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Scope of nationwide heroin 'epidemic' unknown; drug-related death, overdose data lacking

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Elected officials, law enforcement officers and others [proclaim there's a heroin "epidemic"](#) sweeping the country, and it's taking hold in [rural and suburban communities](#) once considered unlikely places to find illicit drugs.

But nobody knows how many people have died.

Nobody knows how many have overdosed and survived.

Nobody even knows for certain where the problem is most severe.

The [Centers for Disease Control and Prevention reported](#) that 3,036 people died in 2010 from heroin overdoses, but due to problems with how death investigations are conducted and how those deaths are documented, the CDC estimates that its tally is at least 25 percent short, possibly more.

"I'm very scared for our nation in how fast this has grown and spread," said John Roberts, a retired Chicago police officer who created [The HERO Foundation](#) after his son died of a heroin overdose in 2010. "This is an epidemic. But it's not getting the attention that it needs because we don't know how bad it is."

In Connecticut, the Office of the Chief Medical Examiner keeps data on overdose deaths. In 2013 there were 257 heroin-related overdose deaths, up from 174 in 2012. In 2010, the latest data available from the CDC, 74 people died of heroin-related overdoses in Connecticut. While that 257 percent increase is reflected in data kept at the state level, it isn't seen in the nationwide statistics, which haven't been updated for years.

[MORE: 'Typical' heroin user in Connecticut is white, suburban; often unaware of what they're actually using](#)

Public health researchers, called epidemiologists, say long-standing flaws in data about fatal and non-fatal overdoses compound the already difficult task of monitoring an illicit activity.

Lauretta Grau, an epidemiologist at Yale University, said her department is in the process of collecting data that will be current through 2013. Prior to this collection, Grau said he department published information on accidental and undetermined opioid overdose death from 1997 through 2007. Grau said the department's data collection should be complete by summer this year.

"It's an arduous process," she said. "There are places around the state that collect these types of data. But to get a good understanding of the problem it's (collecting) not only fatal overdoses but all overdoses to get as much information as you can."

Grau said there are many entities that provide overdose information. Hospitals, emergency medical services, medical examiners and police all have the information. But in order to develop a more comprehensive compilation of data, Grau said it takes time and manpower.

"There are many databases or places where data can be collected to give us a richer and fuller understanding of the problem," she said. "There is data being collected all over the place, but you need to check your sources to make sure you have a clean data set. It takes us time to clean a data set and then be able to sit down with confidence and verify it."

Grau said she thinks the only thing that will speed up the process is more money and more help.

"It's an arduous process to clean a data set and therefore data analysis will always lag somewhat behind real time," she said.

After verifying it, she said, the department tries to analyze and understand the information collected to develop a story.

"The more information you have, the more options you have to think about and perhaps act upon," Grau said.

Having an accurate and timely picture of heroin abuse and its effects is crucial, researchers said, because heroin has much higher risks of overdose and infectious disease than other drugs. That's particularly true when compared to the prescription painkillers that many of today's heroin users started with.

"We need to know what they're dying from, because our ability to measure drug use is very poor," said Caleb Banta-Green, a research scientist in Seattle and former advisor to the White House Office of National Drug Control Policy. "Death is what you want to prevent, and that data can tell you something about how we keep people alive."

To make matters worse, it has taken three years for the CDC to make the 2011 death data available to the public and researchers — a full year longer than usual — at a time when local reports from throughout the country indicate alarming increases in heroin use and overdoses.

The 2011 data is expected to be released later this week, and researchers expect it will show a dramatic spike in the number of heroin-related deaths.

"The rapidly changing picture of substance abuse in the country now demands in the 21st century a more timely reporting of indicators," said Jim Hall, an epidemiologist with the Center for Applied Research on Substance Abuse and Health Disparities in Miami.

Hall and others said more complete, detailed and timely data would help to inform the policy makers who decide how to fight drug abuse, and heroin in particular.

