Makerere University platform improves population health metrics through continuous community registration of births and deaths (and causes of death)

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Makerere University
CENTER FOR HEALTH AND POPULATION RESEARCH
Operating the Iganga - Mayuge Health and Demographic Surveillance Site(IMHDSS)

For a Healthy Population

EMBASSY OF SWEDEN
Kampala

Brief on cause of death data for evidence-based research

This brief contributes to evidence for Policy makers, leaders, health managers, researchers and other stakeholders who are interested in addressing population health problems based on research. It informs stakeholders about population health measurements and burden of disease at community level to guide health policies and interventions by demonstrating the best available research methodology for estimating the burden of diseases based on evidence at community level.

In this brief, we present community based population surveillance activities implemented by Makerere University Centre for Health and Population research (MUCHAP) which is a research and research training platform for Makerere University. MUCHAP has been operating a health and demographic surveillance site (HDSS) in Iganga and Mayuge districts in Eastern Uganda for thirteen (13) years now. The HDSS conducts longitudinal surveillance of the community through routine update of demographic events (births, deaths, marriages, social economic status, education, immunization e.t.c...). The MUCHAP-IMHDSS was established by Makerere University in partnership with Karolinska Institutet in Sweden and is supported through the framework of the Makerere-Sweden Research Collaboration.

The Problem:

Least and middle income countries (LMICS) have a challenge of under reporting vital statistics on birth, deaths, and migrations across all regions in the world. This is due to poor civil registration systems which lack timely updates on registration of vital events as they occur instantly. Research has shown that about half of the world's deaths occur outside health systems, even those which occur within the health systems, their cause of deaths (COD) is not ascertained especially at lower level health facilities because they do not have capacity to carry out post-mortems. Due to cultural and religious beliefs, the exact COD is not known for deaths occurring outside health systems or within a health facility because their relatives decline to conduct post mortems. These and other reasons lead to under estimation of the burden of disease and population health measurements reported globally for LMICs.

Verbal autopsy remains the only option to account for a complete COD in populations and communities where most deaths occur outside health systems.

Verbal Autopsy (VA) is a systematic and standardized indirect method to determine cause of death on the basis of medical histories, signs and symptoms

of illness prior to death and any other circumstances surrounding the death. It involves asking questions to community and family members of the deceased who were present and took care of the deceased to explore first hand facts through face to face data collection or interviews.

The approach

MUCHAP works with a network of community based village scouts to register and report every pregnancy outcome (including still births) and deaths which occur in the population under surveillance. The MUCHAP-IMHDSS population cohort covers 90,153 people from around 20,000 households in 65 villages. Each household is geo-referenced and each individual has a unique identifier for easier tracking and follow up.
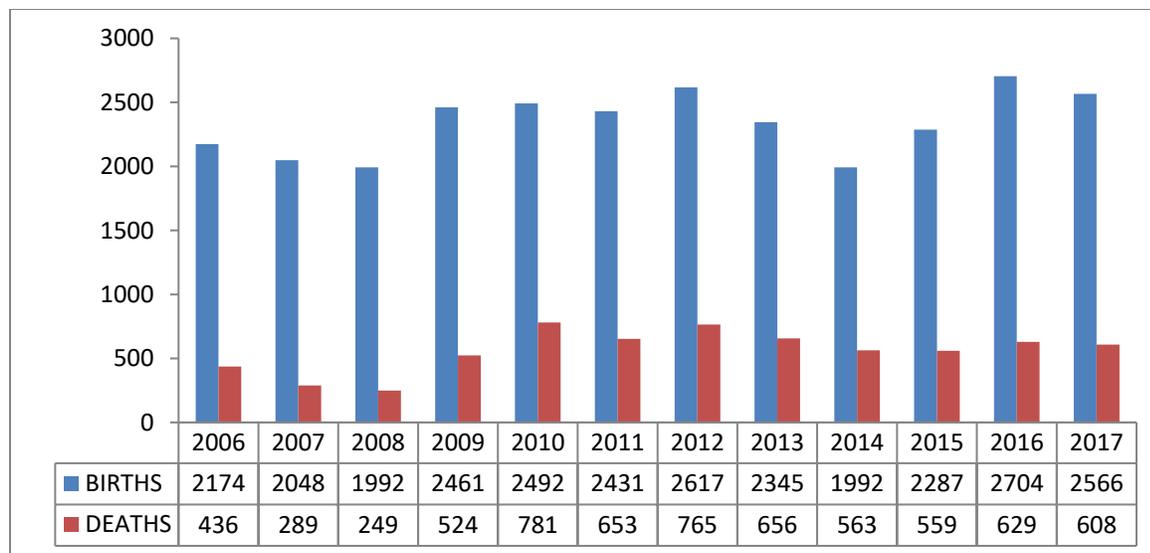
The Centre has piloted and mildly configured the WHO verbal autopsy tools for 12 years and is now adopting an electronic data capture system of WHO tool version 2016. The tools capture VA data for different age groups of the deceased. These include Neonates (0-28 days), Child (29 days to 14 years), and Adult (15 years and above).

