

Malaria deaths are the hardest to count

How do you count the number of people who die of malaria in sub-Saharan African countries, where data collection systems are often rudimentary, and where childhood fever and other illnesses are typically attributed to malaria?

In the early hours of the morning, Aurola Ngueve strapped her feverish daughter to her back and walked almost three kilometres to a tiny Angolan government health post, a white concrete structure sitting incongruously amid the mud huts of the village of Muinha in central Bié province.

In the rudimentary examination room, Aurola anxiously tells the *Bulletin* that 18-month-old Rosalina, who is screaming as a nurse takes a tiny blood sample from her finger, has had chronic diarrhoea for days. Fifteen minutes later, Aurola receives the dreaded, if not unexpected, news. Rosalina has malaria.

Malaria is believed to be one of the chief culprits behind Angola's appalling child mortality statistics. UNICEF estimates that one child in four in this south-western African country is unlikely to live beyond his or her fifth birthday.

Rosalina is one of the lucky ones. At this health post, run by the Health Ministry and supported by nongovernmental organization Médecins Sans Frontières, she has been accurately diagnosed and prescribed medication. Her personal details, symptoms, diagnosis and treatment have been entered into a logbook, and the nurse is confident that with the right care she will bounce back to health in a few days.

But just how many children will slip through the net? How many will never be properly diagnosed, and how many will eventually succumb to this mosquito-borne disease which is, in theory, easily preventable? If only we knew.

In the developed world, where causes of death are registered, collecting mortality data is relatively straightforward. In developing countries and

particularly in sub-Saharan Africa, where malaria is believed to claim most of its victims, the process is far more complicated. And this process becomes more problematic still with a disease like malaria which typically afflicts children, whose immune systems are still underdeveloped, and whose symptoms — fever, vomiting, aches and pains, and diarrhoea — could be attributed to innumerable ailments.

“We need reliable malaria statistics to be able to target control resources and evaluate their impact.”

Allan Schapira, Coordinator in WHO's Global Malaria Programme.

“The major problem with malaria is that it is very difficult to measure its burden, as it is so unspecific and most kids have parasites [in their blood] in high transmission areas,” says Dr Kenji Shibuya, Coordinator of the Health Statistics and Evidence team at WHO.

Establishing “the burden” or in other words establishing just how many people die of this disease is crucial in light of the Roll Back Malaria campaign target to halve malaria mortality by 2010 and again by 2015 and the Millennium Development Goal to halt and reverse the incidence of malaria by 2015.

Yet both the statistics on which these goals stand and the methods for measuring progress towards them can be called into question.

“The fundamental problem of malaria control was the lack of good baseline data,” Shibuya says, referring to the data against which changes in incidence and the number of deaths can be measured.

Often the issue is not malaria-specific. Getting data on all diseases in developing countries is challenging because large sections of the population never set foot inside a medical facility, their ailments and deaths going largely unexplained and unrecorded.

Even if they make it to a health post, persuading busy staff working in difficult conditions to fill in basic patient logs can be tough, especially if they view it as an administrative chore which prevents them from treating the sick or they have no paper or pencils to take down the details.

Then, analysts are often forced to adjust and harmonize already questionable numbers in an effort to make them internationally comparable or tally with other causes of death.

But gathering mortality data on malaria is more problematic than most diseases.

Given that the burden falls on young children — an estimated 90% of malaria deaths in Africa occur in children aged under five years — a principal indicator of the trend in malaria-related deaths recommended by the Roll Back Malaria Partnership is all-cause under-five mortality, routinely measured in malaria-endemic countries by nationally representative community-based demographic and health surveys (DHS).

In its favour, this method should capture so-called indirect, malaria-related mortality — or how malaria contributes to child mortality by exacerbating other common childhood illnesses, by contributing to low birth weight and generally weakening children as a result of repeated or chronic infections.



Angolan mother Aurola Ngueve holds Rosalina while the child is tested for malaria.

Karen Iley

As Bernard Nahlen of the Global Fund to fight AIDS, Tuberculosis and Malaria told the *Bulletin*: “In children in high-endemic areas, indirect, malaria-related mortality may be just as or even more important than the burden of acute, direct malaria-attributable mortality — but it is even more difficult to measure.”

To further clarify the picture, WHO recommends that specific, direct, acute malaria-attributable mortality also be tracked. This is done mainly through demographic surveillance sites (DSS) where disease and deaths are continuously monitored in selected populations and cause of death is ascertained by interviewing bereaved relatives.

