Episode: *Ethics Talk: Yes, Involuntary Sterilization Still Happens in the US*

Guests: Cynthia Chandler, JD, MPhil and Anthony Loria, MD
Host: Tim Hoff
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[mellow theme music]

[00:00:03] TIM HOFF: Welcome to *Ethics Talk*, the *American Medical Association Journal of Ethics* podcast on ethics in health and health care. I'm your host, Tim Hoff. A woman incarcerated in a California facility was in her early 20s when she received a notice that her Pap smear was abnormal. A biopsy was followed by surgery. When recovering from surgery, she was told that surgeons had removed cysts. But her postsurgical symptoms troubled her, and she found our guest, attorney Cynthia Chandler, who then helped her request her health records. These records revealed that without her knowledge or consent, she had been sterilized.

Cynthia Chandler directs the Bay Area Legal Incubator in Oakland, California and teaches law at the University of California, Berkeley. She represented the patient in court and continues to investigate sterilizations in state carceral facilities. Cynthia, thank you so much for being here.

CYNTHIA CHANDLER: Thanks for having me. [music fades]

[00:01:05] HOFF: Voluntariness in health decision making is foundational to patients' autonomy, and it's a cornerstone of any clinical encounter in which a patient has decision-making capacity. Restrictions to physical and decisional liberty in carceral environments should prompt us to wonder whether and when voluntary consent or refusal is even possible in these settings. People who are incarcerated are legally considered wards of the state, so they are expected to obey carceral authority figures, and that includes clinicians. Which criteria and practices are used to determine whether and when informed consent or refusal is given by patients incarcerated in prisons or detention facilities in California?

CHANDLER: So, what's funny to me about that question is this assumption underlying it: that consent is actually relevant in the prison setting. Much of my work is focused on reproductive rights in prison and reproductive justice in prison. And if we look back to reproductive care in the medical profession, its foundation was built on the forced exploitation and forced surgery upon Black slaves. And I mean, the history of gynecology is a history of using an abusive, coercive institution to build the framework of that entire field of medicine, and we have an expansion of that into, I think, the prison setting. And really, informed consent cannot ever truly, purely take place in a carceral setting where every decision people make is controlled by threat of force and where people can be disciplined for failing to obey staff orders, including failing to obey medical staff's orders. And that means that people's liberty is potentially impacted. They're going to do more time, potentially, if they refuse something that a medical provider wants them to do.

[00:03:09] And so, the sort of basic standard in California prisons and frankly, nationally, is that people in prison are entitled to a certain baseline necessary care. And I think that's typically seen as a limit on what kinds of care people can access, but it's also a way of ensuring that people don't get put in a situation of having to consent to abusive care when it's not medically necessary. So it's actually oddly protective, too. And the ways that we see that come up is around medical experimentation in the prison setting. We have a long history of abusing people in prison for medical experimentation, and that's been capped. We're not allowed to do that anymore. And yet, there are times when people might want access to that.

Certainly, I did work in the '90s with people with HIV and hepatitis C in prison when the only treatment available at that time was still experimental. And that was being denied to people in prison because we couldn't experiment on people in prison, right? We're always making sort of a cost-benefit analysis around informed consent in the prison setting, looking at how we can maximize the lifesaving options available to people while reducing the level of coercion that affects them on a daily basis. And that's if it's done purely and ideally.

[00:04:47] HOFF: Mm-hmm, mm-hmm. You mentioned that the limit of necessary care can be protective against potentially inappropriate care.

CHANDLER: Yeah.

HOFF: How and by whom are the boundaries of necessary care defined?

CHANDLER: In California, and in most states, the baseline necessary care is determined through medical panels that are set up. And there's usually a mechanism—and there certainly is in California, and there is in most states, as well as the federal correctional system—a mechanism to evaluate on a procedure-by-procedure level with each patient whether or not a procedure is necessary, and then therefore, whether or not it should be paid for.

The thing that was so shocking to me around the sterilization abuse was that the Department of Corrections created a gender-responsive commission to increase the level of therapeutic programming available to people in the women's prisons, and one of the first things that they did was to recommend the expansion of necessary care to include sterilization. The reasoning was that it was cost effective, that it would reduce the numbers of children reliant on foster care and state benefits. And that is a deeply disturbing eugenic prospect. Also, I want to be clear, it was completely illegal under both California state law as well as federal law to even imagine that program.

