood that trying to speak out about this was gonna result in, uh, something terrible, that you were gonna ruin your career, that you were gonna lose everything, and you were the only one dumb enough to go through it anyway. And so by trying to make some sense of these stories and telling them within [00:55:00] this larger framework of honor and shame, and honor stories are stories in which you don't necessarily have to succeed. What's important in stories of honor is that you be able to respect yourself when it's over, not that you, uh, necessarily vanquish the enemy. That that can possibly be, on a, a sort of deeper level, a more satisfying story, a story that will help people make sense of what they've done in, in a way that, uh, that they can live with.

EW: I want to thank you so very much, Dr. Elliot. I mean, your, your work has, is truly enlightening, inspiring, and, and so necessary, and I really appreciate you taking the time to chat with me today.

CE: Well, thank you. I appreciate it. Thanks for inviting me. These were terrific questions. I'm, I'm grateful for that

EW: A big thank you again to Dr. Carl Elliott for taking the time to chat with me. If you enjoyed today's episode and would like to learn more, check out our website, thispodcastwillkillyou.com, where I'll post a link to where you can find The Occasional Human Sacrifice: Medical Experimentation and the Price of Saying No, as well as a link to Dr. Elliott's website where you can find his other great work. And don't forget, you can check out our website for all sorts of other cool things, including but not limited to transcripts, quarantini recipes, show notes and references for all of our episodes, links to merch, our bookshop.org affiliate page, our Goodreads list, a first-hand account form, and music by

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