

AJPH Podcast—August 2021
When Dying Really Counts
Alfredo Morabia

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[musical interlude]

AM Hello and welcome to the August 2021 podcast of the American Journal of Public Health. In this issue, Vickie Mays, Jody Heymann, and Mary Bassett discuss the contents of the supplement guest-edited by Vickie Mays and Susan Cochran, professors at UCLA, the University of California in Los Angeles, entitled When Dying Really Counts. It is about which data a public

health surveillance system should be collecting to reduce and not worsen health inequalities.

Jody?

JH Hi, I'm Jody Heymann from the WORLD Policy Analysis Center, and it's delightful to be here with you all.

AM Vickie?

VM This is Vickie Mays; I'm at UCLA's Center for Research, Service, and Policy; and I'm a professor in the School of Public Health.

AM Thank you. Mary?

MB This is Mary Bassett. I direct the Francois Xavier Bagnoud Center for Health and Human Rights at Harvard University, and I have a faculty appointment at the Harvard Chan School of Public Health. I previously was a New York City health commissioner.

AM Thank you very much. So, Vickie, what a story! I mean when you first had this idea of [have] a supplement on mortality, I didn't really know where you were going to, and then all of a sudden we have this pandemic and it becomes the most timely issue that we are producing. So, tell us a little bit. What did you think about and how did the pandemic impact your plans?

VM Well, it actually, the idea for the supplement came from an earlier pandemic which was what happened in New Orleans. I spent about five years helping to rebuild the mental health system in New Orleans, so I was there right afterwards trying to help stand up mental health services. But what I observed was the way in which, just like in Covid-19, the systems were overwhelmed. We had bodies that would pile up; we had people who were struggling to get a death certificate so that they could move on with their lives. We saw the anguish of people who, for months, couldn't find out what happened to their loved ones; and even today, our ability to really know what contributed to death is still not as clear as it should have been. And then I saw this

repeated. You know, I saw it in terms of what happened in Puerto Rico; I saw what happened in the British Isles. So what became very clear to me is that we've got problems in our mortality system, but those problems aren't just about the numbers. The problems also impact people, the living. We need mortality data to really help the living to stay alive, but we also during the period of death, we need to be—I almost want to use Nancy Krieger's words about accountability science. It's like we've got to raise our game in order to really be accountable to what we do in public health, to what we do in behavioral health, and to what we do for each of us in understanding better the circumstances of death and how to respond.

AM And I want to open to Jody and Mary too, because in my view, there's been a lot of good things done by public health and epidemiology during the last year and a half. There's no doubt about it. We've had plenty of information about the severity of the pandemic, of the characteristic of the disease, the contagiousness of people who were asymptomatic; we had information about the vaccine, treatment, et cetera. The one thing that was a huge failure is the surveillance system. We were totally in the dark. What was your impression, Jody and Mary?

JH So, I guess I want to shine a spotlight not only on how bad the data is in pockets in the United States but the huge inequalities globally in what data we have and the impact that has. I'll just take one example. The world has acted as if the rates of Covid are low in Africa; and Africa has been late to get vaccines; rich countries that have access to vaccines haven't made them widely available. We don't know that rates are low. When you talk to leaders, to civil society, to health care workers in Africa, that is not what they are seeing in different parts of the continent. And so what's the data that comes out? The data that comes out is that a few countries have higher rates. Those are the countries with surveillance systems. We have to get past the place where people

are guessing, for parts of the planet, death rates by looking at how many caskets are piling up. That is a horrific lack of care about human life.

OO Jody, you've made a really good point. There are big swaths of the world where people go through their entire lives undocumented, so their vital registration systems simply do not take an account of people. But beyond that, during Covid in the United States it really was quite shocking how much was unavailable to us. As you'll remember, the local jurisdictions started revealing racial ethnic disparities and who was dying. Wisconsin out of the first, I think it was 15 or so deaths reported, the county in which Milwaukee is located said that all of the deaths were among African-Americans but the federal system wasn't giving us any data on race, ethnicity, and those data didn't become available until May. So, the US vital registration system was incomplete for Covid, and to be honest [it] seems to me that journalists were really picking up slack and they were keeping the mortality impact on the front of newspapers with just indelible images that none of us will ever forget. And they were highlighting the disparate impact of both infection and death. So, we saw in a very wealthy country a real dysfunction. And I think, Vickie, what your issue highlights is how important it is for us to understand patterns of mortality. It matters how old you are when you die. It matters who's dying and who is not, and we need these data to be complete, and we know even now that for Covid we've greatly underestimated its impact on mortality in our country. But that's not the only place where we're going wrong with mortality data.