A synthesis of available data by WHO and the US Centers for Disease Control and Prevention (CDC) published in 2005, showed that direct malaria-attributable mortality in sub-Saharan Africa among children aged under five years accounted for about 18% of all deaths in this age-group, or between 700 000 and 900 000 children.

However, even these “latest” figures refer only to 2000. With surveys and

precise longitudinal monitoring costly to implement and difficult for poor countries to sustain, it often takes a long time to collect and analyse enough data for a reliable estimate, while problems in data availability and interpretation make comparisons between subsequent estimates difficult. DSS are also typically small-scale, and extrapolation to the wider continent needs to make use of malaria risk maps.

Summing up the problem, Nahlen says that extrapolating malaria mortality rates to the wider continent is “fraught with difficulties”.

Malaria is such a nebulous disease that the chances of getting the numbers wrong are great, and this may adversely affect decision-making.

“We must have accurate mortality and case data so we can evaluate programmes and see the effects of interventions,” says Angus Spiers, UNDP’s Global Fund Malaria Advisor in Angola.

How will WHO and governments know if funding is headed to the right areas? How will they know if interventions such as insecticide-treated

mosquito nets are working? And how can they determine how much more money needs to be spent on combating the disease?

“We need reliable malaria statistics to be able to target control resources and evaluate their impact,” says Dr Allan Schapira, Coordinator in WHO’s Global Malaria Programme. “As long as the distribution of the problem is known and funding is available, the resources will be channelled to those in need, provided that the delivery systems can do the channelling. However, a gross underestimation in a particular area may cause insufficient funding of a given programme.”

No one doubts that malaria places a heavy burden on the countries that can least afford it. But to know just how big a toll the disease takes and whether the projects that are currently in place to fight it are actually working, requires more ingenuity and investment than had perhaps been anticipated, when the Roll Back Malaria movement was initiated, Schapira says. ■

Karen Iley, *Lusaka*

Mexico’s quest for a complete mortality data set

On 1 November cemeteries across Mexico are packed with the living. Death has a special place in Mexican culture, especially on the Day of the Dead — El Día de los Muertos. But while a culture that accepts death may smooth the task of collecting mortality data, poverty is a major obstacle for Mexico in its quest for a complete data set.

Mexico has been recording deaths in registers for more than 100 years, but it was not until the 1950s that the country developed a death certificate system.

“There are two moments when people die [on paper],” says Dr Rafael Lozano, General Director of Information at the Mexican Ministry of Health. “One is the certification of the death and the second is the registration. Before 1950 we only registered death without certification.”

Certification means that a doctor examines the deceased and determines the cause of death. With registry, a person was often listed as dead, but without a cause of death, Lozano says: “So we have a long history with problems of quality before 1950, and also problems of quantity.”

About 500 000 out of a population of 103 million die every year. Since

the 1980s, more than 90% of the dead have been counted due to this switch to a death certification system. In the ’50s, ’60s and ’70s mortality data was only 70% or 80% complete. In the WHO European Region coverage is about 100%, while in the WHO African Region it is less than 10%.

To help WHO’s 35 Member States in the Americas improve their mortality data, the Pan American Health Organization (PAHO) launched the Regional Core Health Data and Country Profile Initiative in 1995.

Dr Roberto Becker, Regional Advisor on Diseases Classification at PAHO in Washington, DC, explains that although most deaths are logged with a civil registry, the cause of death — recorded in the certification process — is often missing. As part of the 1995 initiative, Becker travels to the countries in PAHO’s region to teach health officials how to improve coverage in quality data.

“We don’t have 100% coverage. But we are very close,” Lozano says, citing a study published in the *Bulletin* [2005:83;171–77] that ranks Mexico among 23 countries with high quality data and 90% or more complete death registration. Venezuela was also in that group while the rest of the PAHO region had lower coverage.

Since 1950, Mexico has used the WHO-recommended death

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Dr Rafael Lozano, General Director of Information at the Mexican Ministry of Health.



A man rearranges the bones of his son in a cemetery in Yucatan Peninsula, Mexico. Families clean relatives' bones to prepare for the Day of the Dead, when Mexicans welcome the souls of the dearly departed back to earth. The celebration mixes Indian traditions and the Roman Catholic Church's All Saints' Day.

certification system to fall in line with international standards. This allowed comparison with other countries following the same protocol. Initially, another government agency did the counting. In 1985 that task was moved to Lozano's office.

Having established more accurate ways of determining the numbers and causes of death, Lozano says, the challenge today is to increase coverage.

Current efforts are focused on rural areas where poverty and inadequate infrastructure are major obstacles. "Our main problem is infant mortality," Lozano says. "We have problems with statistics ... when a child is born and when a child dies."