"Policy should rest upon good data. The better your data, the better policies you make in the first place and the better evaluations of the policies are," said Len Paulozzi, an epidemiologist with the CDC's National Center for

Injury Prevention and Control. "If you have to wait four years to get data, you're well behind in terms of trying to arrive at an effective policy."

Prescription painkiller clampdown linked to heroin surge

Fatal drug overdoses have tripled over the past two decades and have become the leading cause of death by injury in the United States, according to the CDC.

Experts say this coincides with the increased use of prescription painkillers, such as oxycodone and hydrocodone.

And now the rise in heroin use — and overdose deaths — seems to be a direct result of efforts to make those painkillers less accessible for illegal use, combined with an unprecedented influx of low-cost, high-purity heroin.

For many, pills were the "stepping stone" to heroin, said Carol Falkowski, a national expert on drug abuse and Minnesota's former drug-strategy officer.

Pill addicts — and now the new heroin users — often defy the stereotypes, bringing more attention to the topic. Banta-Green said they tend to be "young, white and rural."

And an estimated 20 percent of heroin users overdose each year, Banta-Green said.

Deaths are investigated differently in different states and counties

The CDC can say with confidence that more than 200,000 people died from drug overdoses between 2005 and 2010.

During that same time, their data shows that about 15,000 of those deaths involved heroin and about 86,000 involved other opioids, such as prescription painkillers.

But those numbers — especially for heroin — are most certainly an undercount.

The CDC thinks these figures are at least 25 percent short — maybe more — because of a study by Margaret Warner, an epidemiologist at the CDC, and other researchers. They found one-quarter of the death certificates for overdose victims between 2008 and 2010 did not specify the drug or drugs involved in the death.

[Read the CDC's study here.](#)

The study also found that the accounting varies greatly by state. In Louisiana, 65 percent of the investigations of overdose deaths didn't specify what drug was involved, while less than 1 percent failed to mention the drug in overdose deaths in Vermont, New Hampshire and West Virginia. In Connecticut, the drug involved was identified in 76.8 percent of the deaths.

It's this discrepancy that makes it impossible for researchers to say there are more fatal heroin overdoses in one part of the country than another.

Banta-Green said death data is the most crucial piece for assessing drug abuse, because it's the most complete picture of the total population, allowing a researcher to find patterns by age, gender or region of the country.

Other data sources, such as surveys or emergency room treatments, are unlikely to capture the full population.

A Balkanized system

Further complicating the problem, the U.S. death investigation system is made of a patchwork of coroners' officers and medical examiners — local, county or statewide depending on the locale. Though both investigate deaths, coroners are typically elected or appointed and may not be doctors. Medical examiners are typically physicians, are not elected, and depending on the locale, lead county or statewide offices.

Connecticut's death investigation system is centralized in the Office of the Chief Medical Examiner. It is under control of the state Commission on Medicolegal Investigations, which appoints the chief medical examiner, currently Dr. James Gill. That panel is made up of the commissioner of the Department of Public Health, professors, a representative of the American Bar Association, a representative from the American Medical Association and two members of the general public.

Although groups like the National Association of Medical Examiners make recommendations about death investigation, all guidelines are voluntary, and the thousands of professionals in the field are difficult to standardize.

Some medical examiner's or coroner's offices might not have the budget to autopsy every death or pay for the necessary toxicology lab tests.

In addition, there are inconsistencies in how death certificates are filled out. If an autopsy is not done, or toxicology tests are not run, or the tests are inconclusive, the death certificate might say the person died from a "narcotic" overdose, a drug poisoning, an "opioid" overdose, or, least definitive of all, "undetermined."

The tests are particularly problematic for heroin.

Heroin metabolizes in the body very quickly, and toxicology tests typically show evidence of morphine, another opiate. There is a test that can show definitive evidence of heroin exposure, but it's expensive, only effective within a few hours after death and may still be inconclusive.