[00:06:26] HOFF: Mm, mm-hmm. And the accountability for the abuses of these systems required legislative responses, as you just mentioned. How did legislation help, and how could it be scaled as a model, for responding to these state sanctioned health abuses in US Immigration and Customs Enforcement, ICE, facilities, or other federal carceral facilities?

CHANDLER: I mean, this issue of how can we scale the lessons learned from California in reducing coerced sterilization is interesting because actually, we already have federal law that was created in 1979 that makes it illegal for any entity that receives federal dollars, which is most prisons and jails, to sterilize people in total institutions, which includes things like jails, prisons, and ICE detention centers, for the purpose of birth control. And so, that was an

enormously important early victory of the civil rights and women's rights movements in collaboration. They won this victory against eugenics.

And what we did in California, first, when we unearthed this modern eugenic program that started and really escalated sterilizations around 2006—they went from being just a trickle of them per year to many in one day—the first thing we did was a sunshine statute that made it clear to all people practicing medicine in California's prisons, as well as to the Department of Corrections itself, that sterilization for the purpose of birth control inside a total institution such as a prison or jail is illegal and will not be tolerated. It also created a data requirement where the state has to actually keep track of sterilizations and disaggregate that data by the reason that the sterilization was done, as well as by race and gender and age of the person sterilized. And that data has to be provided on a public-facing website for the state so that we can track potential abuses happening moving forward.

And it also required that the state offer second opinions to people who are being offered sterilization for therapeutic reasons that are not for the purpose of birth control so that they can have can have a second opinion that is not just a paper review, but an actual consult with a doctor who is contracted, but not one of the regular prison staff doctors, to provide a second consult, to try to ensure that patients have the most information possible about their options and why the sterilization might be necessary, what other options are available, for example. So that was round one. I think that that's easily replicable in states across the country.

[00:09:31] The second phase that we did was a reparations program, which I think is warranted in states where we know that forced and coerced sterilization is occurring still, and.... But I also think, I also think we've learned a lot from that implementation of that program, where we would make it even better if we were going to scale it out. And that reparation program included not only compensation for people who were forcibly sterilized and sterilized in a coercive manner, it also provided that the state had to erect monuments, public-facing monuments, decrying the history of eugenics and connecting the history of eugenics and the lost history of eugenics to why these modern sterilizations in prisons were able to reoccur. And they also required that the state legislature issue a formal apology. So what we tried to do....

And finally, I should say, it also required that the state notify people who were sterilized in the prison setting after 1979 and actually notify them to let them know that they were sterilized. Because we found multiple instances where people were sterilized during abdominal surgeries, where they had no knowledge that they were sterilized whatsoever. So they had to be notified, as well as then informed about the reparation program. We designed it to stop the violence. We felt that if people didn't even know they had been sterilized, there was a way that the state violence and the harm of it was perpetuated. But also provide reparation and an opportunity of atonement for the state to actually take action to atone for its harms.

[00:11:18] HOFF: Mm-hmm. You mentioned in passing that you had learned lessons of how to potentially improve the implementation of these programs. What were those lessons?

CHANDLER: Sure. I think that there are inherently problems to allowing state agencies that perpetrated modern-day human rights abuses, and there are problems with allowing those perpetrator agencies in managing a reparations program. I would have made a provision where

there was sort of a community oversight board that actually had authority to govern the process, kind of like how police oversight boards are cropping up in communities across the United States, where they actually have power to fire people or discipline people in law enforcement.

What we found was that the state allocated $1 million, for example, towards the monument, and they ended up creating one plaque that was inside the prison grounds in an area where the people in prison cannot access it and where the public cannot access it from outside the prison grounds. So, that's an example. And there were also ways in which classes of people who were sterilized were rejected for qualification. There was actually just a writ that was won on behalf of a group of women who were given ablations, who were given endometrial ablations, who have just won their writ of mandate saying that the state refused to acknowledge that they were sterilized. I think in hindsight, I would've included clearer provisions on penalties for the state if they failed to fairly administer the program as well.

[00:13:16] HOFF: One lesson to pull from this entire story is the importance of civil rights attorneys' collaborations with health professionals. What should health professions students, trainees, and really, all clinicians know about how such collaborations could help patients navigate some key legal determinants of their health?

