Episode: *Ethics Talk: Underrecognized Origins of Epidemiology*

Guests: James Downs, PhD and Rae Anne Martinez, PhD, MSPH
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[mellow theme music]

[00:00:04] 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. The name John Snow is likely familiar to listeners aware of his work tracing water-based transmission of cholera in the mid-19th century London. But we're going to resist calling him a proverbial father of epidemiology, because this Great Man Theory of scientific advancement obscures the countless contributions, willing and unwilling, by the peoples who made clinical and scientific progress possible. Marginalized and unrecognized persons who were enslaved, conscripted, and subjects of empire have made critical contributions to modern epidemiology, and their key roles are focal points in Dr Jim Down's book, *Maladies of Empire: How Colonialism, Slavery, and War Transformed Medicine*. He joins us now to discuss the fraught historical and epidemiological foundations of health care innovations we easily take for granted today. Dr Downs, thank you so much for being here.

DR JAMES DOWNS: Thank you so much for having me. [music fades]

[00:01:16] HOFF: This Great Man trope in the history of medicine is common. There are many fields of medicine and of scientific research that are credited to individuals, most often white men, whose contributions have been deemed so important as to be foundational to the field. Your work, rightly, I think, complicates this idea for epidemiology by focusing on the "under-recognized contributions of enslaved people, conscripted soldiers, and subjects of empire." In which ways did the exploitation of these groups lead to the development of modern epidemiological practices?

DOWNS: So, one of the biggest mythologies surrounding John Snow is that he is a lonely pioneer who journeys into a poor section of London and then identifies that cholera is being spread as a result of water from various people who are drinking from the same well. And what most people don't realize is that Snow was part of a larger cohort of physicians who were beginning to investigate the cause, spread, and prevention of infectious disease. They formed the Epidemiological Society in 1850, during the height of Snow's own examinations into what was actually causing cholera to spread. And so, while Snow emerges as the father of epidemiology in the mid-19th century, the case study that my book offers is of his colleague John McWilliam, who a few years earlier than Snow, traveled to the west coast of Africa to Cape Verde to investigate the spread of yellow fever.

[00:02:58] What had happened was a British vessel known as the Eclair had traveled to the west coast of Africa to police the area around Sierra Leone for any illegal trafficking of enslaved people. And what the British expedition included were a bunch of men who were hoping to find criminal activity so that they would receive some type of reward. They didn't find any activity, and the ship had to sail back to London. It stopped in Cape Verde for a few days, where the men got off the ship, and they had a lot of fun, and they hung out with the locals. And they eventually got back onto the ship and sailed to London. Before they arrived in the harbor, many of the men started to present symptoms of fever, and so it triggered a major quarantine debate on whether or not this ship should, in fact, be allowed to enter into the harbor. And they wanted to know whether the fever originated in Africa or if it was contagious among the men. So they sent McWilliam to Cape Verde to lead an epidemiological investigation.

And what he does is he begins this massive effort to interview local people, which included colonized people who were under the authority of the British crown, enslaved people, military men. And what he did was he compiled this incredibly fastidious, encyclopedic questionnaire that asked all of these various people, from enslaved people to washerwomen to soldiers, to identify things like the major hallmarks of the disease, which many of them describe as "the black vomit." He also asked them, or they actually provided him with information about the incubation period. They talked to him about how the fever allegedly moved from one hut to one hut.

[00:05:07] And so, essentially, what he does is he compiles all of this information, and the washerwomen who were actually allowed on this ship, the British ship, the Eclair, they had the first, the closest sort of first-hand account of witnessing this epidemic. And he depended upon their testimony in order to determine the cause and the spread of the disease. They became, in many respects, the first contact tracers. They were enslaved and colonized washerwomen. The information goes back to London, and he becomes part of the Epidemiological Society. His arguments about yellow fever and what he thinks causes it are all incorrect. But what's really important, what really matters is that he actually helps to develop the epidemiological methods that guide epidemiology today, everything from interviewing to contact tracing to data collection. And these ideas derive from the enslaved and colonized people in Cape Verde.

