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CONFERENCE

2021 Walter C. Alvarez Award Address

The Journalistic Structure of Medical Revolutions

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The Walter C. Alvarez Award is named in honor of Walter C. Alvarez, MD, a pioneer in the field of medical communication. The award is presented to either a member or nonmember of the American Medical Writers Association (AMWA) to honor excellence in communicating health care developments and concepts to the public. The Alvarez Award is presented during AMWA's Medical Writing and Communication Conference.

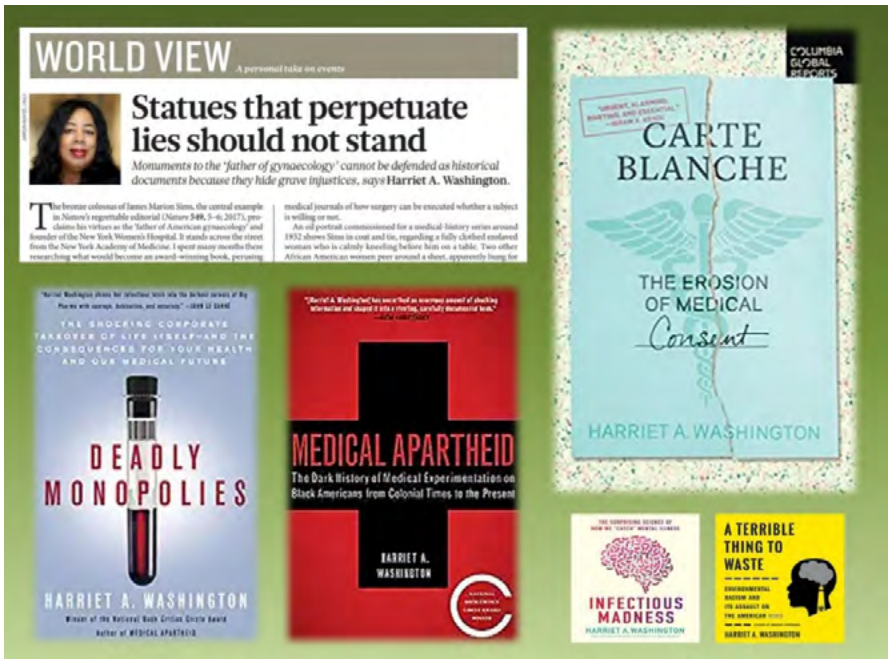

Image 1. *Carte Blanche*, as well as other books written by Harriet A. Washington, and an article written by Washington on the removal of the statue of Dr James Marion Sims in New York City's Central Park.

Hello. I want to begin by thanking the American Medical Writers Association (AMWA) for the Walter C. Alvarez Award. I'm deeply honored and very happy to join this august company of award winners. I'd like to share with you a bit of my odyssey as a medical writer, including some of the very important influences on my work and on my perspective.

My odyssey as a journalist and medical writer has been one of expanding my perceptions of what that means. Like many people, I became interested in both science and then writing early on. Although I wasn't quite sure how to integrate these 2, I perceived becoming a medical writer as a mission of translating science for everyday people and helping them to make the best decisions for their health and welfare and for that of their family and of society. That certainly is an important part of our mission, but with science comes human values.

I also have embarked on a discovery of things beyond pure science—human endeavors, human concerns, human biases and limitations, as well as human ethics and goals and motivations that also affect our role as medical communicators. Now it seems rather clear to me that science is not limited to data—a compendium of information and a bloodless analysis—but rather, it appropriates every human endeavor. Moreover, it's not only the values of humanity that affect science but also its limitations. The same limitations that cause people to express bias, prejudice, a narrowing of one's perceptions, a narrowing of one's horizons…these things affect science, too.

As Thomas Kuhn, author of *The Structure of Scientific Revolutions* tells us, aside from the strictly logical theories and hypotheses that enchant us all and that we rigorously adopt, there's also the effect of politics and of racial concerns and concerns around gender. Anything that affects human societies also weighs in and has some effect on the science that emanates from them. Winston Churchill probably said it most succinctly when he pointed out that "history is written by the victors." We have a view of scientific endeavor and achievement and even science's purpose, that is shaped by the values of people who are triumphant, who are dominant, who are telling their story through the history of science and through science as an endeavor.