JH Yeah, I'd like to add something here because also the impact of not knowing early on who's dying has an impact on how quickly we move resources to where they really need to be. So, one of the things that we've seen in Covid is we keep talking about minorities being reluctant, less likely to want to be vaccinated, and the reality of it is which it reminds me, and I think probably

all of us were very involved in the HIV/AIDS epidemic, is the later that you're discovered to be a significant group that is impacted by a disorder, the later you are to get the education and to respond. And society then looks upon it as it was your fault; there's something you didn't know, nor does it give you the same amount of time it gave those who were highlighted in the very beginning the opportunity to learn to educate and to change. So, what we see is that this lack of knowing mortality and all the things that surround it really leads to stigma in the very groups that are often the most vulnerable and the most impacted.

AM Absolutely, and so if we look forward, what should we do in order to be prepared not for the next time but right now. What do we need to do right now to be prepared to count the deaths where they occur and in whom they occur?

JH Yeah, so I'd to address this and expand it to what's the data we need to have to reduce these vast inequalities in mortality. So, ultimately our goal is, as Vickie really has powerfully, is not just to count who's dying but to count the way that we get data early that prevents deaths and prevents these horrific inequalities and who gets it. So, I think we need three kinds of data. One, we need the kind of data that will really allow us to reduce the risk of getting sick; so, what's that mean? Right now, for example, we still don't know where people got sick even in the United States with all the data we have. We don't know how many people got sick at work. Probably a lot. There are huge racial, class, gender, and other disparities in who had to go to work, who was exposed at work, who wasn't able to take sick leave. We should be measuring that. We should measure who had access to stay home when they were sick. There's new data out around air pollution showing that affected illness and mortality through long-term exposure. But there are vast racial and class disparities in the United States on who's exposed. That's the kind of long-term data we need to collect. We need to not just measure whether the averages are getting

better in the United States but whether everybody has the means to reduce the risk of illness and mortality. The second piece of data we need to collect to really change the outcomes is the data that helps us figure out how our response does not make inequality worse. I just want to give two quick examples. When unemployment was done wrong, we made inequality worse. Some people got the benefits, other didn't. It was good to have that economic floor there that prevents deaths, it prevents lots of negative impact, but when we don't get the data that examines why, for example, Black Americans get less unemployment insurance than white Americans, how that's structured, then when we don't get the data to say were schools really at risk and we just close schools, what happens? Low income children, disproportionately children of color, foster kids, homeless kids, no access to schools. So, we're exacerbating inequalities when it's not reducing mortality. Last note, we have to act on the data. So, we know that there were more illness, more deaths in prisons, in migration detention, totally unnecessarily. The data shows that. The data shows that alternatives to incarceration worked. That alternatives to detention worked. So, once we have that data, we have to act.

[VM] Right. Definitely the ability to identify hotspots, which did happen in workplaces. You'll remember the revelations about warehouses, repacking industry—

JH Just to jump in one sec. We identified hotspots, but it is still not the case today that we don't know how many more people of different groups got infected at work. We can talk about these isolated case[s] but our level of knowledge of workplace spread is still really limited to these outbreak examples.

MB Well, that's true that we need more investment in our understanding of work as a risk to our health, for certain. But for me, if I recall the first death that we had reported due to Covid was at the end of February, and in March we were seeing these huge racial ethnic disparities in

mortality. To me, that tells us this is structural. I know, Vickie, I agree people deserve to be educated and they need to know and have the materials that they need to act on information about protecting themselves, but at that point, none of us knew much. So, we should have assumed, in my view, that the exposures were driving this disparity and not personal behavior, and those exposures were where people lived, in crowded multigenerational housing, how they got to work, in private transport, long commuting times, and what was happening to them. Most importantly, I think we should just assume that work was really important place. So, this really pulled back the curtain on the enduring racial hierarchy that exists in the United States, and there was another thing that happened in that time that also highlighted the impact of police-involved killings. So, we have these two things happening that really brought to the fore the importance of our vital registration system and death statistics to understand the risk to young, middle-aged, and to mid-adulthood and later adulthood the risks to people having shortened lives. I think that for 18- to 34-year-olds, for Black men, police-involved killings is in the top 10 causes of death.

[musical interlude]

AM How should we reform this surveillance? We had lots of data but it was poor data selected non-representative. Shouldn't we be careful of having a surveillance system that really reflects what's happening in the population at large?

JH Well, I just want to say one thing is I think we have to connect them to solutions. So at the same time as we learn who's getting sick at work, we have to learn who has access to sick leave to stay home. At the same as we learn where air pollution is having much worse impact on illness and deaths in certain communities, we actually have to put the policy-relevant surveillance in place. That means sensing where the high particulate matter is by geography, where people are exposed, who has access to the ability to have housing in a better area, what approaches to clean

air are working. So, it's that link of the data on who's getting sick and dying to the link on the policy data on do people have access to an ability to have solutions and is the United States and are other countries putting those solutions in place in a way that they benefit all communities.

And I think the data shows just supports what Mary and Vickie have been saying about structural inequalities that we're all well aware of, but diving deeply into it would allow us to get to structural solutions.