[00:06:16] HOFF: I'd never heard that story before. I appreciate that the value of the contributions of these washerwomen was in the knowledge that they had, the knowledge of their community, of how disease presented. I think often we hear about these under-recognized contributions of marginalized peoples, perhaps especially enslaved people in the US to scientific advancement being boiled down to essentially how their bodies were used, or rather, abused by others.

DOWNS: Right, as thinkers, yes. I mean, because they're working. This is not just, this is not the traditional history of race in medicine of exploitation and experimentation. This is a history of washerwomen as thinkers, and that is an important contribution to the history of medicine.

[00:07:01] HOFF: Mmhmm. Right, right. But while these stories help illuminate the contributions of individuals who have been overlooked, your work also suggests that we ought to focus on how the practices of colonization, of enslavement, of conscription provided the conditions in which epidemiological study could happen in the first place. Can you talk us through that relationship?

DOWNS: Right. So, what happens really between 1750 and 1850, which is the chronology of my book, is that you have major social transformations taking place across the world. You have the expansion of the transatlantic slave trade, you have British imperialism and various forms of other European imperialism, and then you have the Crimean War and the US Civil War. Each of these major transformations create laboratories that allow doctors with an unprecedented view to begin to see the spread of infectious disease across vast populations. The transatlantic slave trade is at its height in the middle of the 18th century, which coincides with the creation of the field of oxygen. And so, what physicians are beginning to witness on slave ships is an unprecedented number of people crowded in the bottom of a particular location. They haven't seen this before. And what they're concerned about is high rates of morbidity and mortality. And so, they begin to investigate why people, why the enslaved Africans, are dying at such a high rate. And it's before the advent of fresh air and ventilation, and they start recognizing that air's changing its quality as a result of the crowded conditions below the decks of the ship.

[00:08:54] When they are witnessing this on slave ships that are crossing the dark Atlantic Ocean, this is happening at the exact same time that British scientists, and British scientists, French scientists, and German scientists are thinking about how air changes its quality in laboratories. And so, all of the sudden, the transatlantic slave trade provides copious data of how air changes its quality below the decks of ships, and so that the transatlantic slave trade begins to crystallize ideas about oxygen which were only theoretically postulated back in the metropole. So, what we begin to sort of see is how the rise of chemistry as a field coincides with the transatlantic slave trade that then leads to epidemiological investigations. This is part of what then continues throughout the 18th and early parts of the 19th century: other environments that crowd populations together.

We can think of the Crimean War and the ways in which someone like Florence Nightingale immediately recognizes that more British soldiers, unlike their French and Russian counterparts, are dying once they enter hospitals. And the problem is because of lack of ventilation. So, Nightingale does two, or does many, important things, but she does two really important things, which is that she starts calling for the importance of ventilation. And then to describe this massive morbidity and mortality, she not only depends upon statistics, but she creates something called a rose graph that's used to pictorially depict this, the changing morbidity and mortality rate. So, epidemiology as a science grows out of these military hospitals, which are not only beleaguered but are also infested with disease because it happens during a time, at a time before the advent of germ theory and an understanding about microbes.

[00:11:05] And so, as a result, epidemiologists understand that there's a type of value that these wars and colonial endeavors and the expansion of the transatlantic slave trade offers to science. And I think this is really important, in part because a lot of people recognize that we should, as you said in your earlier question, note the achievement of dispossessed populations, particularly in the United States, of Black people and of slavery. And what that normally leads to is reaching back into the past and finding people who were heroes, like Harriet Tubman or Rosa Parks or Frederick Douglass. My work argues that the contributions of enslaved people and the ramifications of slavery and colonialism were not just in shaping our understanding of what freedom means, but that slavery and colonialism also fundamentally shaped and informed science. And that it's not, our goal is not necessarily to reach back into the past—and yes, we might be able to find an enslaved person who was a thinker in the case of the Cape Verde study—but to really think about how did the institution of slavery create a built environment that helped to facilitate the production of scientific knowledge? We wouldn't have epidemiology today if it were not for British physicians, and then later in the American context, American physicians studying these various populations and then creating the methods of epidemiology which we depend on today.