Counting the dead is crucial for a number of reasons.

"To count the deaths according to the cause and ages gives you an idea of what's going on with the population and how you can develop health priorities for intervention programmes to reduce deaths in those areas," says John Silvi, a statistician at PAHO. "For instance in Mexico, diabetes is an extremely important cause of death."

Lozano explains that Mexican

health officials use these data to allocate resources and to manage health-care programmes. For instance, in one programme in Mexico, a formula is used to allocate some of the funding, and mortality is one of the variables. In addition, the Ministry of Health can study the data to check for epidemics and other health problems.

Each of Mexico's 32 states, too, uses its mortality figures to set priorities for health policy, and the data are also used during Mexico's annual Health Week. "Deaths are part of the calculations that almost everybody uses," Lozano says, "and not just in the public health sector, but also in the private sector."

When someone dies, the family usually notifies health officials. A doctor will certify the death, determine the

cause and give the family the certificate. That's easy enough if the person dies in a hospital or nursing home.

"If not, it's more difficult be-

cause you have to call a private doctor," Lozano says. The doctor may charge 500 pesos, which is about US\$ 45, and most poor families can't afford that, but the Ministry of Health can't prohibit doctors from charging. "It's a problem for rural areas or very poor families," Lozano says.

Next the family calls the funeral parlour, which fetches the body, and that starts the process of administrative registry. A relative must then go to the office of civil

registration and exchange the certificate for the "acta de defunción." The acta is the only one of the two that is legally valid.

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The certificate, meanwhile, goes to the Ministry of Health. One copy goes to Mexico's National Institute of Statistics and Geographical Information (INEGI) and the other stays in the civil registry office. The Ministry of Health's forms are coded monthly by doctors assigned for just that purpose according to International Classification of Disease rules, and for its part, INEGI compiles monthly statistics.

Later on, Ministry of Health officials classify the data by cause of death and other factors, Lozano says.

Two types of families don't report: those who can not afford to call a doctor

and those who live too far away from an administrative centre.

"This lack of reporting is most frequent in a rural environment," says Lozano, adding that the Ministry of Health can not force people by law to report.

Mexico's Ministry of Health has tried to educate people in hospitals and other facilities in some parts of the country about the need to report every death. Lozano says that the non-reporters represent a small number of people and that, overall, figures are accurate.

Mexico's mortality data has, among other things, helped to highlight the gaping disparities between poor and

affluent in this middle-income country.

Although average life expectancy in Mexico is 75 years for men and 77 for women, there is a wide range of disparity between rich and poor. For adults the main causes of death tend to be chronic diseases, such as diabetes, heart disease and stroke. For children pneumonia is still a leading cause of death, while perinatal problems are a big killer of newborns.

"The problem ... is the gaps within the country," Lozano says. "The difference [in life expectancy] between the poorest and the richest states in Mexico is something like 11 years." ■

Theresa Braine, *Mexico City*

Counting the dead in China

In China, home to 1.3 billion people, or one-fifth of the world's population, complete registration and medical certification of every single death is, at present, logistically and financially unattainable. As part of a major revamp of its health information system, China is merging two systems for collecting mortality data to gain a more accurate picture of how many people die and why.

Cause-of-death data are playing an increasingly important role in the public health policy of China.

"When we have this kind of information, we can see how patterns have changed," says Dr Wu Fan, Director of the National Center for Chronic and Noncommunicable Disease Control and Prevention, China's Center for Disease Control and Prevention (CDC). Recently, CDC took part in a research

project led by the Center for Statistics of the Ministry of Health on the disease burden and long-term health problems in China; the results were dramatic.

"Now we know that infectious diseases are lower, and noncommunicable diseases are greater, and that in rural areas injuries are increasing. We can know which population has major problems and so we can target them, and we can know which diseases will have a long-term impact. This helps us to understand what our priorities should be."

Cause-of-death data have led to a better understanding of changing disease patterns in China, but public health officials are still forced to hazard a guess at disease patterns in the less-developed west, where mortality data are scant to non-existent.

China has two systems to count deaths: the Ministry of Health (MOH) vital registration system and

the disease surveillance point (DSP) system, which is monitored by the country's CDC.

In 2003, there was a growing concern that the DSP system was not reflecting the true situation across the whole country. "The problem with the DSP system is that currently it's not completely representative of China," says Dr Wu. "They [disease surveillance points] tend to be in developed areas and cities along the more prosperous east coast, and less in the rural areas in the less-developed west."