CHANDLER: Sure. This work of exposing sterilization abuse in prison, and also working around this very complex issue of consent and how and whether one can limit or make access to different kinds of medical care, it's all very complex. And to me, it doesn't have any authenticity unless it's truly led by people who are in prison themselves. One of the most important components to this work that I was able to bring as a lawyer was the fact that I can access and work with people in prison without being censored by the state apparatus. And so, because I was working to document crimes by the state, I was able to have access to clients who could provide communication and then therefore, bring in also medical providers to consult with those clients and do that work in a way where the medical providers didn't have to worry about having sort of a green card to get access into providing care to those people inside. And so, I think for me, one of the things that I really provided was that bridge: the bridge between the people inside and the medical community outside.

[00:14:51] And I think that also, medical providers obviously provided both my clients inside and myself with incredible wealth of expertise so that we could actually understand the implications of what we were doing for people's health, right? And be able to really assess whether or not what remedies we were constructing were medically viable. And so, really, none of this work could've happened without a really strong collaboration across prison walls, between people in prison themselves, people in the legal community, activists also, in the outside free world as well as inside, and then medical providers, right? So, this collaboration that was necessary to expose sterilization abuse, while really tragic, was really beautiful in how it highlighted how folks working across sectors can make really important change happen. [theme music returns]

[00:15:58] HOFF: Cynthia, thank you so much for your time on the podcast and for sharing with us your expertise.

CHANDLER: You're very welcome. Thanks so much for having me.

[00:16:09] HOFF: People who are incarcerated have a constitutional right to health care, but surgical outcomes for patients who are incarcerated are complicated by factors like compromised transportation to follow-up visits, accompaniment by carceral personnel that can undermine their privacy and sense of autonomy, and insufficient health literacy. One group that conducts research about surgical outcomes for incarcerated patients is SHORE, the Surgical Health Outcomes Reaching for Equity group. One member of this group is our next guest, Dr Anthony Loria, a research resident at the University of Rochester College of Medicine in Rochester, New York. He's here to discuss a recent literature review conducted by SHORE and future avenues for research into surgical outcomes for incarcerated patients. Dr Loria, thank you so much for being here.

DR ANTHONY LORIA: Thanks for having me, Tim. It's really a privilege to be here speaking with you. [music fades]

[00:17:04] HOFF: So let's start with the review that I just mentioned that you and your colleagues conducted of literature about surgical outcomes among incarcerated persons. What did you find?

LORIA: I think it's important, briefly, to state for some of the listeners who may know, but incarceration in the United States is a pressing issue. It's one of the.... The United States has one of the largest incarcerated populations in the world. Kind of despite this, we don't know very much about their surgical care at least. So this prompted myself and co-authors and our team to do a systematic review looking at studies reporting surgical outcomes of incarcerated individuals. Initially, we had started in the United States but opened it to all countries, and we reviewed over 8,000 articles and included 17.

And our findings really, the first thing, most of the studies were published in the last five years or so, suggesting this is kind of a growing area of interest in surgical health services research. Second, most of the literature emphasizes trauma or acute care surgery. And we really know very little about the elective surgical care for our incarcerated individuals. And that's important for things like major oncologic operations, transplantation, and cardiac surgeries, and some of our larger surgeries. And finally, that there is evidence—although minimal at this point, but it is growing—there is evidence to suggest there are some worse outcomes in particular operations. Most notably in our study was that traumatic orthopedic injuries had lower rates of non-healing.

[00:18:50] HOFF: So what do we know about the reasons for these poorer outcomes? Is it due to sort of a one-to-one relationship with the quality of care, or are there other reasons, such as having to wait maybe longer to get care than you would otherwise, leading to a poorer outcome? What do we know about that?

LORIA: Yeah, it's an important question and one I think we're still sort of teasing out at this point. We're really in the nascent stages in terms of the surgical research on incarcerated patients' care and their health care delivery and as well as their outcomes. And, of course, those are interrelated issues, but we're still really trying to figure it out.

[00:19:29] HOFF: Mm, mm-hmm. I think that leads well into this next question. What do you think are the most important findings that you think should inform future research about surgical outcomes among incarcerated persons?

LORIA: Yeah, absolutely. I think some of the main takeaways are this is a growing area of investigation. And despite some of the challenges given these patients' protected status as vulnerable research participants, they are, it is possible to study these patients. And we need further data and more groups studying this population. In terms of specific examples of issues, it's helpful for me to contextualize the findings in the phases of surgical care as defined by the American College of Surgeons. That's defined in five steps: preoperatively, perioperatively, intraoperatively, postoperatively, and post discharge.

