TRANSCRIPT

STATCAST, JANUARY 2021: DISCUSSION WITH ROBERT ANDERSON, CHIEF OF MORTALITY STATISTICS, ABOUT DEATH CERTIFICATE DATA.

HOST: Death certificates serve a very important legal purpose in the United States. The death certificate is the only legal proof that a person has died, and the State uses it to stop social security payments, pensions, and other benefits. Families use the death certificate to settle their affairs. Reporting of death began back at the dawn of the 20th century – in 1900 – and the information required on death certificates has helped monitor and reflect how society is changing. But there is also a vital role that death certificate information plays in public health as well.

We're joined today by Dr. Robert Anderson, the Chief of Mortality Statistics at CDC's National Center for Health Statistics.

HOST: So data from the death certificate has guided public health policy for now over a century. Can you touch on a few historical examples of how these data has informed and guided public health over the years?

 ROBERT ANDERSON: They've been used to surveil influenza mortality for quite a long time and also to document and track deaths due to epidemics including HIV, drug overdoses, and most recently COVID-19.

HOST: This goes back to the beginning of the 20th century – so how is the information that's required on the death certificate, how has that changed over the years?

ROBERT ANDERSON: Well every so often the U.S. standard certificate of death is revised, and this is a guidance document that is produced in collaboration with state vital registration offices to sort of standardize the information on the death certificate and there have been changes over time. The cause of death section was revised some 60, 70 years ago to elicit a more useful underlying cause of death. We've had additions to information on race and Hispanic origin that have been added over time. Most of the other demographic information has pretty well stayed the same from the beginning. What the overall content of the death certificate has shifted slightly over time to give us an additional information that's useful to us from a public health standpoint. And of course we've been better able to retain information as we moved into the electronic age as storage of data has improved and gotten cheaper. We've been able to retain more information than bring to in the past.

HOST: So for those who aren't familiar with the process, could you sort of walk through that, from the moment a person dies to the endpoint when NCHS actually publishes analysis of the death certificate data? Could you sort of walk us through what happens?

ROBERT ANDERSON: Yeah when a person dies, state laws require that a death certificate be completed and registered. And then typically, the funeral director starts the record and provides personal and demographic information about the decedent. Then a physician, medical examiner,

coroner — depending on the circumstances — provides the cause of death information. Now, in most cases, these days this is done electronically using electronic death registration system. Most states have these electronic systems and in those states most of the records are filed and registered electronically. Now once the death is registered with the state, the statistical information from the death certificate is then sent to NCHS which incorporates it into the national data file. National Statistics have been generated from that data file and then the data and statistical reports are released to the public when they're all ready to go.

HOST: So the people who actually fill out the death certificates — these are doctors, medical examiners, coroners — they're trained to follow certain steps when they fill out the certs. Can you explain a little bit about the steps they're supposed to follow?

ROBERT ANDERSON: Sure, yeah you know the physicians, medical examiners, and coroners they're the ones that provide the cause of death information, so the funeral directors typically provide the demographic information and that's generally straightforward. The cause of death, however, is not as straightforward. The death certificate is really designed to elicit an underlying cause of death and the underlying cause of death is defined as the disease or injury that started the chain of events leading to death. And this is considered to be most useful information from a public health standpoint. The idea is that if we can prevent the underlying cause, then we can stop that chain of events from happening altogether. So the physician, medical examiner, and coroner — and the physicians will typically certify the cause of death when that cause is natural, the medical examiners and coroners typically handle injury-related deaths, suspicious deaths or deaths where the decedent wasn't attended by a physician. So these folks are instructed to report a causal sequence beginning with the immediate cause and then working back to an underlying cause. So for example, we might see a chain of events such as acute respiratory distress due to chronic obstructive pulmonary disease. So acute respiratory distress would be the immediate cause of death and then the COPD – the chronic instructed pulmonary disease – would be the underlying cause of death. The idea is that the COPD caused the acute respiratory distress, which caused death and so the main focus is going to be on that COPD, rather than the acute respiratory distress, because we want to get at that underlying cause. The certifiers are also asked to include any other conditions and diseases that may have contributed to death but were part of that causal sequence.

HOST: Now it's time to take a look at new data released this week by NCHS. A new report on Tuesday shows that one out of 10 emergency department visits in the United States involves some form of respiratory illness. The report uses comparable years of data from the National Hospital Care Survey and the National Hospital Ambulatory Medical Care Survey. Also on Wednesday, the latest data from the Household Pulse Survey was released, documenting that nearly 40% of adults delayed or did not receive needed medical care in the last four weeks because of the ongoing pandemic. The data were collected from December 9th through the 21st and represent an increase from data collected in October. Over 42% of adults experienced symptoms of anxiety or depressive disorder, or both, in the last week. Over 56% of adults ages 18 to 29 have experienced these symptoms. And over 12% of adults say that they needed mental health counseling or therapy but did not get it in the past four weeks.

HOST: What happens in the instance if the certifiers cut corners or fill out the death certificate quickly and maybe leave out certain things…how does that impact the data?