Without a definitive toxicology test, a death investigator may not feel confident enough to say the person died from a heroin overdose.

Banta-Green spent time digging through death investigation records in the King County, Washington, medical examiner's office a few years ago and found an inordinate number of cases where the file showed plenty of physical evidence that heroin was involved, but the death certificate merely said "morphine" or "opiate."

He convinced the King County medical examiner's office to add a new field to its death records database, essentially a yes or no to indicate if heroin was involved.

"It's made them be more explicit and made them look into this more," Banta-Green said.

Falling behind

Another problem is that much of this data is slow to get to researchers, policymakers and others interested in

assessing the problem at a national level. This has been exacerbated in recent years due to computer problems at the CDC and the shutdown of a surveillance system that measured non-fatal overdoses.

“We have a blind spot in our rearview mirror the last couple of years,” said the CDC’s Paulozzi.

Until recently, researchers relied heavily on the Drug Abuse Warning Network survey, conducted by the national Substance Abuse and Mental Health Services Administration.

That survey, which made it possible to measure emergency room overdose cases, stopped collecting data after 2011. The CDC is now working to collect similar information as part of a larger effort, the National Hospital Care Survey, but there’s no estimate on when data might be available.

The death certificate data was delayed by more than a year due to problems with a new computer system at the CDC’s National Center for Health Statistics. Normally, this data is released two years after deaths occur, but the 2011 data isn’t getting to researchers and the public until this month.

“(Timeliness) is a challenge, because we won’t know for a couple years whether the efforts we’re engaged in right now to fight prescription opioids are having an effect on overdoses,” said Rafael Lemaitre, spokesman for the White House Office of National Drug Control Policy.

The computer problem is related to the national center’s efforts to get every state to use electronic death registration systems.

The center launched a new computer system and found flaws early last year just before it was ready to release the 2011 data, according to Bob Anderson, chief of the mortality statistics branch.

The 2012 data might be released this summer and the 2013 data might be out before the end of the year, which would be earlier than ever before, Anderson said.

“We’ve seen dramatic improvements,” with states going to electronic registration systems, Anderson said. “We’ve retooled our systems so we can look at data as it comes in.”

Anderson said this would give his agency more ability to monitor health trends in near real-time.

“Within the next five years, things will be a lot different,” Anderson said. “We’ll be doing a lot more surveillance work using the mortality data ... We’ll be able to say things about the previous year early in the new year.”

Experts have to make do with what they have, as they confront a public health crisis

The opioid crisis has pushed state health departments, medical examiners and others to improve their death data, as well.

“It’s getting greater scrutiny and people are figuring out that this dataset is pivotal,” said Falkowski, a Minnesota drug abuse expert.

These improvements will make it easier for researchers, but they will likely still have to piece together a variety of sources — surveys, treatment admissions, deaths, emergency room visits, law enforcement drug seizures, arrests and even wastewater testing — to come up with a picture of the relative trends.

“The mosaic has a lot of cracks and spaces in it,” said Hall, the epidemiologist in Miami. “But what pieces we do have give us the best picture we can see.”

Numerous epidemiologists said more precision would always be great. But their job — raising the alarm bells about new drug abuse problems — isn't unduly hampered by the flaws.

“We get a pretty good feel for what's up and what's down,” said Jane Maxwell, a senior research scientist at the Addiction Research Institute in Austin, Texas. “If all indicators are going in the same direction, I feel pretty comfortable.”

But Roberts, who lost his son to heroin, feels differently. He would especially like to see better accounting of non-fatal overdoses, and he's been asking Illinois lawmakers to require hospitals to report those numbers to the state.

“People are starting to embrace the idea that it's a health crisis,” Roberts said. “How do we turn anecdotal evidence into real evidence? Let's do real-time reporting from a reliable source — our hospitals.

“Let's just find out how bad it is,” Roberts added. “And then try to solve it.”

Mercy A. Quaye and Tom Cleary contributed to this report.

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