[00:13:08] HOFF: The general structure of this conversation so far might remind longtime listeners of our January 2021 issue, *Legacies of the Holocaust in Health Care*, which attempted to help orient readers to the history of Nazi medical crimes that influenced modern bioethics. As you've just outlined, the history of epidemiology mirrors that fraught relationship wherein epidemiology, as we know it, owes much of its existence to the realities of slavery, colonialism, and militarism. To wrap up, which lessons should our audience, perhaps especially health professions students and trainees, take in order to recognize and respond to this fuller history that you present?

DOWNS: I mean, I think to recognize that a lot of the tools that guide epidemiologists today—things like data collection, surveillance, and interviewing, contact tracing—those were all rooted in slavery and colonialism, which was undergirded by violence. And so, we sort of sometimes think of these tools as apolitical, or just we understand them in terms of their efficacy for their ability to produce new scientific knowledge. But I think it's also important to acknowledge that there was a sort of violence undergirding them. And I actually kind of struggle with this.

[00:14:39] So, I'm going to leave this with your audience, and you can grapple with it on your own. In the wake of the COVID-19 pandemic, there were lots of obvious debates around mandatory vaccination and people reporting their COVID status. And many people on the left would argue it was important to disclose this information as a form of prevention, and that it was important for people to follow the government's initiatives in these respects. But as a historian—and I actually agree with all of that. I mean, I agree with that, of course—but as a historian and as a gay guy, I kept on thinking about HIV and the outbreak of HIV in the early 1980s and the ways in which epidemiological efforts were targeted at surveilling gay men about recording their status and using it against them.

And I can remember, and again, this is a personal anecdote that I'm hoping people can grapple with, that the same clinics and sort of makeshift public health testing centers that were established to provide people with both vaccination and testing regarding their COVID status were used when I was in my 20s for HIV testing. And I was told by older members of the gay community, "Do not give them your name. Go to use anonymous testing." I was 6G7532. Or confidential testing, which we would make up names, and we would, we had to fill out a name, but we would say our name was Brian So-and-so. So, in other words, it became very clear to me as a person who would go through regular HIV testing how that type of surveillance had a clear genealogy to the violence of colonialism and slavery. As during COVID, we took it in a different direction. The ideological sort of landscape flipped. So, I just think it's important to be aware of it. I'm not saying we sh—, I'm not supporting one way or the other. In fact, as a historian, my goal is to simply to provide that historical context and to consider the larger chronology about how these methods developed, and to sort of understand that the actual root of them comes, emerges out of violence and dispossession. [mellow music returns]

HOFF: Dr Downs, thank you so much for your time on the podcast today.

DOWNS: Thank you so much for having me.

[00:17:22] HOFF: Epidemiological best practices have advanced considerably in many parts of the world from the mid-19th century, but tracking, collecting, and interpreting data are still foundational to doing epidemiological research. Race and ethnicity data is particularly key to health equity research, but what counts as good race and ethnicity data that should be used in epidemiological research is not always so clear. A lack of demographic clarity is exacerbated when minoritized populations' data are just left out of research entirely or are obscured by imprecise methods that mask how a person's health is influenced by a person's identities, or perpetuate narratives that frame health consequences of transgenerational, deeply entrenched patterns of oppression as biologically or genetically determined "facts." Joining us now to discuss ethical and clinical complexities in how we conceive of and use race and ethnicity data in epidemiological research is Dr Rae Anne Martinez, an epidemiologist and population health postdoctoral fellow at the Minnesota Population Center. Dr Martinez, thank you so much for being here.

