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Gift From the Grave

With better counting of who died and how, developing countries can help the living.

By STEPHANIE NOLEN

FUNKOYA, SIERRA LEONE — Augustine Alpha begins gently. "Who lives in this home?" he asks the young man, who has come in from the fields to answer his questions.

Your name? Age? Religion? Marital status? In what grade did you leave school? Do you own a bicycle? Mr. Alpha taps the young man's answers into the laptop perched on his thin knees.

Then comes the key question: "Did anyone die in your home in the last two years?"

"Yes," the young man says, "my mother."

Mr. Alpha expresses his sympathy, asks him her name — it was Mabinti Kamara — then plunges in: Was she sick? How long? Fever? Rising and falling, or steady? Vomiting? Diarrhea? Tremors? Did she see a doctor? Get medication? Have pain? Where was the pain, and how long did it last?

Ms. Kamara's son is reticent at first but is soon caught up recounting the story of those last few weeks of his mother's life, describing the fruitless trips to the local clinic. Mr. Alpha taps away until every detail has been entered in the software of a public health survey called the Countrywide Mortality Surveillance for Action, or COMSA. Then he snaps his laptop closed, applies a sticker to the wooden shutter of the front window marking the Kamara house as surveyed, reiterates his condolences and moves on to the next home.

In this way, Mr. Alpha and three colleagues will, over a few days, gather the details of every death that took place in the village of Funkoya since 2020, using a process called an electronic verbal autopsy. The data they collect goes to the project's head office at Njala University, in the city of Bo, a few hundred kilometers to the east. There, a physician reviews the symptoms and de-

Above, the body of Francis Kailie being carried to a plot behind the family home in the city of Bo in Sierra Leone in February. Nearly half the deaths around the world are not recorded.

In a Gift From the Grave, the Dead Help the Living

scription, and classifies each death according to its cause.

It is an extraordinarily labor-intensive way of establishing who has died, and how, but it's necessary here because only a quarter of deaths in Sierra Leone are reported to a national vital statistics registry system, and none of the deaths have a cause assigned. Life expectancy here is just 54 years, and the vast majority of people die from preventable or treatable causes. But because there is no data about the deaths of its citizens, the Sierra Leonean government plans its programs and health care budget based on models and projections that are, ultimately, only best guesses.

There are a variety of reasons families do not report the deaths of people like Ms. Kamara to a national registry, none of them complex. The registry office may be far away, and they can't afford the transportation costs, or find the time to go there, or pay the nominal fee for the death certificate. It may be that they've never even heard of the practice; the state has very little presence in their lives. The dead are buried behind their homes or in small village plots, as Ms. Kamara was; the local chief might then make a note in a ledger, the contents of which never travel out of the village. Sierra Leonean hospitals don't automatically share their death records either.

Sierra Leone is not an anomaly. Vital statistics collection across the developing world is weak. While progress has been made in recent years in terms of birth registration (which is increasingly tied to access to education and social benefits), nearly half of the people who die around the world each year do not have their deaths recorded.

"There is no incentive in death registration," said Prabhat Jha, who heads the Center for Global Health Research in Toronto. He pioneered these kinds of efforts to count the dead two decades ago in India; doing it now in Sierra Leone, one of the world's poorest countries, has shown that the model will work anywhere, and has helped bolster a government eager to root its policies in evidence and hard facts.

The topic of vital statistics registration is not glamorous, but it is critically important for understanding public health and socioeconomic inequality. Covid-19 has brought new attention to the topic. Debate over how many people have died from the coronavirus, and who they were, has become political, and in countries such as India, lower death counts have served the agenda of national governments hoping to downplay the role of failed pandemic policies.

It matters that we know not only how many people died, but who they were and when they died, said Stephen MacFeely, director of data and analytics for the World Health Organization: "As we come out of the eye of the storm, this is when you talk about learning lessons."

There is, for example, fierce debate among epidemiologists about whether Africans are dying of Covid-19 at the same rate as people elsewhere in the world, and, if they are not, about what might be protecting them.

