

FEATURE

PUBLIC HEALTH

Coding a million deaths in India, one interview at a time

A huge 10 year study assigns cause of death by verbal autopsy, giving information essential for informing health policy, writes **Meera Kay**

Meera Kay *journalist, Bangalore, India*

“Most deaths in India occur outside hospitals and are not attended by doctors; nor are they medically certified,” according to Abhay T Bang, director of the Society for Education, Action, and Research in Community Health (SEARCH). “This crucial information is incomplete and often of poor quality.”

Knowing the cause of death is vital in formulating development strategies. “Without such information, governments, donors, and other development partners are proceeding in the dark,” says Alan D Lopez, director of the global burden of disease group at Melbourne School of Population and Global Health.

“They do not know the comparative importance of the various causes of health loss in their populations, for many of which cost effective interventions to prevent deaths, particularly premature deaths, already exist. And they do not know how effective are their efforts to address them,” he adds.

Registering all deaths and assigning them a medically certified cause is difficult. “Doctors are either not trained, not available, not competent, or not interested in certifying causes of death. And they are generally unfamiliar with the critical role that this information plays in generating evidence for health policy,” Lopez says.

One way to improve information in settings without a dedicated registration system is to use verbal autopsy to determine causes of death.¹ Verbal autopsy was used to determine cause of death among people younger than 70 in the recently concluded Million Deaths Study. Non-medical field workers were trained to record written narratives from families or other reliable informants in the local language describing the events that preceded the death. Answers to standard questions about key symptoms were also recorded.

Prabhat Jha, an epidemiologist from the University of Toronto and the director of its Centre for Global Health Research, was at the helm of the study, which was conducted in conjunction with the Indian Council of Medical Research and several Indian and global academic institutions. The study cost about \$1m a year and was funded by the US National Institutes of Health, the Canadian Institutes of Health Research, the Bill and Melinda Gates Foundation, and the International Development Research Centre.

Jha hopes that the information collected will not only help to track the nation’s health but also provide measures of the success of disease control programmes, improving accountability in spending and informing health policy and service planning.

Counting deaths the old way

The Indian government has three separate systems that collect data on deaths: the civil registration system, the sample registration system (SRS), and medically certified data. (The National Crime Records Bureau also records unintentional deaths and suicides.) The civil registration system is unreliable because many deaths are not registered² and it also gives no detail about deaths beyond attributing them to accident, violence, or disease.^{3 4} Medically certified data are unrepresentative because two thirds of deaths in India occur outside hospitals.³

The SRS has been providing fairly reliable data since the 1970s. India is divided into a million small areas of about 1000 people. The SRS randomly selects about 8000 of these, and resident part time enumerators record births and deaths in these village and urban blocks as they occur. The data are then checked in an independent six monthly retrospective survey by a full time supervisor.⁵ The SRS also collects data on marital status, occupation, education, alcohol use, and other risk factors for disease.⁵

Value of verbal autopsy

Since 2000, verbal autopsy has been included in the SRS as part of the Million Deaths Study. The study sent the narratives recorded by the resident field workers to two doctors, randomly selected from a pool of 300 trained assessors, who independently assigned a probable underlying cause of death to each case with a code from the 10th edition of the *International Classification of Diseases*.⁵

If the doctors suspect different causes, they are given each other’s notes and review the cases. A senior doctor resolves any persistent disagreements. The interviews assume that most causes of death have clear cut symptoms and signs that can be recalled and relayed by family members or attendants.⁵

Jha says that most deaths below the age of 70 are avoidable, especially in childhood. “Our earlier work shows that households recall [the cause of] deaths even up to five years well, except for very early neonatal deaths and deaths in old age . . . where recall is more complicated. This is because deaths are such a memorable event,” he adds.

Although the study has surveyed less than 1% of the population (about 300 000 people in 1997-2003 and 650 000 in 2004-14) it is designed to give representative results. The key measure of quality of verbal autopsy is reproducibility, Jha says. The autopsy reports for about 3% of the deaths were randomly resampled by a team of 60 staff reporting to the lead researchers, and they generated similar results to those of the local field workers.

Verbal autopsy has been used by other researchers in India to estimate cause specific mortality in small samples.^{3 6 7} These show that the method has a sensitivity of 94%.

Understanding deaths is not easy

Once analysed, the data collected by the study are supposed to guide policy making. But Lopez is critical of how data have been released so far, “The MDS [Million Deaths Study] has only reported the data collected for 2002-04, and even then not the full ICD detail that would allow a more comprehensive interrogation of the data and the extent to which they are fit for purpose.

“Rather, the data have been used to investigate specific health issues, such as malaria, and the authors’ findings—but not the detailed data—have been published in scientific journals.” Other analysts, using alternative methods and with different perspectives, might conclude something different or quantify uncertainty around outcomes differently.

In a study published in 2010, the study attributed 200 000 deaths to malaria in India. The authors said, “Despite uncertainty as to which unattended febrile deaths are from malaria, even the lower bound greatly exceeds the WHO [World Health Organization] estimate of only 15 000 malaria deaths per year in India (5000 early childhood, 10 000 thereafter).”⁸

This almost 15-fold difference is concerning. “While we cannot confirm the microbiology . . . we are certain that this was an acute fever death, not just in kids but in adults,” Jha says.

“When we look at the patterns of falciparum malaria, they occur in nearly exactly the same places as fever deaths, at least as of 2005 . . . We have other pieces of evidence, such as routine blood parasite surveillance data collected in each district by the National Vector-Borne Disease Control Programme, to examine if these acute rural fever deaths were malaria or other causes,” he says.

Other information published from the study has not led to obvious changes in government policy or allocation of resources.

Future use

Verbal autopsies are far simpler and more economical—at about 120 Rs (£1.20; €1.60; \$2) a household a year—than other methods of recording death. The SRS will therefore continue to use verbal autopsy even though the Million Death Study has concluded.

“The tool is already in use in Mumbai and other settings,” says Jha. “We are also modifying the verbal autopsy tool and training to help doctors to fill out death certificates in hospitals correctly,” he added.

However, although the technique works quite well for deaths in young and middle age, Jha admits that it “does not work so well after age 70, when there may be multiple conditions contributing to death.”

Colin Mathers, coordinator of mortality and burden of disease at WHO, wrote in 2009, “Such methods naturally produce more uncertain attribution of cause of death than physician diagnosis.

“Categorical assignment of cause of death is inherently difficult for diseases without distinctive symptoms, such as malaria in children, or some forms of cardiovascular disease in older adults. WHO is working to standardize verbal autopsy instruments for use with children and adult deaths.”⁹

Information on cause of death is important and has had a big effect on public health worldwide. The hazards of smoking, particularly lung cancer, were highlighted after research on deaths from lung cancer around the time of the second world war.¹⁰ Similarly, routine analysis of cause of death showed an increase in immune related death in young men in San Francisco in the early 1980s, marking the advent of the US HIV epidemic.¹⁰

Nevertheless, registration is a huge undertaking, and some poor rural parts of the United States did not routinely record cause of death until 1975.¹⁰ While countries should of course develop formal registration systems, they will not yield reliable estimates of causes of death for decades. Till India registers all deaths with medical certification, random sampling of deaths with verbal autopsy is an attractive proxy.

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