DR RAE ANNE MARTINEZ: It's a pleasure to be here today and talk about this work. [music fades]

[00:18:38] HOFF: You and your co-authors conducted a literature review of how epidemiological research conceptualized, operationalized, and utilized race and ethnicity data. To begin, can you please outline for our audience the key points of that review?

MARTINEZ: Sure. So, we reviewed the treatment of race and ethnicity in peer reviewed US human subjects research from five of the top epidemiology journals between January of 1995 and December of 2018. In the review, we really focused on examining what I call our most core or basic methodological decisions: our definitions, choice of

measures, coding, and the scientific rationale. So, these core methods correspond to relatively simple questions like, what is this? How do I measure or code it? And why is it important for my study question or my population? We answer these questions all the time for almost every variable in health research, even if it's not a formalized part of our research practice or analysis plan.

What we've found for these core methods decisions—again are definitions, measures, coding, and scientific rationale—about race and ethnicity was that they were routinely omitted. They're missing. So while the proportion of studies that use racial and ethnic data increased over about 25 years, only 1 percent of studies—again, these are studies that are using racial or ethnic data—included a definition for either race or ethnicity. Studies typically also did not provide us with enough information to discern how race or ethnicity were measured. And in some cases, we even observed that the coding schemes—so the levels of that variable—were omitted. I personally find this pretty sobering.

[00:20:29] Fundamentally, the absence of information can undermine our ability to do rigorous and transparent science, but in this case, related to race and ethnicity, it can also stymie our progress towards more equitable research. So, without core methods information for race and ethnicity, it might be difficult for us to correctly interpret our findings, reproduce or replicate work, but it can also be really difficult in some cases and contribute to more tangible harms, like contributing to the erasure of some populations, or make it difficult for us to transform science into interventions when it's unclear who is actually under study and why.

[00:21:12] HOFF: Mmhmm. In fact, some have called to abandon racial and ethnic data entirely, often because of their misuse as biological or genetic data points. But that, as you were suggesting at the end of your response, there has been met with some pushback, as the use of these data is important for, like you said, identifying and addressing some kinds of health inequity. So, what does good use of patients' race or ethnicity data require?

MARTINEZ: So, I would say that's a really big question because we use data in so many different ways in different contexts. And I'll address this from more the researcher side of things, so whether you're an epidemiologist, a public health, or other clinical researcher. Really what we want to move away from is attributing biological difference to racial categories. You might hear this referred to as biological essentialism, biological determinism, or perhaps as biological racism. Generally, this is the idea that racial groups are separated by immutable, inherent biological and behavioral differences that can be explained by variations in genetics or other biological factors. We fundamentally know that this is not true from a wealth of interdisciplinary scientific evidence. Markedly, this idea has been around since at least the mid-1700s and has permeated most of our legal, social, and scientific institutions.

So, generally, it can be really difficult to move away from a practice that is so deeply entrenched. With that, there may be ways in our science and in health care settings that we're still perhaps implicitly basing decisions on this outdated and harmful notion. If

biological determinism is what we don't want, how then do we get to good use? So, whatever the context, I think this means that we have to be as clear and explicit as possible about our methodological decisions and assumptions, beginning with being able to articulate what race and ethnicity are or are not, and being able to identify structural, historical, and contextual mechanisms that drive racial health differences.

[00:23:26] HOFF: Hmm. And that articulation presumably depends on our own social and cultural understandings of race and of how we use data to inform our conceptions of health justice. And those understandings themselves have changed between the time you conducted this research and the present. So, how does current epidemiological research more robustly consider race and ethnicity data than it did in 2018?

MARTINEZ: I think that there are maybe two questions here. If we think about our review as capturing the population mean or maybe the average epidemiologic practice, then this question is maybe really about first, has the average practice actually shifted? And second, how has it shifted? To that first part, I can't definitively say if the average practice has changed without data, so perhaps we should re-review research in these journals starting again in 2019. To the second, how has practice shifted, I can perhaps offer some generalities or kind of anecdotal evidence I think that I've observed.

