

A NATIONWIDE HEALTH TRACKING NETWORK

19. Introduction and Overview

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DR DANIELS: Our next topic is surveillance and tracking, a subject dear to my heart. As moderator, I'm going to move as quickly as possible, but I am going to start with one short story before I introduce the first speaker. My story concerns the kids in my neighborhood several years ago before DDT was outlawed, and when it was very common for the fog machine, as we called it, to come through the neighborhood. And the game for us during the summer was to stay in the fog. Now, if we were doing surveillance and tracking, I wonder if we could find any residual effects from those experiences. There were five kids in my family, and four of us have reduced lung function, either from calcification or scarring of the lung. Was it caused by that? We'll probably never know, right?

Tracking of health issues, especially from the environmental standpoint. I remember the first time I heard about tracking, it was through the Pew Charitable Trust Foundation report. So let's go ahead and start with our first speaker, Ms. Laura Rasar King. Ms. Rasar King has an M.P.H. and a C.H.E.S., and she's the outreach director of the Environment and Health Program for the Physicians for Social Responsibility.

MS. KING: How many of you, as physicians, nurses, other health professionals, have heard questions like this, my guess is many of you. I was talking to my father-in-law the other day. He has a house in Florida, and he told me he had had a migraine all day and that he was pretty sure that the migraine was due to the sprayer, the fogger that was being used for mosquitoes. Do we know? Not really, but we hear these statements and questions all the time.

Figure 19-1 shows some examples of the sorts of gaps that we have in public health data. In a little place called Brick Township in New Jersey (Figure 19-2), and if you know about townships, you know that they are really very small places, parents noticed that a lot of kids in the community had autism. They were astute parents, and they called the National Alliance for Autism Research, and they said, "Hey, can you help us figure out what's going on here?"

CDC and ATSDR were notified about a possible cluster. Cases were investigated, and it actually showed that one of 150 kids in this tiny town had autism. Unfortunately, there wasn't really enough data to confirm whether or not this was actually a cluster, and certainly not whether the cluster could have been environmentally related, if it was a cluster. Where is the baseline data? We don't know.

Figure 19-3 shows another example of gaps in our exposure knowledge. One of the worst cases of pesticide misuse was in Mississippi in 1996. There had been illegal spraying in homes and businesses, and thousands of people were exposed. People were complaining of foul odors, and doctors were being flooded with patients with flu-like symptoms. Once officials were notified and an investigation undertaken, they discovered the illegal pesticide spraying, and EPA was then tasked with decontamination and relocation. Should we have known about it before it actually got to that point? Maybe we could have done better. We had some understanding of the acute effects that the doctors were dealing with, but what about the long-term effects? We don't really know. We couldn't have answered questions about the long-term effects. We have gaps about environmental exposures.

What we do know is that more than 40 million people live within four miles of a Superfund site. Twenty-five percent of community water systems don't meet EPA standards for biologic and chemical contaminants, and more than 50 percent of citizens reside where outdoor air exceeds EPA standards for airborne contaminants. We also know that only 632 of the 80,000 chemicals used by industry must be reported to the Toxic Releases Inventory. The TRI is a sort of data warehouse held at the EPA where certain industries have to report certain chemicals only at certain levels. So there is a vast underreporting of the types of contaminants that are released into the environment, but at least it's some place to start. And for 77 percent of the nation's chemicals produced in the greatest quantity, we don't have available screening information to address potential developmental or neurological consequences in children. A lot of our studies are done on animals, not humans and certainly not children.

We have gaps in trends addressing chronic disease. Seventy percent of the deaths in the United States are attributable to chronic disease. We do know that chronic disease is multifactorial. I am not standing up here telling you that it's all because of the environment. We know that we have nutritional issues. We have tobacco use. We have obesity. We have many, many other factors that are contributors to chronic disease. But we do know that we have increasing cases of asthma, some certain birth defects, and certain types of cancers.