Furthermore, at that time the DSP system was being used only in

areas with a population range of 20 000 to 100 000, and nationwide covered just 1% of the population. "That was a very obvious weakness," Dr Wu says, adding that because of the small sample base, the numbers for rare diseases were not stable, and changed every year.

Since it was launched in 1989, the DSP system has reported on causes of death through a mix of verbal autopsy and medical certification. Many indicators were not reliable, and the

system needed to be readjusted.

Over the last two years, adjustments have been made to the DSP system. The number of sample sites has risen

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Yang Yankang

Two boys stand in front of their grandfather's coffin in Sanyuan county, Shaanxi Province in 1998. The boys are wearing gifts given to them by family members who have come to attend the funeral, a local custom. A hooded mourner is dressed in white, the colour of mourning in China. People in cities are usually cremated, but rural residents prefer to be buried.

slightly to 160 all over China from the initial 145. This makes the DSP system more representative because sites are selected on the basis of the census data to make them better reflect the entire population.

“We are now trying to make the system more representative of the whole of China and add more sites in the north and west, and especially in poor areas,” Dr Wu says. She says that China has extended the DSP coverage of the population to 6% of the nation. In addition, Dr Wu says that if government departments collaborated more closely, gathering such data would be easier.

The Chinese Government is planning to merge the DSP and vital registration systems — which are already complementary — to reduce running costs and increase efficiency; last year, unified guidelines were drafted to do this and software was created.

The two systems will continue to run for several more years before being merged, according to Wu Xiaoling, Director, Division of Statistics, Center for Statistics Information at the Ministry of Health. Ms Wu says that the delay is due to the need to train more doctors to certify deaths. The merger will also depend on when the DSP system is able to provide data that can be converted into usable statistics, Ms Wu says.

Ms Wu says that in a large country such as China, it was often difficult to gather statistics. “In western China there are not enough personnel, and infrastructure may be lacking,” says Ms Wu. “Or there may be snow in the winter, and it is difficult to get the information you need.”

Before 1950, the only causes of death reported were tuberculosis, measles, acute infectious diseases, “infant disease”, respiratory disease, heart disease, “urinary disease”, digestive disease, stroke and ill-defined causes and these data covered only Beijing and Nanjing. Cancer was not listed.

In 1957, death registration was expanded to other major cities, including Shanghai, Tianjin, Harbin and Wuhan, according to a study by Yang et al. published in *Population health metrics* (available at: <http://www.pophealthmetrics.com/content/3/1/3>).

1. China’s vital registration system started to record the fact and cause of death in 1987, classifying by ICD-9 (International statistical classification of diseases and related health problems). In 2002, the vital registration system started reporting according to the ICD-10 rules. This system now covers 41 cities and 85 counties and roughly 8% of the national population.

There are many challenges to obtaining a more complete picture of the number of people who die and why in China. About

70% of people die at home, and this can make it difficult for a local doctor to determine the cause of each death and make an accurate report due to distances and unfamiliarity with each case. And there are not enough doctors who are adequately trained to do this. In southern China, especially in rural areas, access to hospitals is difficult and for cultural reasons people don’t always want to die in hospitals, preferring to stay at home.

There are two types of doctors in China: one is trained in a similar way to doctors in developed countries and the other — the village doctors — have basic education from a junior college. “We have to rely on them, or we could not do our work,” says Dr Wu referring to the village doctors, adding that the current system “is better than nothing.” But she says that these personnel need to be trained and retrained.

One challenge to gathering meaningful statistics via the DSP system is that the sites are included on a voluntary basis. That means communities volunteer to collect data on their populations and these communities tend to be in more affluent areas.

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Another problem is that when a person dies at home in rural areas, a village doctor visits the family and asks about the person’s symptoms before he or she passed away as part of a verbal autopsy and write their findings based on those symptoms. Formal death certification — the most reliable method for ascertaining cause of death — has been introduced in such areas, but the quality needs further improvement, Dr Wu says.

“Using these symptoms, we can later speculate on the cause of death,” says Dr Wu, referring to the findings of these verbal autopsy reports. The village doctor’s report is sent to the local Centers for Disease Control and Prevention, where it will be checked. If any problems arise, they will refer back to the village doctor for clarification.

One or two medical personnel then do the coding and enter the data into a computer for input into the national computer system. Local Centers report to the provincial and national Centers for Disease Control and Prevention once every three months, up from the previous once a year. “At every level, we have quality control measures,” says Dr Wu. ■

Paul Mooney, Beijing



Yang Yankang

A funeral procession winds its way through the snow-covered fields of Jingbian county, Shaanxi Province, carrying large funeral wreaths in 1998. As is the custom in China, family members carry portraits of the deceased at the head of the procession.