VM And ones that don't just depend on individuals, sorry, but it seems to me that we're very focused in our public health thinking on telling individuals what they can do to individually reduce their risk. But if we thought about the workplace or congregate settings, whether they're places where people are incarcerated or they're kept in nursing homes. If we thought of these as risk situations, we wouldn't have just told people individually wear a mask, wash your hands, keep your distance. We would have said these are places where we can expect trouble and talked about collective interventions.

VM I was just going to say one of the exciting things about the special issue is how many solutions that people are suggesting. Some of them somewhat, I think, very demanding that the system of the vital records change, that first of all, how we collect this data needs to change. Like for example, there's one of the papers that really challenges OMB to think about putting social determinants of health as a part of the death record because for those of us who do mortality research, it's very expensive and laborious because we have to pull from so many places because why the vital statistics is really about an individual and the circumstances of that individual. And one of the articles says we need to have the lived experience, the racialized sense of a person's life in order to really understand what they died from, because they didn't die just of a disease; they died because of a disease but the disease occurred because of all of these racialized

experiences. So, for example, that paper suggests that we do something like have social determinants of health as other fields that would be included in the death record. There are other papers that I think have very interesting solutions as well, that for example, one of the things we aren't doing is really following some of the recommendations of—the ICD talks about all the genetic abnormalities, but it turns out particularly in children that we're not linking up this wonderful and very rich genetic data that we often test and get as to why the person died, but it's not being put into the records. Remember, the federal government collects the data up. The original collection of the data is in the states; and in the states, one of the things is is that you might have a coroner that is elected or you might have a medical examiner that is a physician. The quality of the collection of that data, whether you're a red, blue or purple state, might impact how likely you are to use Covid as a primary cause of death if you're in a state where the politics are let's not talk about Covid. So, there's so many solutions that the issue suggests whether we can get there or not is a totally different story because death records are done in states, and the federal government can't tell the state what to do. It can set out what it requires. But at the same time, unless the federal government is really ready to change to a more federated systems, make greater contributions to the collection of data, we have a problem, and the problem is structural, political, and economic.

AM For me, and I'm not sure the discussion is clear about that, the mortality is one aspect of the total surveillance problem, because if you don't have denominator data and you have only the mortality data, you can't tell everything you want to say about the causes and structural determinants of those deaths. So, we need a system that is globally transformed so that we actually have random sample of population and we can relate that with death.

MB Well, your words just remind me why we in public health care about the census, and we really have to be because we rely on it for our denominator data. And we know that the census is always contested politically. It's tied to our political system, but we really want the census to be accurate to—

JH So, what we are ultimately looking for is the data that would make everyone healthier and to reduce mortality. That means we do this powerful representative data you described, Alfredo, and I think we absolutely need what Vickie was detailing which is much more comprehensive data when we do collect the mortality data. We need to know the social determinants of health. We need to know where were living, where they were working, what policies they had access to, and we need that fundamental census data, as Mary highlighted, because we need to know who's at risk, who has the opportunity for a healthy life. And I'll just close on the note of, we've spoken about the challenges in the United States. In some ways, they're greater in the United States than elsewhere; in some ways, they're less than elsewhere. But for any of these massive threats—the pandemic, climate change—we need data everywhere.

MB I'm going to start with what the actual title of the issue is, When Dying Counts. So, I think where we reach a point that every death matters is when we're going to reach a point of having a better system. Part of the problem is not every death counts; not every death matters. Some losses are considered more important than others; and it isn't until we understand, and I hope Covid did this, that how connected we are when it comes to living. For some people, it doesn't seem it, but in Covid, my walking past you and not wearing a mask can impact you. My living in worse quarters and then being impacted by a disaster impacts you because then you don't have a worker and you can't run your business. So hopefully, what we've learned is that every death matters and that it's the route to making sure that others live and live full lives.

[musical interlude]

AM Alright. This discussion is a formidable reminder that public health involves the art of making sense of population data to generate health and equity. Of course, individuals who are not counted in all the types of registries used by public health from the census to the National Death Index are invisible for public health. But today's conversation has emphasized that if the data registries do not collect information on the social, occupational, and racial and ethnic context of the death, whole communities become invisible for public health. And since affluent people are more likely to be counted, an incomplete registration of death is likely to worsen inequalities. This is why surveillance [and] surveillance systems are a key component of public health. This supplement offers many clues on how to fix the system, and there are many more articles to come on this topic in the AJPH.

[musical interlude]

I'm grateful to all the members of the panel for taking the time to share and discuss their ideas. I'd also like to thank Michelle Livings and Michael C. Constanza for edits on an earlier version of this podcast. Anthony Bansie is the student producer for today's episode. Francis Jacob produced the track and solicited the voice and lyrics of Roe D, a poet, singer, songwriter, and rapper from Brooklyn, New York. The supplement discussed in this podcast is available in open access on the Journal website. For more podcasts including podcasts in Chinese, visit us at www.ajph.org or subscribe to it on your usual podcast app. A full transcript of the podcast is available on our website for persons with hearing disabilities. This is Alfredo Morabia at AJPH. That's it! Thank you for listening.

[musical postlude]