We have changes in the rates of autism and Parkinson's disease. We know that chronic disease is responsible for a huge national cost. A study out of the CDC just recently estimated \$750 billion; that includes not only health care costs but costs due to early death and family costs and lost work costs and child care costs.

Figure 19-4 is a little bit of Texas-based data, from the Health of Texans 2002, the Texas Department of Health. Chronic disease claims more than 100,000 Texans annually. Coronary heart disease is the leading cause of death in Texans. Cancer is the second leading cause of death in Texans; 22.2 percent of the deaths in 2000 were attributable to cancers. A little over 10 percent of all Texans have asthma, and it is the most prevalent chronic disease in kids.

Now, we know that many states are tracking, and by tracking I mean sort of finding out any information they can about these diseases, often based on self-reports from health departments around the United States. The Pew Environmental Health Commission asked them, "Are you tracking these diseases?" It could be a question on a survey, or it could be actually monitoring for something in a very active way. Only four states report tracking autoimmune conditions. Only six states track learning disabilities. Most states don't track developmental disabilities like autism, and less than half of the nation's population is covered by a birth defects registry.

Most states don't track endocrine, metabolic, or neurological disorders. We do know from the National Health Interview Survey, however, that there has been an increase in the self-reporting of many of these conditions dramatically from 1986 to 1995. For endocrine and metabolic disorders, people report an increase of 21.7 percent. For neurologic disorders like multiple sclerosis and migraine headaches, a 20 percent increase. Again, this is a self-reported survey, but it is one of the major ways that the National Center for Health Statistics gets information about these diseases in our country. Respiratory problems like asthma and chronic bronchitis are up 19.6 percent in self-report. Skin conditions are up 2-1/2 percent. So we know that something's happening, at least in the perception of people.

Figure 19-5 is a map of asthma. The dark gray states are the states that do not have any kind of tracking for asthma; there are 27 states that do not have any tracking for asthma. Texas, as you probably imagine, is one of them. Texas also is one of the top ten states in the U.S. for the highest number of days exceeding federal standards for suspended particulate matter, for the largest total number of air releases of recognized and suspected respiratory toxins, and the highest number of days exceeding federal standards for ozone. So Texas certainly should be looking into why asthma is the most prevalent chronic disease in little kids.

We have gaps in quantifying disease. There are data limitations on physician reporting which is often incomplete. Who can blame the physicians? They're busy, and they're looking for a hundred other things on any typical visit.

State data is often not available. Sometimes we have national prevalence data, but we certainly don't have state data and certainly not community data on some of these conditions. Diseases have a long latency. We don't know where an exposure occurred, even if we can relate some diseases to exposures.

We have vulnerable populations, such as Dr. Bondy was talking about yesterday when she tried to map cases of cancer and lost 25 percent of the patients. And who were that 25 percent? They were people who weren't giving their address because they couldn't pay their bills or people with P.O. boxes, or perhaps people who were moving around. Those are vulnerable populations that we have a hard time quantifying.

There are gaps in infrastructure and systems. Even when we do have systems to track chronic disease, they are not consistent. Different states track different things. They're interested in different things. They're often funded by different agencies. In some states, the environment and the public health agencies are one and in some states they're separate. Poison control centers and insurance companies have data, but none of these data are integrated. We don't know the prevalence of chronic diseases. We don't know the causes of them, and we don't know the role of environmental factors. Our infrastructure is not set up in such a way that these data are easily quantified, and the linkages aren't occurring. So what role is the federal government supposed to play in all this? We think that the development of a nationwide health-tracking network is appropriate to address chronic disease and environmental exposure in order to help us quantify the relationship between those two things.

In 1999 the Pew Environmental Health Commission, which brought together scientists, doctors, business leaders, policy-makers, and lots of other folks came together and produced a landmark report with recommendations for how this network might occur. (Figure 19-6) If you want to download the report you can at www.healthyamericans.org. It's very interesting reading, and you can see lots of the references to what I've been talking about.