When countries don't know who has died or how, it complicates efforts to reduce preventable deaths. The government of Sierra Leone allocates its budget, as many developing countries do, based in part on models provided by UNICEF, the W.H.O., the World Bank and other multilateral agencies that project the number of people who will be killed there each year by malaria, typhoid, car accidents, cancer, AIDS and childbirth. These models are built on global estimates and draw on dozens of studies and individual research projects, which can do a reasonably good job of estimating the larger picture but are sometimes far less accurate at the national level. As Dr. Jha explains it, malaria data that came from Tanzania or Malawi isn't necessarily going to be accurate for Sierra Leone, even though all three countries are in Africa.

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From top: Isata Kaitongi, center right, gathering data in Mabin; a backyard grave being dug in Bo; and Alpha Mohammed Kamara in Mabin showing Kadijatu Jiallo where he buried his wife.

'When you count the dead, you just get information that you didn't expect.'

The information collected through this painstaking door-to-door work has shown that the models can be drastically wrong. "When you count the dead, you just get information that you didn't expect," Dr. Jha said.

The first COMSA study looked at the households of 343,000 people in 2018 and 2019, of whom 8,374 died. The verbal autopsies produced discoveries so surprising that Dr. Rashid Ansumana, a co-principal investigator for the project, refused to believe them for months, until the revelations had been checked and rechecked a number of ways.

"I got convinced with facts and evidence," said Dr. Ansumana, the dean of the college of community health at Njala University. "And now I can convince anyone: The data is awesome."

The first big surprise involved malaria. The research showed it to be the biggest killer of adults in Sierra Leone. Dr. Ansumana said that in medical school he was taught that malaria killed children under 5, but people who survived childhood had an immunity that kept repeated malaria infections from taking their lives.

Pretty much everyone working in health care in Sierra Leone believed that, he said. In fact, the plotted data showed that malaria deaths formed a U-shape curve, with very high numbers among young children and lower ones for young adults; the numbers then rose again in people over age 45.

The second shock was regarding maternal mortality. The study found that 510 of every 100,000 women die in childbirth — a staggeringly high rate, but still only half of what the United Nations bodies reported for Sierra Leone. The finding was a relief for the government, Dr. Ansumana said, because it showed that resources being poured into making childbirth safer for women and babies was paying off.

Now a second round of the national survey is underway, seeking to illuminate, among other things, the health impact of Covid-19.

To secure this kind of data without having to go from door to door, Sierra Leone is working on reforms to its civic registration, and is one of many countries trying to figure out how to make certain that more deaths are counted.

Many of these fixes are straightforward and don't cost much, said Jennifer Ellis, who leads a program called Data for Health, run by Bloomberg Philanthropies, that aims to increase health data collection in low- and middle-income countries.

It starts with overhauling an extant death certificate to collect usable information on who died and why, and training doctors to be aware of why a specific cause of death is important (that is, for instance, why it matters whether a death is logged as "pancreatic cancer" as opposed to "abdominal pain").

"You need to change how the data flows," she said, because it may be collected by a national interior ministry and not shared with a health ministry. Data should be digitized, so it doesn't just sit moldering in ledgers. It should be easy for people to go somewhere to register a death, and free.

Another step is routine collection of verbal autopsies for all who die outside a health system. This involves identifying and training people at the community level, such as midwives or community health workers and others who might do basic primary care in low-income countries, to collect information on every death.

Digitization is expensive, Ms. Ellis said, but the other steps cost very little. Fewer than 5 percent of deaths in Zambia included a recorded cause when Data for Health joined up with the government there in 2015; by 2020, that figure had risen to 34 percent. Peru introduced a digitized cause-of-death reporting system that now makes death information available in real time; because it had solid and swiftly accessible data, it reported some of the highest Covid death rates in Latin America.

Information captured by new death registration systems has quickly been translated into health policies. When improved cause-of-death collection revealed that road accidents were among the top causes of death in Colombia, its government moved quickly to introduce safety protections in the worst-affected areas. In India, the recorded number of people dying of snakebite exceeded the W.H.O.'s estimate for the entire world; antivenom was made available at more primary care centers in heavily affected areas.

But while many countries are eager to transform what they learn from death statistics into policy, others are hesitant. "I'm not sure all governments really understand the power of data — and let's be frank, a lot of governments probably don't want to measure it, either," Mr. MacFeely of the W.H.O. said. Some view higher Covid death counts as an indictment of their pandemic responses, he said.

Still, he said, the W.H.O. is encouraging countries to treat vital statistics data as they do other forms of infrastructure, such as gas systems or electrical grids.

"This is part of managing a modern country," he said.