

Studies of HIV in African communities

Born, lived and died - but counted or not?

Vital information for vital statistics

Much of the developing world, especially sub-Saharan Africa, is characterised by incomplete or no vital registration systems. With the majority of deaths occurring at home in such poor settings, they are usually not registered and causes of death are hardly ascertained. The unavailability of cause-of-death information in these areas limits efforts to establish a solid evidence base for health policy formulation. It also presents significant challenges for effective planning, monitoring and evaluation of health care delivery systems.

Over the past two decades, a number of field research sites have adopted, tested and continue to refine a technique called "verbal autopsy" (VA) to derive information on causes of death in remote rural settings in sub-Saharan Africa and South-East Asia. Together with recently developed computer-based programmes to facilitate a consistent assignment of cause(s) of death, the method has become an attractive alternative to potentially fill a sizeable chunk of the health information gaps that exist in the world's poorest nations.

VA is an indirect technique of ascertaining biomedical causes of death from information on signs and symptoms, as well as circumstances preceding death, obtained from a lay interview of the deceased's main carer prior to death. It involves the administration of specially designed questionnaires by lay, but trained, enumerators to solicit the necessary information. Each case is reviewed by at least two qualified physicians to assign direct and underlying causes of death. Only concordant causes are adopted, and discordant reviews are returned with an undetermined cause of death.

This method, therefore, has great potential for generating the much needed cause-of-death data that is vital for health planning, intervention design and implementation, as well as for ensuring equitable resource allocation in settings with incomplete or no vital registration. This has been demonstrated in many, albeit small, demographic surveillance sites in sub-Saharan Africa, and sample registration systems in India and China.

The VA procedure demands considerable human resources. Its use of physicians to review cases and assign cause of death has restricted its applicability to the research

setting where it has evolved over the past twenty years. With the alarming levels of doctor-population ratios in the areas where the VA method is most suited, the few available physicians will be better utilised treating the sick than reviewing VAs. As a result, scaling up of the use of VA beyond the current research setting can only be achieved with the adoption of an efficient alternative to physicians for assigning causes of death. Computer-based algorithms have been designed to rapidly process symptom-level information from VAs and produce consistent outcomes of probable causes of death. The InterVA model is one such programme that has been widely tested and validated in Africa and Asia. Designed to support the most widely used VA questionnaire with little human resources requirement, it has demonstrated much promise as the main avenue for the scaling up of VA through sample registration with a view to making cause-of-death information available at district, provincial and national level within a short period of time.

With the need for population-based cause-of-death information becoming increasingly urgent for effective health care planning and resource allocation, the time has come for the relevant policy decisions to be taken and backed by the appropriate legal framework to adopt the available standard VA questionnaire and the InterVA model to scale up and integrate VA into national vital registration systems.



A fieldworker conducting a verbal autopsy interview in rural Gambia. Main carers of deceased residents of a demographic surveillance area are visited at least 40 days after death to answer questions relating to circumstances in the few days or hours leading to the death. The information gathered forms the basis for determining the probable direct and underlying causes of death; and is collectively used to inform local health authorities about the cause-of-death distribution in the area for effective health intervention planning and evaluation.

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Who is counting?

The fifth Millennium Development Goal (MDG5) aims to reduce maternal mortality by three quarters between 1990 and 2015. However, measuring progress towards this target is proving challenging. In practice, MDG5 is being measured country by country, assessing at national level whether each one is achieving the target.

Maternal mortality is commonly assessed using the maternal mortality ratio (MMR) which is the number of women dying during pregnancy or immediately afterwards, whose deaths are somehow connected to their pregnancies, divided by the number of babies born alive within the same population. Unfortunately, very little is known about the number of such deaths in many countries and consequently, MMR is often estimated using mathematical models developed by experts at the global level.

Such models can provide predictions of MMR for each country, based on the relationship between maternal mortality, the level of fertility, gross domestic product (GDP), HIV prevalence and other indicators which are thought to be easier to measure. But how confident can we be with these modelled estimates? They may be useful in the absence of anything better, but the results do need to be interpreted with caution. Mathematical models are only as good as the data on which they are based, and in the case of maternal deaths, these data are often very poor.