Their recommendations were for a national baseline tracking of priority diseases and exposures that would use existing networks of hospitals, poison centers and public health agencies to monitor acute environmental health crises. There would be pilot programs for regional and state initiatives, and that's actually in the works, and I believe Dr. Daley is going to be talking a lot about that. We should develop federal, state, and local rapid response capacity to investigate chronic disease clusters, and to support community efforts and community need for getting this information.

This is how I kind of boiled down all of the work that they did. It's just my way of understanding it. (Figure 19-7) There are basically three different types of environmental health tracking, and if you want good health tracking you need to overlay all three of these. Hazard tracking measures whether or not the hazard or the chemical is present in the environment. Is it in the air? Is it in the water? Is it in the soil? Is it out there, and can we measure it? One way that we do this is by the Toxic Releases Inventory. Primarily, EPA and state environmental agencies are responsible for monitoring things like this.

Exposure tracking is measuring whether or not that contaminant or chemical, whatever it is, is actually present in the body. Can you measure in the blood? Can you measure it in the urine? Can you measure it in hair? Is it actually there?

Just because a chemical is present in the environment doesn't mean it has a route of exposure and can get into the body. One of the major ways that we do this is through the National Health and Nutrition Examination Survey, which is basically a mobile examination unit out of CDC. It travels around the country and does complete health workups on folks, including lab work. Last year they started measuring chemicals in the human body. They started with 29. At the end of this year, beginning of next, they're likely to come out with a report on over 75 chemicals that they have been measuring in people.

The third component is health outcomes tracking. There's active and there's passive tracking. There's physician reporting, which I'm sure you all are familiar with and know about, but there are also things like the NHANES which I mentioned before, surveys that the CDC and health departments do.

All of these things need to be linked, overlaid, and correlated. You can think of it like a GIS system or mapping, sort of what Dr. Donnelly was trying to do. That would be good environmental health tracking.

Figure 19-8 puts all this into context, into the big picture. The important part is getting the data. We need the data, but we also need analysis, evaluation, and dissemination. This should lead to public health action, with the goal of the improvement of the public's health, and that's something that CDC is tasked with.

Basically, on the policy level and for school year 2002, \$17.5 million was appropriated to the CDC to begin this process, and that is what Dr. Daley's presentation is going to be about. They have given grants out of that \$17.5 million to states. Currently, the appropriations process is held up. Congress is busy campaigning right now. They're concerned about reelection, so they've kind of passing a team resolution and we're just operating. Hopefully, when they come back in session they'll actually pass appropriations bills. The number on the table this year is \$30 million. The president asked for level funding in his budget proposal, so it will be somewhere between \$17.5 and \$30 million to continue this project. There is also authorizing legislation on the table. S. 2054 and H.R. 4061 are basically the same bills in Congress. These were sort of waylaid in Congress this year, because there are a lot of other priorities that Congress is dealing with right now—homeland security and bioterrorism, defense, and the war on terrorism. It's likely that these bills will be taken up again next year.

Figure 19-9 is what I think is most important, because of everything that you've heard yesterday and today. Obviously, if you're here, these are issues that you care about, and you're here to learn more about them. Get involved. You are health professionals, and policy-makers want to hear from you. You need to explain this to them; you need to educate them about what you've learned here, and there are so many ways that you can do this. You can work through an organization like Physicians for Social Responsibility, which, contrary to the name, is not all physicians. It's all health professionals. We set up grand rounds around the country as educational sessions for your colleagues. We've flown physicians in to Capitol Hill and talk to their policy-makers about these issues.

There are so many ways that you can get involved.

One website that you should check out is www.environmentalaction.org. That's an education and action center, where you can learn a lot about these issues. You can send letters to your congressman or congresswoman. That's a one-click, computerized way to get involved. There are many, many more things that you can do. If you're interested in getting involved, please contact me. (Figure 19-10) I'm more than happy to talk to you. Thank you so much.