ROBERT ANDERSON: Well there are really two issues that we see with cause of death certification, two main issues. Sometimes certifiers leave out the underlying cause and sometimes that they will provide an underlying cause but not provide sufficient details. So for example we see sometimes acute kidney failure as the cause of death. There would be a lot of other causes of death that would be applicable here but acute kidney failures is I think illustrative. In most cases this is probably not incorrect – the decedent may very well have died from acute kidney failure but it's not really enough information. Acute kidney failure is typically caused by something else and we need to know what that underlying cause was. Was it diabetes? An infection? High blood pressure? Or some specific disease affecting the kidney? There are bunch of things that can cause acute kidney failure. We need to know that information. We didn't know what that underlying cause was because that's what we want to focus on from the public health standpoint.

HOST: Is there anything that can be done when this sort of thing turns up? I mean, is there any follow up or once its complete basically that's what we have to deal with?

ROBERT ANDERSON: Well unfortunately once it's complete that's generally what we have to deal with. In an ideal world, all death certificates get reviewed by an expert and information is correct or added as appropriate. Unfortunately, resources are such that that's not a practical solution. So very often we just have to deal with what's given to us. Yeah, we also deal with this issue where the underlying cause may be provided we don't get sufficient detail and drug overdoses provide a good example of where the lack sufficient detail is a problem. In these cases, sometimes we'll simply see just "drug overdose" or "multi drug toxicity" reported on the death certificate. And again, while this is probably not incorrect, we really need to know which drugs were involved. If all we get is "drug overdose" we don't know – was it a heroin overdose? Was it a fentanyl overdose? And knowing which drugs were involved helps us to better understand the nature of the public health problem that we're dealing with.

HOST: Usually, when you have a high profile person dying of an overdose there's often a long period where they're waiting for the toxicology report. Does that restrict certifiers getting details like that for the death certificate?

ROBERT ANDERSON: It really doesn't. In most instances when a death investigation is required it's going to take more than a few days. The cause of death can be certified pending investigation. And so that's typically the way these are handled – the medical examiner or coroner who deal with the drug overdose deaths, they will file the death certificate with the cause and manner of death pending investigation. And then, so we will get actually that fact of death with pending cause in a very timely manner. Then once the death investigation is done, the medical examiner or coroner can go into the system and update the cause of death – that's actually the way they're supposed to do it, they go in, they amend the certificate with the new cause of death information and then that information is transmitted to us. So, while we may get the fact of death in a very timely fashion for drug overdose deaths, we very often don't get cause of death until maybe three to six months later.

HOST: So the data that NCHS ultimately publishes – that's coming from all the death certificates in the country that are recorded. It's not just a sample of death certificates like we would get with a survey sample for example, is that right?

ROBERT ANDERSON: That's right. Yeah, we don't do, we're not sampling data here. All deaths are required to be registered and we collect all of these from the states for the national statistics. Now, that doesn't mean that when we publish information that we necessarily have all of them in that moment. We do publish some provisional data that are incomplete. Our final statistics are based on all deaths registered and sent to us by the states.

HOST: Before we get to the provisional vs. final topic, can you – I know the number changes each year – but how many death certificates are we talking about roughly each year?

ROBERT ANDERSON: We're talking about in the most recent years about 2.8 million – 2.8 million deaths in a year.

HOST: Right. And so as the population grows you're going to see more of a volume to go through.

ROBERT ANDERSON: Yeah that's certainly what we've seen. I mean not only has the population been growing but the population has been aging somewhat and of course an aging population means more deaths as well because older people are more likely to die. So yes we have been seeing increases in the total number of deaths over time even though in most instances the death rate has come down.

HOST: Right. And the death rate is the number of deaths per a certain number of population is that right?

ROBERT ANDERSON: That's correct. Yeah, usually .for mortality we characterize it as deaths per 100,000.

HOST: You touched on provisional data – could you walk us through what provisional death data is and then also explain when the data are final?

ROBERT ANDERSON: So the provisional data allows us to see a picture – an incomplete picture – of the situation with regard to mortality in a much more timely fashion. So when we provide data that are incomplete we will call it provisional because it will change over time as more information comes in. We generally have to wait nearly a year after the end of the data year to have final data ready. Now in contrast, we've already been releasing provisional data for 2020 but those data are incomplete and subject to change but they do allow us to see a picture, albeit incomplete of the situation with regard to mortality.

HOST: So then the final data are basically when 100% of the death certificates have been recorded and analyzed is that correct?

ROBERT ANDERSON: Yeah that's correct – those data have been thoroughly checked and we've made any corrections that are needed and we feel comfortable that these can form the basis for official mortality statistics.

HOST: So what explains the lag time in the data and the different times each year the date are released? Some years it comes out earlier and other years not as early.