According to the WHO, about 148 countries out of a total of 172 have conducted surveys in which women were asked questions about their sister's experience of maternal mortality, or have other direct data on maternal deaths – the rest are totally dependent on modelled estimates. Of the 148, 110 have data from the last 10 years and the rest rely on trend extrapolation. Furthermore, the complex modelling methods are hard for most people to understand.

A big uncertainty in these models is the relationship between HIV and maternal mortality. If an HIV-positive woman dies during pregnancy, it is hard to judge whether her pregnancy might have aggravated her HIV-related illness, or whether she would have probably died irrespective of being pregnant. This information can only come from community-based data detailing mortality among a range of women whose HIV status and pregnancy status is well known at the time of their death.

Research sites in the ALPHA and INDEPTH networks have rich data on people living in well defined areas in Africa, together with their causes of death. Each site can contribute to overall understanding of maternal mortality by calculating MMRs and comparing these to modelled estimates to help ascertain whether the MMRs produced by the models are reasonable. Furthermore, using HIV status data from the ALPHA sites, provides a unique opportunity to gain a



A mother carrying her child to the maternal and child health clinic at Kisesa health centre in Tanzania. The data from the various ALPHA Network sites provide unique opportunities to gain a better understanding of the relationships between pregnancy and HIV, and therefore improve the design of models.

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We could only manage without models if reliable national data for every country were available, and this is still a major challenge for many developing countries. Meanwhile, data from areas within countries lacking national data can be used to validate current models and provide better estimates of the parameters driving the models.

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See also

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The ALPHA Network

The ALPHA Network aims to maximise the usefulness of data generated in community-based longitudinal HIV studies in sub-Saharan Africa for national and international agencies involved in designing or monitoring interventions and epidemiological forecasting.

The project links several existing HIV cohort studies and runs training workshops to facilitate replication of analyses of demographic correlates and consequences of HIV infection previously published in just one or two sites. Comparative studies and

meta-analyses are undertaken on comparable data sets, imposing a common format on data collected and stored in a variety of ways.

α - network

**Analysing
Longitudinal
Population-based
HIV/AIDS data on
Africa**

How do we know who dies of what?

Not all deaths in the world are handled in the same way. In many countries there is a legal requirement for a doctor's certificate stating cause of death. But in other places, deaths are handled less formally and no cause is recorded. For health planners, though, cause-of-death information is very important. So when the cause of a death is not formally recorded, another approach is to later interview family and friends about the circumstances of the death. Then their information can either be considered by a doctor, or fed into a computer model, to decide the likely cause of the death. This process is called "verbal autopsy" – not perfect, but much better than nothing.

What is killing pregnant women?



Antenatal check-up in a maternity clinic in Kenya. To reduce and bring down the high maternal mortality, the government has to address several challenges including the need to ensure the availability of adequate maternity services and skilled personnel to attend to complications caused by unsafe/induced abortion, malaria, and HIV/AIDS, among others. © Peter Barker/Panos

Every year, half a million women die of pregnancy related causes. These deaths have long term devastating effects for surviving children and families. We all know that pregnant women are at risk of death from direct obstetric causes such as obstructed labour, excessive bleeding or severe infection after delivery. This has led to the prevailing perception that pregnant women are more vulnerable than non-pregnant women. However, most of these pregnancy-related deaths are preventable by well-established health interventions and therefore, such loss of young women's lives is inexcusable. What about other causes of death unrelated to pregnancy such as tuberculosis, viral/ bacterial infections, pneumonia, etc.?

It may be surprising to learn that pregnant women die much less from these causes as compared to women who are not pregnant. The reason why pregnant women are at a lower risk of death from causes unrelated to pregnancy is because in general, women who are able to get pregnant tend to be healthier than their counterparts of similar ages who are not pregnant. Given that

pregnant women are young and healthier, why is it that we do not see pregnant women's initial health advantage translate into significantly lower mortality as compared to non-pregnant women on the whole? A simple answer is that healthy pregnant women are subjected to significant levels of additional risk from direct obstetric causes that are preventable by medical and public health interventions.