[00:20:30] From a preoperative standpoint, I mentioned it a little already, but we have minimal data on elective surgical care for these patients. So, in terms of their preoperative workups and testing and risk stratification, we know very little. In the perioperative setting, we know something we'll discuss a little further is sort of a risk stratification. We don't have great risk stratification for these individuals because they have different comorbidity profiles than our traditional surgical calculators are calibrated for. Intraoperatively, we have found that these patients have lower rates of minimally invasive surgery, particularly robotic surgery. Very little of that is utilized for these patients, at least in the literature that's been reported. Postoperatively, we found that lengths of stay seem to be similar to non-incarcerated controls. But we're not sure if these patients are getting the same levels of services for sort of total functional recovery, like physical therapy, occupational therapy, and social work as our, these are benefits that are afforded to non-incarcerated individuals. And then lastly, the last sort of finding in a post-discharge phase of surgical care, are these individuals getting the follow-up that they're needing? And the literature that we reviewed showed that there are very low rates of follow-up visits after discharge for incarcerated individuals.

[00:22:09] HOFF: Mm, mm-hmm. You've already highlighted a few of the key inequities that this research illuminates, but there are some others that deserve direct attention as well. For example, nearly half of incarcerated patients were unemployed or homeless prior to incarceration, two thirds of incarcerees lack a high school diploma, higher risks of comorbidities: HIV, cirrhosis, substance use disorders. How should surgeons and their teams respond to these inequities when evaluating their patients who are incarcerated?

LORIA: It's important for clinicians and surgeons and surgical teams really to understand that there's a large body of literature, and not necessarily in the surgical literature, but more the medical side of demonstrating that the chronological age of incarcerated individuals does not match their physiological age. And what I mean by that is these individuals are younger than similar patients who are not incarcerated who are undergoing the same operations or similar operations. And because of that, and combined with living in highly, highly intense environments and stressful environments, they are at increased risk for advanced aging and physiologic abnormalities that are not captured in surgical calculators.

For example, the NSQIP calculator does not capture many of the comorbidities that are reported frequently in the literature that we found, including HIV, cirrhosis, substance use disorders, and mental health diagnoses. From a practical standpoint, I think that surgical teams, once we have

these patients within the health care system and in the hospital, it's important that we use all the resources that we have and really load the boat in terms of our care teams and use services that we would typically reserve for our older adults and consider using them for incarcerated individuals who may be younger, for example, the physical therapy, occupational therapy, social work. These are things that I think we should have a lower threshold for using in our incarcerated patients.

[00:24:22] HOFF: Some of the surgical outcomes you studied, and in fact, you mentioned this in passing already, were about postsurgical follow-up. Can you give us an example to wrap up of when the follow up to the surgery is just as clinically and ethically important as the surgery itself? And what should surgical trainees know about responding to the postsurgical follow-up needs of patients who are incarcerated?

LORIA: Certainly. So, from an ethical perspective, whenever we have a postoperative patient, these are patients that we have permanently altered their anatomy and physiology in many cases. And hopefully by our interventions, we've extended their lives or improved their quality of life. And we have an ethical obligation for avoiding harm and fair treatment of these individuals. And integrally related to that is understanding the outcome longer term. So we need to see these patients after discharge in a similar time frame as our non-incarcerated individuals. From a practical standpoint, this can be challenging from a number of different levels, but these incarcerated patients live in facilities where there are some basic health care services, and there are medical directors at these facilities. I think that we need groups who are willing to reach out, and residents, trainees, fellows, who are willing to reach out and develop pathways for ensuring that we can bring these patients back for follow-up visits, so that we can make sure that they're recovering as expected and receiving the care that they need, given the surgeries that they've undergone. [theme music returns]

[00:26:04] HOFF: Dr Loria, thank you so much for your time on the podcast today and for sharing this research with us.

LORIA: Thanks so much for having me. It's been a privilege.

HOFF: That's all for this episode of *Ethics Talk*. Thanks to Cynthia Chandler and Dr Loria for joining us. Music was by the Blue Dot Sessions. To read the full April 2025 issue of the Journal, *Surgical Care for Incarcerated Patients*, visit our site, journalofethics.org. For all of our latest news and updates, you can now find us on Bluesky @amajournalofethics. We'll be back next month with an episode on Private Equity in Health Care. Talk to you then.