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Dr Felix Okoye, a professor of African history, said basically same thing: "Don't let the lion tell the giraffe's story." As we look at the history of science, a history whose first draft is written by medical journalists, we come to understand that much more than bloodless numbers affect science. I didn't know this at the beginning. At the beginning, I was given a very different idea of my mission as a medical writer.

WHO CAN BE A SCIENTIST? WHO CAN INTERPRET SCIENCE?

My first job as reporter was at my college newspaper, like a lot of people. I was quickly confronted—in a polite but very powerful way—by the editors who gathered together to talk to me. The only thing they had to say was, "How can *you* be an objective journalist?" This was the 1960s, a time of racial tension on campus, and they pointed out that as an African American, I would almost certainly be promulgating the experiences and the aims of African Americans, and I could not be objective. And if I could not be objective, how could I be a good journalist?

I was a bit shocked by that and quickly pointed out that one could say that of any ethnic group; I mean, why are you singling me out? I didn't understand why they were singling me out at the time. Later, I came to understand that it had to do with who is perceived as someone who can be a scientist, and for that matter, who can be a journalist. We've long had the attitude in society that only certain people can be scientists, that objectivity is out of reach for certain people. Notably, for a time, we thought women could not be objective for various reasons, and it was also felt that African Americans couldn't be objective.

But one's definition of "objectivity" actually shrouds the uglier bias: That certain people are simply not equipped to craft an analysis that is devoid of unwanted emotional or social perspective that would "pollute" pure science. Donna Haraway articulated this point very powerfully when she pointed out that the word *objectivity* has come to stand for, in many cases, the requisite tone of the White male scientist, who was assumed to be without these kinds of encumbrances, to be objective by nature. That's actually a flaw in our society—we assume certain people can be objective by nature. Of course, objectivity itself, as we know, is a bit of an elusive goal.

This idea of who can be a scientist spills into who can be a medical journalist. For a while, I tried to hew to this ideal of someone who was demonstrating that yes, I can be objective. Yes, I can discuss things without invoking the messy business of race or of social frictions or, for that matter, of women's concerns. Discussing the science, writing about science, analyzing science, without polluting it with these concerns, became something that I set as a goal for myself. It was a goal shared by many of the people that I wrote for and worked with.

I remember, around the same time, in the 1970s, being told that medicine was an unrealistic career goal for me. I originally wanted to be a doctor, but I was told that no, there were no Black women doctors, and Black women were simply not suited for medicine, without more explanation than that. So having sterling grades and all the experiences that one would normally associate with being a good candidate didn't seem to matter. I simply was constitutionally not an appropriate candidate. At 16 years old, I didn't know any better. I've never since let someone tell me what I can and can't do in that manner.

Up to that point, I was used to being encouraged by my academic guides and leaders and teachers, so I believed them. I don't believe them anymore. And as I matured and learned more about who can and cannot be a chronicler of science and what is and isn't an appropriate addition to science, I began to understand that my mission had changed. My mission was no longer to be a translator, simply translating science without any presumptions or bias, but to analyze and also criticize science when it was appropriate.

ACADEME AS CATALYST

Criticizing science was very difficult because doing so seemed to evoke hubris. And yet I saw racial bias in the hospital that I worked in during the 1980s. I also saw racial bias in reporting about medicine and science. This troubled me. How do you counter that and still adhere to promulgating scientific rigor? I felt it must be possible, but I didn't see examples of this until I was fortunate enough to land a journalism fellowship at Harvard School of Public Health (HSPH) in 1992. They selected 3 medical journalists a year.