Policymakers and the medical community need to focus on preventing mortality from such pregnancy-related causes. The research community can play a key role in this endeavour by undertaking a careful examination of the causes of death in pregnant women. A key limitation in this regard is the lack of good cause-of-death information that distinguishes direct obstetric causes of death from those arising from causes unrelated to pregnancy. One way to address this gap is to make better use of verbal autopsies collected by several demographic surveillance sites (such as ALPHA Network and INDEPTH sites) to identify the direct and indirect causes of maternal mortality. Quantifying excess

mortality due to preventable causes will help policymakers design prevention and treatment programmes to decrease the excess burden of maternal mortality.

Urgent action is needed to stop this unnecessary loss of healthy women, especially if the Millennium Development Goal of lowering maternal mortality by 75 percent by 2015 is to be achieved.

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INDEPTH



The International Network for the Demographic Evaluation of Populations and Their Health in Developing Countries (INDEPTH) is

a global network of members who conduct longitudinal health and demographic evaluation of populations

in low- and middle-income countries (LMICs). INDEPTH aims to strengthen global capacity for Health and Demographic Surveillance Systems (HDSS), and to mount multi-site research to guide health priorities and policies in LMICs, based on up-to-date scientific evidence.

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How do we know if someone has died from AIDS?

Ongoing investment in HIV prevention and treatment systems requires evaluation of the success of these systems and in particular, monitoring trends in deaths due to AIDS. This in turn requires accurate data on the causes of death, and reliable methods for identifying deaths due to AIDS. Many countries where AIDS is a major cause of death have poor or non-existent vital registration systems and cause-of-death certification. This makes it difficult to accurately determine the numbers of AIDS deaths in these countries.

Verbal autopsies (VAs) can be used in the absence of vital registration to ascertain causes of death. Interviews are conducted with caregivers or other friends or relatives of the deceased who were living with or close to them during their final illness. Questions can be asked about the perceived cause of death and the health of the deceased prior to death, including key signs and symptoms of common illnesses. The data can be collected by trained interviewers, and then reviewed by a doctor or analysed by a computer programme to ascertain causes of death.

It can be difficult to identify deaths due to AIDS using VAs. This is because HIV affects the immune system and makes sufferers more at risk of developing other illnesses. It is often these illnesses that ultimately lead to death and it is the symptoms of these diseases that are usually reported by caregivers or friends during the VAs. In many countries, large proportions of the population have never had an HIV test, so the person being interviewed and the deceased themselves may not have been aware of their HIV status. In such

circumstances, it is difficult to ascertain deaths due to AIDS. Other factors, such as stigma associated with HIV and confusion over the meaning of medical terminology can further exacerbate these problems.

Research is needed to investigate alternative methods of collecting and interpreting data from VAs in order to increase the accuracy of identification of deaths due to AIDS. In particular, the development of simpler, shorter VA questionnaires, and standardised methods for their interpretation is important. The ALPHA and INDEPTH networks have collected VA data from several study sites from across the world and are currently working collaboratively to analyse their data. Prior knowledge of HIV status of many deceased persons in ALPHA sites can be used to improve diagnostic accuracy and address many of these issues.

Improved coverage of HIV testing and HIV and AIDS education services may also help to increase the number of people living with HIV, and their families, who are aware of their status, which would improve reporting of this during VAs. In the longer term, further investment in establishing vital registration, health records and death certification is also required.

In conclusion, obtaining accurate data on the frequency of deaths due to AIDS presents many challenges. This is because HIV affects the immune system so that those dying from AIDS suffer a wide variety of illnesses and symptoms. Furthermore, many people are not aware of their HIV status or that of their close family members and friends. Further work is required to improve methods for collecting and analysing VA

data in the context of the HIV epidemic and to improve coverage of HIV testing and HIV and AIDS education services.

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See also

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