The VA procedure has explored a range of bereavement period in the HDSS population cohort after demise and burial of their loved ones. However, this depends on the age and religion of the deceased. For Muslims, burial takes place usually within 24 hours of death. The Christians and other sects wait for up to 2-4 days before burial can occur.

Therefore, the period between death and VA interviews require further consideration as most respondents feel emotionally stressed while talking about the death of their loved ones.

Verbal autopsy interviews at MUCHAP-IMHDSS are conducted for every death which occurs in the population after 3-4 weeks. These are then forwarded to two physicians who independently review the data collected from caretakers that includes the narrative of illness episode, signs and symptoms and any other information provided by the caretaker, who then assign the COD using the ICD-10 classification of diseases.

	2006	2007	2008	2009	2010	2011	2012	2013	2014	2015	2016	2017
BIRTHS	2174	2048	1992	2461	2492	2431	2617	2345	1992	2287	2704	2566
DEATHS	436	289	249	524	781	653	765	656	563	559	629	608

Since 2006, MUCHAP has registered and conducted verbal autopsies on 6,712 deaths and ascertained COD for each. The graph above also presents the number of births (N=28,109) that have occurred in the same period.

It is possible to track health and population metrics including maternal mortality risks such as miscarriages, still births, and their trends over time. Other indicators include; Age Specific Death Rates (ASDR), Maternal Mortality Rates (MMR), Neonatal Mortality Rates (NMR), Infant Mortality Rates (IMR), Total fertility rates (TFR).

Policy Issues

This approach is efficient since it makes the best possible use of scarce resources like healthcare workers. However there is need for sustainability strategies to enable operations that are independent of external inputs in the medium term.

Comparing costs of this approach with other strategies for generating COD data will be helpful. Distinction has to be made between the opportunity costs, for example using existing health teams including VHTs and trained community scouts to collect data, and the additional costs which are incurred by hiring survey staff for a specific purpose (e.g. the DHS and census). Using this approach would make operational costs manageable especially for expansion purposes. This should be distinguished from the start-up costs.

The Makerere University Centre has developed capacity in collecting, collating and curating VA data at community level that is available to support anyone planning to implement VA and cause of death determination initiatives.

The Centre also has established morbidity surveillance by linking HDSS data with health facility data using HDSS member's unique IDs. This complements mortality/COD data in the population when estimating the summary measures of population health like the DALYS and YearLYs to guide policy.

In conclusion, the COD data from MUCHAP can be used to assess health seeking patterns, monitor progress toward SDGs, guide policy dialogues and debates about prioritization of interventions to improve population health, monitor trends for diseases and injuries, and inform health research priorities. MUCHAP also provides technical expertise and training/capacity building in VA and other population surveillance implementation methodologies. The datasets are available for secondary analysis on request.

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