> **"The key role of writers in the evolution of medical thought and practice has been both exaggerated and, at key junctures, effaced. Writers are blamed for failings that they share with an inherit from scientists. Medical news has been a catalyst for change when it revealed momentous events such as 'Mississippi appendectomies,' the abuses at Willowbrook, and the USPHS study at Tuskegee."**
>
> **– Harriet A. Washington**

The years at HSPH inspired me to venture beyond translation and focus on divining the medical truth by navigating conflict of interest, financial bias, sexist, and later, racist assumptions. I was exposed to thought leaders,

public health leaders, ethics leaders, very powerful, brilliant people who were advancing public health and medical ethics. The director, Bob Meyers at the time, was deeply invested in us and in our holistic education as medical writers. He put me in touch with people like Jonathan Mann, Larry Gostin, Allan Brandt. This opened an entire world for me. I began to see my mission as something that encompassed both my desire to address troubling facets of medical problems in this country and also being true to my desire to be a rigorous chronicler of science.

None were so transformative as Marcia Angell and Patricia Thomas. We were lucky enough to meet Marcia Angell while she was editor of *The New England Journal of Medicine*. By challenging the conventional wisdom that medical practice and research were purely motivated by scientific rigor, she pointed out the immense corporate influence on any number of conflicts of interest, which had nothing to do with scientific accuracy and everything to do with promulgating power and money in the hands of people who held it. In meeting her and hearing her talk about her work so fearlessly, I felt I'd been given permission to look into things that troubled me, to see whether they were as accurate and rigorous as I'd been told or, perhaps, whether they were also being affected by conflicts of interest. And that was revelatory.

Patricia Thomas, who was then editor of *Harvard Health Letter*, commissioned me to write some pieces, but I learned more from her than simply as a medical editor. She was also challenging conventional wisdom, in part by looking at the reporting around women's issues. And one of the very basic tenets was that very often journalists were writing reports that did not include the perspective of women's health experiences. Thomas, who took me to my first AMWA meeting in 1993, helped me to see beyond the role of translation and generating accurate useful messages from medical journals, to then seeing the unsupported assumptions, subtle and missing data, unasked questions.

An example was the "inappropriateness" of including women in research because of their hormonal fluctuations, pregnancies, and monthly cycles—messy things that would disturb the pristine data, conclusions, and health portrait that could be gleaned only by investigating that 150–pound White male. And just like Marcia Angell, Thomas was fearless and pointed out that this is wrong—you're excluding more than half the population and emerging with a very inaccurate picture.

These fearless women, these fearless scientists, made me see that my mission was something deeper. I wanted to certainly promulgate medical truth, but I also wanted to look at deeper truths. How were women being mischaracterized and affected by medical missteps? How were people of color being affected?

That became my mission which I have devoted myself to for 20 years. I could not have done it without the examples set by these other scientists early on. I followed this up with a few years at Harvard Medical School where I was a medical ethics research fellow and emerged with my first important work, which was *Medical Apartheid*, essentially a correction of the history of medicine, which has systematically excluded the experience of people of color.

I went on to teach ethics at Columbia University. I teach a course on journalism and bioethics in which I talk about parallels between medicine and journalism. Very often we find scientists and physicians accusing journalists of sensationalism. Quite frankly, I can't say that we were innocent, but they also share these limitations. I remember, very frequently, having articles disparaged by scientists who'll say, "ah, that's not accurate," and more to the point, "it's written to sell more papers and attract more attention."

And yet, at the School of Public Health, I remember during the very first year being mystified by how many professors who, after having the students introduce ourselves, would flock to me. They didn't flock to the people who were brilliant, had done research, worked in the developing world, done all kinds of fascinating science. They flocked to me because they wanted media attention. A lot of these scientists had biotech companies, and they understood that media attention could help them to attract investors, and they wanted to know if I could help them do that.

There's nothing wrong with seeking attention if it doesn't interfere with the accuracy and ethics of your work. But to accuse journalists of that when the field itself engaged in it is really not fair. When I worked at *USA Today*, I interviewed a doctor who astonished me by asking, "Can you get me on *Oprah*?" He also was seeking attention for his work.

