



SAVING LIVES, ONE DEATH AT A TIME

What one of the world's largest mortality studies
is teaching us about public health

by **MARCIA KAYE**

An Indian youth walks past a pesticide cloud during an anti-malaria fumigation drive in Mumbai, India. August 2, 2010



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n their quest to track health patterns across populations, epidemiologists often call themselves “disease detectives.” Not Dr. Prabhat Jha. He uses a somewhat more radical term to describe the work that he and his team are doing. “I like to think of ourselves as epidemiological terrorists,” he says jovially. “We blow up assumptions.”

Here’s one example. It concerns malaria, a disease that the West doesn’t pay much attention to. The World Health Organization (WHO) had long been reporting that in India, malaria claims 15,000 lives a year – a significant but not overwhelming loss in a nation of more than a billion people. But Jha learned that the WHO figure was based solely on patients who receive proper diagnoses from clinics or hospitals. Jha, who was born in India, was well aware that such a statistic would exclude many rural and poor Indians with no access to formal medical care. So, more than a decade ago, he set out to design a different system for gathering data. The Million Death Study, which Jha launched in 2002, began sending trained teams to homes across the country to conduct door-to-door surveys about recent deaths.

This method has produced startling new findings. A paper Jha published in fall 2010, for example, indicates that the death toll from malaria is an astonishing 200,000, or 13 times the WHO estimate, most of them adult deaths. And that’s just India. Jha believes that many other countries, especially in Asia and Africa, may similarly be basing their public health policies on incorrect statistics. “Deaths from malaria in our view have been vastly underestimated worldwide,” Jha says, suggesting a total death toll of close to 1.3 million – 50 per cent higher than the WHO’s estimate. Jha believes that at least 200,000 malaria deaths among adults in Africa currently go unreported.

Here’s another widely held assumption that Jha is challenging: the United Nations had been reporting in the mid-2000s that 400,000 people in India die of HIV-AIDS every year – more than any other country. The numbers had been based on clinical testing for HIV in young pregnant women. But Jha’s team found that the figure is likely far lower, probably closer to 100,000. That’s good news, especially as Jha has published widely on HIV-AIDS prevention. But if malaria kills twice as many people as HIV-AIDS, why does malaria receive only a fraction of the attention? Jha is determined to redress that inequity. “HIV-AIDS is something we treat, but malaria is something we cure,” he says, citing the now-standard combination drug therapy that can cure malaria if given promptly. The drugs are free in Indian public clinics and affordable in private ones. “Those malaria deaths should not occur. That’s why these findings are exceedingly important. What gets measured is what gets done.”

The findings on malaria and HIV-AIDS are only part of Jha’s Million Death Study, one of the largest studies of mortality ever undertaken anywhere in the world. Jha, the founding director of the U of T–affiliated Centre for Global

Health Research, created and designed the study to focus on India – a country that doesn’t require death registration and where most deaths occur at home without medical attention. Jha believed that visiting individual households and talking directly with family members was the only way to acquire the necessary information about how loved ones died. Not that he’s obsessed with death, he points out, so much as with death numbers. “People say to me, ‘Don’t you do depressing work, just concerned about deaths?’ Actually, no. By studying the dead you can get a real sense of the opportunities of life. The best investment for the health of the living is to count the dead.” Indeed, it was the data on lung cancer deaths in the West in the 1930s and ’40s that led to the link with smoking, and it was the statistics on unusual diseases killing young men in California and New York in the early 1980s that led to the identification of HIV. Public health measures ensued, preventing millions more deaths.

Jha, the Canada Research Chair in Health and Development at U of T’s Dalla Lana School of Public Health and the university’s Inaugural Endowed Professor in Disease Control, has long been fascinated by the power of mortality statistics to drive global health initiatives. Born in the industrial city of Ranchi in central-east India, he immigrated at age six with his family to Winnipeg, where his father worked as a civil engineer (and is now an NDP member of the legislative assembly) and his mother raised Jha and his older brother and younger sister. Jha, with twin interests in medicine and economics, received his medical degree from the University of Manitoba, then a doctorate in epidemiology and public health from the University of Oxford in England, where he studied as a Rhodes Scholar. It was during his time at Oxford that he became aware of the extent of the miseries of the global poor, when world-renowned epidemiologist Sir Richard Peto, Jha’s professor and mentor, spoke passionately about the huge burden of disease in developing countries from completely preventable factors, such as tobacco. It motivated Jha to want to research the issues further, and then turn that research into action.

