

Developing and Validating a Standardized Verbal Autopsy Tool to Elicit Most Probable Cause of Death for Low- and Middle-income Countries

INDEPTH Network Secretariat



INDEPTH Network
Better Health Information for Better Health Policy

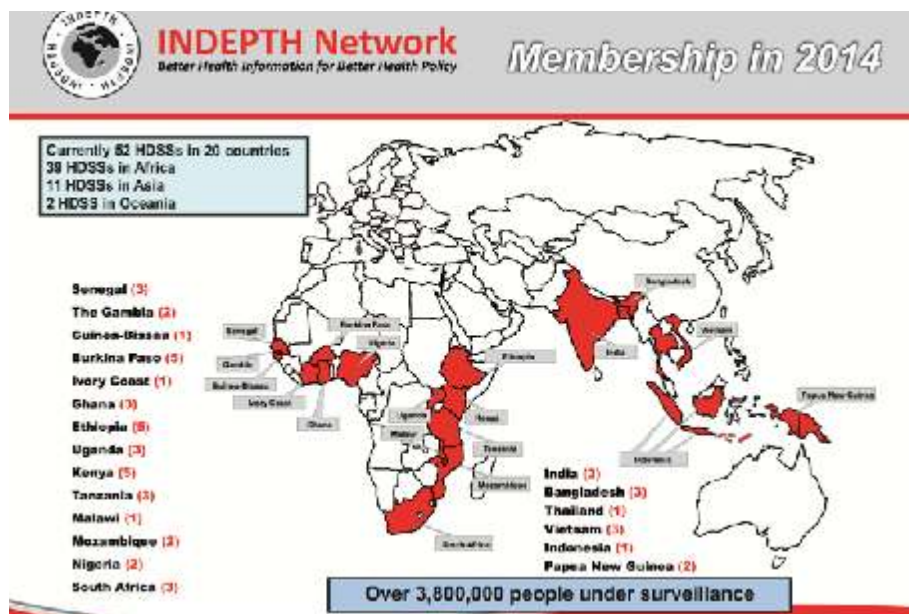
Introduction

INDEPTH is a global leader in health and population research, providing robust answers to some of the most important questions in development. The lack of a reliable information base to support the identification, prevention and treatment of health problems is a major hurdle to addressing the high burden of disease in low- and middle-income countries. INDEPTH — through its global network of 52 health and demographic surveillance system (HDSS) sites run by 45 research centres (including Dodowa HRC) in 20 countries across Africa, Asia and the Pacific region — is the only organisation in the world capable of developing that information base. It tracks a total population of over 3.8 million people, providing high quality longitudinal data not only about the lives of people in low- and middle-income countries (LMICs), but also about the impact on those lives of development policies and programmes.

Summary of the Impact

The INDEPTH Network, in collaboration with the World Health Organization, has developed a verbal autopsy (VA) tool for determining causes of death in settings where civil registration of vital statistics are incomplete or non-existent. This work has had significant global impact on national and international agencies, the global research community, and indirectly on millions of rural people who have been affected by the health policies influenced by this work. The VA tool has been particularly useful in rural areas of low- and middle-income countries (LMICs) where deaths occur in the absence of medically trained personnel or where clinical autopsies are not available. This has enabled better tracking of premature mortality and its causes in LMIC settings, and appropriate allocation of budgets towards diseases with the highest burdens.

As this was the first tool developed by INDEPTH, the global impact of the VA tool confirmed the viability and usefulness of the Network's coordination and HDSS platform for the development and of harmonized research tools for data collection. Other tools that were subsequently developed and are now being used by others include the INDEPTH Socioeconomic Status Tool and the INDEPTH Social Autopsy Tool.



Verbal autopsy standards:

The 2014 WHO verbal autopsy instrument



The Underpinning Research

Many low- and middle-income countries are unable to determine the causes of deaths that occur in their population and this problem is most acute in rural areas where deaths occur at home and burials of the deceased happen without medical certification or clinical autopsies. Determining the cause of death is a core demographic surveillance activity but over time many different questionnaires were being used by members of the Network so that it was necessary to harmonize the methods for comparability and quality control. From the early 2000s, the INDEPTH Network in collaboration with WHO developed a questionnaire, named the Verbal Autopsy (VA) tool, which is used by trained field workers to elicit the most probable cause of death. The completed questionnaire is independently assessed by two physicians and using the International Classification of Disease codes, the most probable cause of death is determined if there is agreement between them. Where there is no agreement, a third physician assesses the information. A cause of death is given if the third physician agrees with one of the first two causes given; otherwise the cause is given as undetermined. The original tool, which was published on the INDEPTH website in 2003, was intended for use in research settings hence it is a very long, covering many diseases most common in different life stages (e.g. child, maternal, adolescent, adult and old-age deaths). The VA tool was validated in several Health and Demographic Surveillance System centers in mid to late 2000s.