I had been told that when I worked at *USA Today*, any scientist I called would call me back immediately. That had not been my experience, but they would call back because it was *USA Today*, which at that time had a large circulation. Therefore, accusations of sensationalism or sloppy reporting can frankly go in both directions, as can less than rigorous standards. It's important to remember that and perhaps not become defensive about it.

AN APOLOGY AND A BANISHMENT

During the 20 years that I have done the work I felt greatly blessed and enabled to do by meeting these fearless scientists, there have been a few things that stand out as

especially significant. One was a 2008 apology from the American Medical Association (AMA) to the nation's Black doctors based on a paper that my coauthors and I wrote and published in the *Journal of the American Medical Association* (*JAMA*) in July 2008.[1] I then popularized the report findings in a piece I wrote for *The New York Times*.

The apology was a good sign, but what's really important about apologies is what happens afterward. In this case, what happened afterward was very promising. There were a few projects that AMA and the National Medical Association worked on together, a committee to end health care disparities and such things, that were the lasting significant events emanating from that apology.

The other event that I'm especially satisfied with was in 2018, the banishment of the statue of Dr James Marion Sims from Central Park. This was after I had detailed the unethical nature of his research with enslaved Black women who, of course, could not give consent. The statue sat right across from the Academy of Medicine in New York. Women living in the area—mostly Black and Hispanic women—ceaselessly besieged City Hall and the Parks Department to have the statue removed. They did so with assistance from mostly White medical students who also lived in the area. This happened 10 years after I had given a talk at the Academy of Medicine in which a medical student jumped up and said we ought to tear his statue down.

These are 2 really important things I have had a role in bringing attention to.

AN EROSION OF INFORMED CONSENT, A CALL TO ACTION

I'm still working on the third thing, and it is something that I hope other medical writers will find worthy of looking into. In fact, we might need a groundswell of attention. It's my contention that informed consent is waning in US research. Two laws have passed that formally allow research to be legally conducted without people's permission or without, even, their knowledge. And many, many enterprises are burgeoning.

EROSION OF CONSENT[2,3]

- Department of Defense obtained a waiver to force 8.9 million ground troops headed to the Persian Gulf to be inoculated with experimental anthrax vaccines. (1990-2005)
- Poor Black women in North Carolina were forced into racialized nonconsensual drug studies. (1994)
- New York City law enforcement officials helped researchers to coerce Black parents to enroll their boys in a study that south to establish a genetic propensity for violence without their consent. (1994-1995)
- Modifications to the Code of Federal Regulations (21 CFR 50.24) permits investigators to conduct research with trauma victims without their knowledge or consent. (1996)
- Northfield Laboratories ran a national trial in which ambulance crews randomly administered blood substitute PolyHeme to unconscious victims of car accidents, shootings, and cardiac arrests. (2003)
- Resuscitation Outcomes Consortium is recruiting 21,000 subjects in the United States and Canada to test experimental drugs and devices for severe injury and cardiac arrest without consent.