While working in the mid-1990s at The World Bank, whose mission is to provide loans and resources to improve lives of people in developing countries, Jha chose India to study the link between smoking habits and smoking-related illnesses and deaths. Not only did he have a cultural connection, but he was interested in the impact of smoking in a country that was undergoing a massive transformation, with rapid development, increasing urbanization and a growing middle class. Jha discovered that Indian smokers tend to pick up the habit at a later age than smokers in the West. They tend to smoke less, and often still smoke locally manufactured cigarettes called *bidis* that contain only one-quarter of the tobacco of western commercial brands. Were Indian smokers therefore causing less damage to themselves than smokers in the West? While smoking mortality studies had been done in developed countries, no one knew the health impact of smoking in India.

Jha met with India's registrar general, whose government department oversees that country's census, to suggest a simple proposition: include a mention on an individual's death certificate of whether the deceased was a smoker or a non-smoker. But with only about 20 per cent of India's estimated 10 million annual deaths reliably registered, millions of people would still be missed. How, then, to reach those next-of-kin to ask about their deceased loved ones? "That's when we came up with the idea to apply verbal autopsy," Jha says.

Verbal autopsy involves asking family members about the events that preceded the death. Countries have long relied on information gathered through in-person household surveys. Such a method in India could go far beyond asking about smoking habits, Jha realized, and inquire about a range of signs and symptoms involving every deceased below age 70. (The cause of death among older people is more complex to ascertain, as there are often multiple symptoms.) This method had never been used on the scale Jha envisaged. Death is such a formidable event, he says, that it stays imprinted in people's memories. "Just think back on your own family experience of death, and you'll find you remember the details even years later," he says. When he asked his own grandmother, who lived in a rural village in India, about how his grandfather had died 20 years earlier, she recalled the details so vividly that Jha immediately identified the classic symptoms of a stroke.

India already had a "sample registration system," in which government-paid census takers would make monthly visits to each of about 200 homes in their district to ask about births, deaths and other changes in the household. Every six months an independent surveyor would repeat that work, to confirm the accuracy. Piggybacking on that system, Jha designed the Million Death Study to use those twice-yearly surveyors and train 800 of them to do verbal autopsies in 7,000 districts across the country. Their completed questionnaires would then be sent to two of 130 physicians to establish a probable cause of death. In case of disagreement, a senior physician would be the final arbiter.

Jha says the study, which coded 300,000 deaths in its first five years, has exceeded his expectations. The participation rate of the communities is close to 100 per cent – at least as high as Canada's response rate of 98 per cent in the 2011 census. Jha, who speaks Hindi and who has accompanied field staff on home visits, says communities have been quick to recognize the legitimacy of the study. While residents may be leery of a drug company rep, they trust the government field staff who tell them upfront that while the study probably won't be of direct help to the respondent, it may help identify health priorities that will benefit the community and may improve their children's or grandchildren's lives. Households become willing participants, offering warm hospitality and cups of chai. Jha says that in a sub-study of selected households on blood pressure, the participation rate was 105 per cent. "The neighbours showed up, clamouring over each other to say, 'Why aren't you including us?'" So we just included them all." He adds that Indians also respond well to the study's connection with the University of Toronto, an institution they respect that's situated in a city where everyone, even those in the smallest Indian towns, seems to have a cousin.

Since 2005, the Million Death Study has produced 15 publications in major medical journals such as the *Lancet*, the *New England Journal of Medicine* and the *British Medical Journal*, as well as four major reports in both India and Canada. The publication of each new finding has resulted in a hail of publicity, with crowded media conferences, TV reports and front-page headlines in India and beyond. Smoking was named a much bigger risk than previously thought: Jha combined his own findings with government statistics to report that 70 per cent of smoking-related deaths occur in middle-aged people aged 30 to 69; even a few *bidis* or cigarettes a day may be lethal; smoking is a leading cause of tuberculosis; and oral cancer, highly related to smoking and chewing tobacco, is higher in women than men. Citing these results in Parliament, the country's health minister successfully introduced warning labels on cigarette packages, soon followed by higher tobacco taxes.

Jha and his researchers also found that while selective abortion of females following prenatal sex determination is growing in this country that favours boys, families generally don't act on it with the first pregnancy. If that child is a boy, families will often happily accept a second child of either sex. But if that first child is a girl, a significant minority, especially among educated wealthy families, will opt for selective abortion with the second pregnancy in their quest for at least one boy. The study, to which media outlets attached the headline "Ten Million Missing Girls" (now up to an estimated 12 million over the past 30 years), has caused an ongoing heated debate in India that has reached into popular culture, Jha says. "The Indian soap operas have started covering this issue, with the strong-willed pregnant daughter-in-law resisting pressure from her equally strong-willed mother-in-law and the husband in between." He adds that evidence is emerging,

NUMBERS FROM THE MILLION DEATH STUDY

Estimated annual deaths in India from malaria:

15
THOUSAND
(WORLD HEALTH ORGANIZATION)

vs

200
THOUSAND
(THE MILLION DEATH STUDY)

Participation rate of selected households in a study on blood pressure:

105%

Publications in medical journals since 2005:

15

Number of major reports published in India and Canada:

4

partly as a response to the debate, that the practice has begun to slow in the northern states.