Following the summer of 2020 and the national Black Lives Matter movement, that ignited or reignited for many individuals and institutions the need to devote real energy and action towards equity and addressing various forms of racism in science and in institutions. As a result, I think we've seen a lot of efforts towards teaching folks about social constructionist perspectives of race and discouraging biological perspectives that I previously mentioned. And so, more folks might also be familiar with or able to engage with the role of social structural determinants in their health research and perhaps in patient care.

[00:25:12] As for some more specific shifts, we are seeing some growing momentum in a couple of ways. The first is to address various forms of erasure within group heterogeneity. So there's a lot of work that's being done to address the erasure of Afro-Latinos or Black Latinos from health knowledge production. So a lot of great work by Drs Nancy López, Deshira Wallace, and Kathryn García Pérez. There's also an increase in momentum to address or create mindful practices around small sample size populations, who are, again, commonly erased in health research. There are some really lovely writings by Dr Brittany Morey, Stella Yee, and Landon talking about how the lack of data about some minoritized racial and ethnic groups is, in and of itself, a form of structural racism. So, while we see these various efforts, I'm not entirely convinced yet that this has really resulted in a shift of the average epidemiologic practice, as I think that, as a discipline, we maybe haven't actualized all of these necessary changes in all of the aspects of the spectrum of research, from how we form questions to our data collection, sampling, and measurement, and the analytic and perhaps interpretation and communication challenges that we face. But I'm hopeful.

BOTH: [chuckle]

HOFF: I am too, especially if, as this month's issue explores, the exchange between epidemiology and clinical practice is well considered.

MARTINEZ: Mm.

[00:26:43] HOFF: To that end, which three key lessons should health professions students and trainees learn about how racial and ethnic data use in epidemiological research affects their interactions with patients?

MARTINEZ: As an epidemiologist who does not work with patients or in a clinical setting, I think the first element here is that you have to see things in context. The differences in power and opportunity that drive racial health differences have played out over decades and generations and continue to be reinforced through policy and social-political climate. We often solely focus on the individual choices folks make in relationship to their health and can forget about the various structures that shape the opportunity and ability that we have to make those choices. So it's really important to recognize that these structural mechanisms exist both in relation to the health knowledge or data that we have, but also as conditions that patients may be facing in their everyday lives.

The second is the flattening of race and its complexity through health research. Epidemiology tends to focus or emphasize self-reported race, using a close-ended question with options from the US census. But there are many more dimensions of race or racial identity, such as ascribed race, how one is seen by others, reflected race, how you might believe other people see you, or a self-reported race that is open ended without preset options. All of these dimensions can differ from one another, and all may be important for understanding health. Just additionally in flattening in this kind of complexity, because US social and political discussions center around race so much, consideration of other aspects of identity can be sidelined. So, race may not be the most salient aspect to an individual's identity or their health. Immigration status, citizenship—which might include tribal status or tribal citizenship—language, religion can all be perhaps more important for individuals. And finally, for anyone, but especially clinical researchers, be explicit. [mellow theme music returns] Part of how we combat scientific racism is to make the implicit assumptions and decisions about racial and ethnic data explicit, in order to better illuminate or address potentially harmful practices.

[00:29:07] HOFF: Dr Martinez, thank you so much for your time on the podcast today.

MARTINEZ: Thank you for having me.

HOFF: That's all for this month's episode of *Ethics Talk*. Thanks to Dr Downs and Dr Martinez for joining us. Music was by the Blue Dot Sessions. To read the latest issue, *Epidemiology and Clinical Practice*, for free, visit our site, journalofethics.org. Follow us on X for all of our latest news and updates, and we'll be back next month with an episode on the history of the pelvic exam. Talk to you then.