ROBERT ANDERSON: At the national level we're only as fast as our slowest state so we have to wait to get this information in from the states because we want to have all deaths represented from all states. And there's quite a bit of variation in timeliness by state and in cases where lengthy death investigations may be needed and the jurisdictions may be strapped for resources, it may take several months to get the cause of death information. Some states – there are a few states that don't have electronic systems and so they tend to be slower as well. And so we really have to wait to get all of the information in and if we have one really slow state, that may slow us down a bit. In addition, if we find significant problems with the data, the data file, that may take some time as well so normally we go back and forth with the state to make sure that we understand what the problems are and that they are corrected to the extent that we can correct them. And so if we identify significant problems – and this does happen sometimes, particularly as states are implementing electronic systems or maybe implementing new electronic systems, there tend to be bugs in the system and we find issues and those really have to be corrected because we want the data to be as accurate as possible. So when those things arise, that may cause us to adjust the release date for the file data. We don't have a sort of "static release date" where we release on the same day every year – it really depends on how long it takes to make sure that the data are as accurate as we as they can be.

HOST: So as far as NCHS's analysis on death certificate data… NCHS does not go into all areas of analysis – sometimes there's outside research done. Is there untapped information on the death certificate that that could be useful for the public health community – what's your thoughts on that?

ROBERT ANDERSON: Well I mean you're right that we don't we don't publish on every item on the death certificate in our standard reports. There are some information there that we don't publish on. We do make the data file available and the data is a public use data file but has some limited information. And then there are some other files that require a research proposal and a data usage agreement that have additional information. Those are made available to researchers and researchers can do that but one thing in particular that I'll mention that doesn't get a whole lot of attention but should is what we call multiple cause data. Now I talked about underlying cause information before and the basic official national statistics are based on underlying cause. But multiple cause information is important. We record all of the causes that are reported on the death certificate. So we record that entire causal sequence that's reported and we also record any contributing conditions as well. And so there's a lot I think of good information in those multiple cause fields that can be used and one thing that we've just begun to start looking at in the last several years is specific drug information which is gleaned from that, from those multiple cause fields. The underlying cause may be due to overdose due to heroin or whatever but there may be multiple drugs reported or there may be some other information in there that can be useful in those multiple cause fields. So that's something that we don't typically publish on – it's quite

complicated to present a statistical picture based on multiple cause but that could be very useful I think from a research standpoint.

HOST: So NCHS is the agency that ranks the leading causes of death in the country, and this is based on data from the death certificates. Could you tell us a little bit of how NCHS goes about ranking leading causes of death?

ROBERT ANDERSON: Sure, well we have a standard tabulation list that we use typically to present cause of death data and the causes that are eligible to be ranked are determined by that cause list. So you know, there's this nothing sort of magical about leading causes of death - I mean we decide which causes can be ranked and then we rank them you see that list. Other lists could be used and other lists are used in different countries or on an international level for ranking. The rankings for the United States in comparison with other countries, for example, that may look a little bit different but in the United States we have a sort of standard process for ranking leading causes and we try to keep that process as consistent over time as possible because those rankings actually are used for planning and funding in those agencies responsible for doing this work.

HOST: OK - and then another topic that NCHS is the source for is longevity, or life expectancy in the U.S. How does the death certificate data help us learn about that?

ROBERT ANDERSON: Right. So you know, life expectancy information is derived from the death certificate data. Now in this case we don't need cause of death because we are only interested in whether people die or not, and so the life expectancy is based on the information. And what we do is we construct a life table based on all of the death certificates and life expectancy is derived from that table.

HOST: One more question here - what about future initiatives or modifications that might be in the works to build on what we have already in terms of information on the death certificate?

ROBERT ANDERSON: Yeah there's a couple of things that we've been working on, and one of these involves improving timeliness. We've seen dramatic improvements in times over the last few years, but there's still more improvement that could be made. And that mainly involves development of electronic registration systems – these have had the biggest impact on timeliness in the past. And making these systems interoperable with other systems - for example, systems that involve electronic medical records our systems that involve medical examiner or corner records. If we can make these systems talk to each other, we can get more timely information because then information doesn't then have to be transferred manually from one system to another system. This can also help us with the quality of the data as well, which is another thing that we're really working on. If the physician, medical examiner, coroner that has to certify the cause of death has information from the, let's say the electronic health record, at their fingertips then they have better information on which to base the cause of death statement. So these are these are things that we're working on right now and we hope to see improvements, further improvements in timeliness and improvements in the quality of the data as we move forward.

HOST: So to follow up on that, you had mentioned about the provisional data being incomplete. Is it possible then that in the future provisional data may be more complete or might provide more details?

ROBERT ANDERSON: Yeah that's the hope, is that if we can improve the timeliness of the data that allows us to get a more complete picture in the provisional data in a more timely fashion. So it means that we can actually publish something sooner than we currently can. Now we have to wait until the data are complete enough to provide a picture. It's sort of like putting together a puzzle. You know, when you get enough pieces in you can kind of see what the puzzle looks like, but if you're still missing a lot you may not be able to see that picture. So we have to continually put these pieces in until we have something that we can recognize. And then when we do that then we can push that information out and publish it as provisional. And then when we get all the pieces in of course the data become final but the sooner we can get those pieces into the puzzle, the sooner we can show a picture of what's happening with regarding mortality in the country.

HOST: Thanks to Robert Anderson for joining us on this edition of "Statcast."