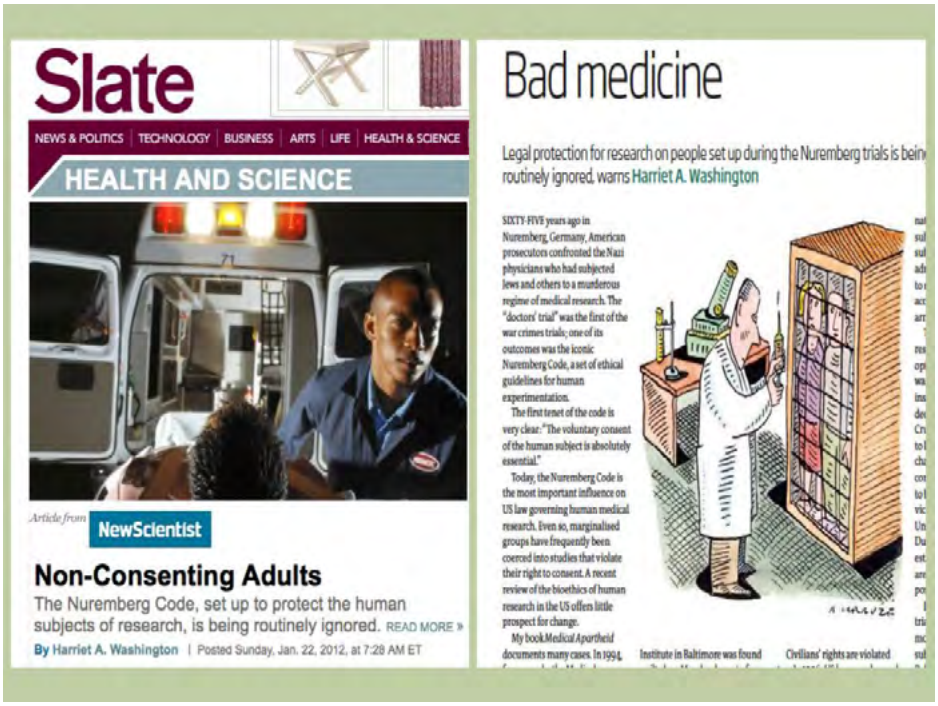

Image 2. Screenshots of articles Washington has written on lack of consent in medical research.

My concern is that there is little attention to this—people simply don't know. Unless we take a stance and examine this ethically and determine whether it's the way we want to conduct medicine and science in this country, I'm afraid people won't realize it until it's too late, until we've lost informed consent. I don't know if you'll agree with me, but I hope that people will at least think about this and whether they think it's worth their time.

Here's a copy of the article that we wrote for *JAMA* detailing the treatment of African American doctors by White doctors and *The New York Times* article accompanying that. And here are some pieces I wrote about how informed consent is being slowly and insidiously taken off the table in American medical research. And here's the book I published just this year, *Carte Blanche*, in which I talk about the erosion of informed consent, how the law is allowing informed consent to be dispensed with, and how the pandemic is, not surprisingly, escalating this tendency.

I want to share an image with you. Dr Sims' statue was carted away from Central Park and banished to Brooklyn, out of sight, and I was there.

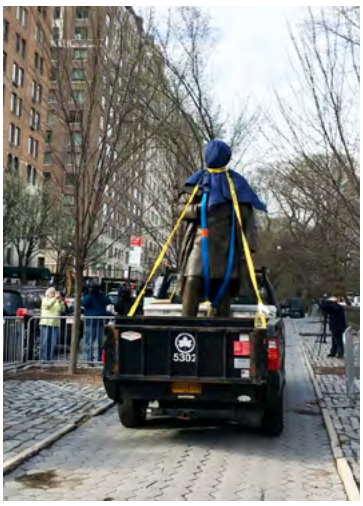

Image 3. Sims statue being removed from Central Park.

RESEARCH IN THE DEVELOPING WORLD

The final thing I wanted to touch on is something that medical journalists should be writing about more frequently and, perhaps, should take a departure from much of the ethical literature. We are using the developing world more and more frequently to conduct research on which our medications are predicated. And yet, informed consent in the developing world, is—if anything—less frequently observed than it is in the United States. That's been a concern for a very long time. Some researchers, for a very long time, have cast a rather jaundiced eye toward informed consent in the developing world, offering various reasons why it's not appropriate, or efficient, or convenient. But the question is, is it right? Is it ethical to dispense with it? I say no.

I think that sometimes we have failed to understand the ethical breaches because they're cloaked in language that hides them. If you look at the 2014 West African Ebola epidemic, the outbreak was deeply concerning, not because of the loss of life, the many illnesses, but because there was a potential remedy, Zmapp, that was being promulgated. Only a few doses were available and discussions about who would get the medication troubled me greatly. There was a consensus that it should be given to White and Western caregivers and not be given to West Africans.

The excuses covered the gamut. Some people said the caregivers have to survive in order to treat people, so they should get it first. I can see prioritizing them, certainly. But withholding it from Africans was excused by saying that, well, Africans don't really trust Western medicine, it would be a waste, they wouldn't take it anyway, they wouldn't take it properly. And some people, including Dr Kent Brantly, who treated West Africans and contracted Ebola, said they can't really understand the informed consent as I can.