INDEPTH set up the Cause of Death Determination Working Group to spearhead the development and validation of the tools. To enable as wide consultation and collaboration as possible, the Secretariat and WHO have been organizing international workshops with the participation of experts from INDEPTH member centers and the global scientific community.

In order to be able to use the tool for many deaths as in a national scale, there was need to shorten the research questionnaire. INDEPTH and WHO, with other partners, embarked on a study between 2011 and 2013 to shorten, simplify and standardize the verbal autopsy (VA) so that it could be applied on a larger scale such as routine civil registration and vital statistics systems. The study involved reviewing the existing VA instruments, revising the cause of death (CoD) list and the reduction of the interview time by about 40%.

Members of the Secretariat, namely Fred Binka and Osman Sankoh, played key roles in scientific leaderships of this work. The development of the verbal autopsy is continuing, and members of INDEPTH who are on the WHO Taskforce are Osman Sankoh, Peter Byass (Chair of SAC), and Sam Clark (member of SAC).

Details of the Impact

INDEPTH research on the VA tool attracted WHO to become partners in its development and as a result, the potential for global influence was created from the outset. The INDEPTH VA tool is used in numerous low- and middle-income countries, especially where civil registration of vital statistics is non-existent or weak. All the 20 countries in Africa, Asia and Oceania where HDSSs operate now use the INDEPTH/WHO verbal autopsy tool. In South Africa, for instance, the most recent census introduced the use of VAs on a sample of deaths to determine causes. In India and Tanzania, a nationally representative program is being implemented, called Sample Vital Registration with Verbal Autopsy (SAVVY).

The VA and data generated from it are also being used by national agencies, international organizations including World Health Organization and UNICEF, and researchers globally to determine cause-specific mortality and the burden of diseases. For example, the World Health Organization used the INDEPTH data on causes of deaths in their publication on the global burden of diseases (WHO, 2004 update). The Institute for Health Metrics and Evaluation (IHME) in Seattle included estimates from the application of VAs for their recently published Burden of Disease Estimates 2010 which received global attention. These publications have global reach and significance and they are used by national governments and international agencies in informing their global health policies and planning. Another example demonstrating the use of the tool at national level is in Tanzania, where the Tanzanian Essential Health Interventions Project used the INDEPTH VA tool to generate district-level disease profiles which enabled district health officers to allocate appropriate budgets based on the districts' disease burden.

Several international research institutions are now developing methods for the analysis of VAs. There have been meetings organized by WHO to discuss the application of methods such as FOREST (Institute of Health Metrics and Evaluation (a computer-aided technique for deducing cause of death), InterVA-4 (Umea). In December 2013, a new Working Group on VA was established by WHO; the INDEPTH Executive Director is a member of this Working Group. In 2010 and 2013 the Institute for Health Metrics and Evaluation organized a global scientific symposium on the application of the VA tool to give opportunity to researchers globally to share their experiences in the application of the VA tool and the analysis of the data generated. In 2012 INDEPTH was invited to be a member of the core group of institutions that regularly discuss issues related to the strengthening of civil registration and vital statistics (CRVS) systems in African countries. This group is led by the United Nations Economic Commission for Africa. The use of the shorter form of the VA is always a key item for discussion.

In terms of ongoing work, the Network and its collaborators are continually seeking to improve the tool and to take advantage of innovations in technology (e.g. computer-assisted interviewing and software for coding causes of death). INDEPTH's major advantage over other VA tool developers are the multiple sites which enable the Network to validate and generate cause of death data and mortality patterns in a range of settings.



Prof. Sankoh



Prof. Binka

Sources to Collaborate the Impact

- See “World Health Organization, Global Burden of Diseases, 2004 update. Geneva” as evidence of user of INDEPTH cause of death data.
- Institute for Health Metrics and Evaluation. Global Burden of Disease Estimates 2010 published extensively in The Lancet, JAMA. The publication was promoted by Bill Gates and IHME was invited to the White House in Washington to present this work which is based on VA application.
- Tanzania Essential Health Interventions Project: <http://www.idrc.ca/EN/Documents/Burden-of-disease.pdf>

COLLABORATORS AND THEIR ROLE

Other networks such as WHO and Population Health Metric Research Consortium were involved in the development and validation of the VA questionnaires. As indicated above, some of the collaborators made financial and technical contributions.

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References

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Contact Details:

Osman.Sankoh@indepth-network.org
38 & 40 Mensah Wood Street, East Legon
P.O. Box KD213 Kanda
Accra, Ghana