Among the most recent findings from the Million Death Study: the number of suicide deaths in India has been underestimated, especially among the 15–29 age group; unintentional injuries such as drowning kill more than 82,000 children under five every year, which is up to three times more than previously thought; and simple, affordable prenatal care could prevent one million newborn deaths caused by prematurity, infections and birth trauma.

The study has raised not only awareness but also controversy, particularly with regard to the malaria findings. The World Health Organization, whose malaria numbers looked like an embarrassingly low underestimate, came out with a statement asserting that while verbal autopsy may be efficient for some causes of death, it's poor at differentiating malaria from other fever diseases, such as septicemia, encephalitis or pneumonia. Nata Menabde, the WHO's representative in India, told reporters, "The new study uses the verbal autopsy method, which is suitable only for diseases with distinctive symptoms and not for malaria."

But other specialists have hurried to the study's defence. Dr. N.K. Ganguly, the former director of the Indian Council of Medical Research, says that while some may question the reliability of verbal autopsies, there's no denying that the results correlate with local doctors' reports as well as with the seasonal variability of mosquitoes. And Dr. Roger Glass of the U.S. National Institutes of Health says, "It's important that we not underestimate malaria deaths, particularly among adults living in rural areas." He adds that the study indicates that population-based disease surveys are valuable. Jha, who in the early 1990s served as senior scientist at WHO, says that the Indian government has now set up an independent

task force to verify malaria deaths. He adds, "I think they'll come up with something much closer to our estimate than the WHO estimate, and that in turn will get the government to say, 'We should do something about it.'"

The Million Death Study is scheduled to continue until 2014, but Jha predicts that because the data-gathering system is solidly in place, data collection will continue well beyond that year, eventually coding many more than one million deaths. He expects future findings may cover health data that have previously gone unnoticed or under-reported. For instance, although coronary heart disease is considered to be the leading killer in wealthy, developed countries, it's also proving to be the number 1 cause of death among poor, rural Indian men aged 30 to 69. Another area of interest is the role that alcohol may play in causing disease or accidental deaths. Alcohol consumption has been difficult to track in India because home production for self-use remains common. The study is also finding that snakebite deaths could be up to three times higher than current estimates, as many victims never make it to a clinic.

Currently logging four or five annual trips to India, Jha, a married father of two school-age daughters, plans to cut those visits back – especially as the Million Death Study becomes more automated and self-sustaining. He plans to turn his sights toward rolling out the program to other countries. The government of South Africa has expressed a keen interest, and several other African countries as well as China are lacking accurate death statistics.

"My dream project would be not the Million Death Study," Jha says, "but the Ten Million Death Study."

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THE HEALTH OF NATIONS

Why improving the well-being of people in other countries should concern Canadians

Global health is an area of study, research and practice that aims to promote the improvement of health of people around the world. It includes the traditional areas of medicine and public health, and now crosses disciplines, engaging researchers in fields as diverse as economics, sociology, management, international development and engineering.

At U of T, the Faculty of Medicine is forging partnerships with other disciplines – and with universities in developing countries. For example, the department of psychiatry has partnered with Addis Ababa University to create Ethiopia's first psychiatry residency program – raising the number of psychiatrists in Ethiopia, a nation

of 90 million, from 11 in 2003 to 41 today.

Global health has its own value in improving the lives of people in other countries. But in today's global economy, the repercussions spread far beyond national borders. Healthier, more stable societies become better business partners, says epidemiologist Prabhat Jha. "Canadian businesses won't get excited about working in countries where there are risks like malaria. Who'd want to go there?" Moreover, Canada, and especially Canadian universities, have a tradition of creating connections with other cultures – and long-term relationships with healthy societies can only improve collaborations that benefit both places, opening two-way doors for students and researchers. "If you think about global markets, it just makes sense for Canada to invest in global health because it improves our prospects," Jha says.

While once focused on epidemics such as smallpox (successfully eradicated since 1979), global health now looks to larger issues such as health equity. That includes improving outcomes

for people everywhere, including our own country, says Dr. Catharine Whiteside, dean of U of T's Faculty of Medicine and vice-provost, relations with health care institutions. "We don't separate issues of inequity in certain groups in Canada, such as aboriginal populations or people in lower socio-economic environments, from groups in developing countries," she says. "Many of the social determinants are very similar. By addressing those we can transform health care, whether for an elderly Canadian in the inner city or for a mother of several children in Kenya."

U of T is planning to create an Institute for Global Health Equity and Innovation, which, in addition to medicine and public health, will encompass disciplines such as management, global affairs, engineering and bioethics. Whiteside also hopes to enable the Dalla Lana School of Public Health to hold at least two more endowed chairs in health equity, as well as increase the numbers of global health scholars and fellowships. – MARCIA KAYE