At the end, Brantly received it, but Sierra Leone's chief virologist, Dr Sheik Umar Khan, was never told it was available. He died without ever receiving Zmapp. The discussion around that was rather uninformed sometimes. One CNN doctor–journalist said, you can't give it to Africans because the medication has been only tested in monkeys, and now if you give it to Africans, people will say that that sounds racist. And I thought, surely, he must know that by law, every medication must be tested in animals first. I don't know if he did or not. But his opinion seemed to carry the day.

I had a discussion with CNN about it.[4]

Interviewer: You know, you bring up a point that I have certainly heard among some friends of mine just asking this question, you know, who is it to decide, at the end of the day, who lives, who dies. Who gets this drug if, in fact it, you know, manages to help these Americans or not?

Washington: Right. Well, that is the obvious question. And certainly, no one intends to withhold the drug from Africans. But for economic and historical reasons, that is precisely what tends to happen. It's not an accident that they, so far, have not had access to it, which I hope will change as more becomes available. There are economic reasons, a network, to which Westerners tend to have access but not people from developing countries that influences who gets scarce drugs.

Interviewer: Let me flip the script because we could be having, Harriet, a very different discussion if the headline instead were "experimental drug only used in monkeys and now being tested on West Africans." I mean, I think that there would be outrage that people would be saying they're being used as guinea pigs.

Washington: Well, those people would be wrong because it happens all the time. We have to remember that the way our system of testing drugs is designed, some people are always the first to get a drug. And increasingly, those people are people in the developing world where now 2 out of every 5 clinical trials are being held… So, it's frequently the case that these people are the first to get a drug that's been tested in animals. And that's perfectly acceptable—we've decided those are acceptable risks. What is important and what is not acceptable, sometimes, is the way in which the trials are administered and conducted.

Interviewer: What about the drug maker itself and the fact that, you know, this had only been tested, according to Sanjay Gupta, you know, in monkeys and now this is the first time it's being used in humans. Your point just being that this happens—we just don't talk about it as often?

Washington: No, my point is that this is actually more akin to the normal course of things than it looks. Our clinical trials are set up so that every drug that is tested in humans has to first be tested in animals. But if you think about it, some group of humans is always the first group to get the drug tested in them before any other humans. So, there's always a case that there are…are people who are initially tested. The questions arise when who these people are seems to be a product of some kind of bias, whether it's intentional or economic or some other kind of bias.

And when the testing violates ethical principles that are very well entrenched like informed consent, what we are frequently hearing about, in the Third World, are trials in which there's not informed consent. As we would expect to have in Connecticut, someone explain to us, according to our laws, what the drug is, what the known side effects are, what the possible results of taking a drug are, all the possible options of taking a drug, these are very carefully spelled out in our law in the Code of Federal Regulations. But once researchers begin testing drugs abroad, all too often, these rules fall by the wayside, and there's not as much oversight, so it's easy to cut corners abroad. That is actually the problem—not the fact that some people become the first group to get the medication.

Interviewer: I've got it.

Today we remain in the throes of difficult ethical decisions about the people in the developing world who are testing medications, making them possible for us to use, and then ending up without access to those medications themselves. What we're going to do will be the result of how well we're able to analyze what's happening and what the various people's rights and needs are. Medical journalists will play a key role in that. If we thoroughly look at all the issues and promulgate them, whether or not these are the issues being discussed by doctors and ethicists, then we will have fulfilled our mission to help us make the best decisions. If we fail to do that, then we will not.

I want to express, in closing, my deep, deep gratitude at not only having had the chance to pursue things that I think are really important but also to widen my horizons to be able to address what I think is important. Whether or not I look objective enough to suit other people, the example of the seminal scholars that I've learned from and the seminal writers who have fearlessly explored what they thought was key—without regard to what others thought about their objectivity—has meant everything to me.

Again, I thank you very much. And thank you for listening to me.

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