Potential use of Verbal Autopsies to record the causes of death in Ethiopia

Dr. Venanzio Vella, Epidemiologist Italian Cooperation, Addis Ababa 18/12/10

SUMMARY

In the absence of a functioning vital registration system, verbal autopsies (VA) are used in many developing countries to fill the information gap on the causes of death. This involves interviewing close relatives of the deceased through a standard questionnaire which (in most places using VA) is then reviewed by physicians to assign the main cause of death. However, VAs have been mainly used in Demographic Surveillance Sites (DSS) and in limited surveys and no experience is available on the use of VAs administered by lay people in the mainstream of national health information systems. Furthermore, lay interviewers have been always used to collect information on standardized questionnaires and not to assign causes of deaths which is still carried out by medically trained staff. As the Family Folder has a section on the causes of death there is a need to assess the feasibility of collecting such information on the basis of the present knowledge on VAs. Therefore this note tries to reply to the following question "given present knowledge about VAs, is it feasible to use the Health Extension Workers (HEW) to assign the causes of death ?".

Understanding the implications of using lay people in assigning the causes of death requires a full understanding of what is involved in carrying out VAs. Due to the absence of published experience on the use of lay people in reliably assigning causes of death, this note reviews first the VA methodology and then suggests what could be done to pilot test and carefully validate the involvement of HEWs in assigning the causes of death. The note reviews the assumptions and criteria behind the use of VAs, limitations, different roles between collecting the information and assigning the causes of death and other issues which are critical to produce reliable information on the causes of death. On the basis of the present knowledge on the complexities of conducting VAs this note identifies minimum criteria which need to be tested in pilot areas where HEWs will need to interact with trained VA interviewers and higher level medical staff. The experience which will be built in these pilot areas will be used to assess the feasibility of using the HEWs to assign a limited list of causes of death.

BACKGROUND

Information on the causes of death is critical to plan appropriate health services and monitor their impact but such information is not available in Ethiopia. Most deaths occur at home where they are not captured due to the absence of routine registration of vital events. If setting up a universal registration system to count the number of births and deaths is already a challenge, establishing a recording system on the causes of death is much more difficult. It is therefore important to consider that a recording system of vital events will not be automatically followed by the registration on the causes of death. While births and deaths can be recorded by low cadre personnel, successfully implementing a recording system on the causes of death require more complex skills that are unlikely to be easily available any time soon at the periphery of the Health Management Information System.

Demographic surveillance sites (DSS) have been providing a useful surrogate in countries without a universal recording system to estimate mortality rates and causes of death (1). DSSs are resource intensive efforts covering limited populations, where after an initial census each household is visited at regular intervals (e.g. every four months) to update the vital events. In case a death occurs, trained enumerators use a standardized questionnaire to interview the family members of

the deceased on the signs and symptoms preceding the death. The causes of death are usually assigned by physicians on the basis of the information collected on the questionnaire. This data collection strategy, known as verbal autopsies (VA), has been developed and validated in DSSs around the world but it has not been applied in wider settings and within the context of routine information systems. The advantage of the DSSs is that they allow to apply in a standard way the complex procedures required to formulate a reliable diagnosis on a limited set of causes of death. The disadvantage is that being resource intensive, DSSs cover limited populations and thus the mortality profile, although informative in areas without reliable mortality statistics, is not generalizable to wider settings.

Therefore, the first thing to keep in mind when discussing the use of VAs is that the experience has been limited to DSSs and to limited surveys and any adaptation and wider application of this instrument need to be carefully assessed to maintain its reliability. On one hand standard VA questionnaires are complex and lengthy and thus unsuitable for a Health Extension Worker (HEW). On the other hand, any simplification should be carried out with caution because it would reduce the checks and balances (allowed by the lengthy questionnaires) that are important to ensure internal consistency and reduce misclassifications. Therefore, the main issue of concern is how feasible it is to streamline the questionnaire without reducing its reliability to a point where information risks to become meaningless. This would fail to achieve the necessary reliability required to meet the objective of collecting causes of death to inform decisions and evaluate their impact.

Assessing the above issues is especially relevant in Ethiopia because the Family Folder has a section on the causes of death which is supposed to be filled by the HEWs. The objective of this note is therefore to review the information available on the VA methodology to check the feasibility of adapting it to a simplified format. The note is divided into Introduction, VA methodology, Implications for the HEWs, Way Forward, Next Steps and Conclusions.

INTRODUCTION

The wider use of VAs outside the DSSs has been limited because assigning causes of death is complex and requires a standardized methodology. VAs can easily lead to misleading information if its methodology is not applied consistently to reliably assign a main cause of death. The assumptions derived from the literature (2-8) for the correct use of VA include: (a) signs and symptoms which are associated with the major causes of death can be recognized and reported by the caretakers/relatives who assisted during the illness preceding the death; (b) signs and symptoms are so typical of certain diseases that the likelihood of misclassifications is low; (c) the recall period is clearly defined, usually between one and twelve months; (d) interviewers have a level of education which is usually not less than high school graduates; (e) the training is of sufficient high standard to transfer the required skills to interview bereaved family members and the trainees are frequently supervised by medically trained supervisors to ensure that such high level skills are maintained; and (f) in most settings using VAs the assignment of the causes of death is carried out by more than one physician who independently review the VA questionnaire to reach consensus on the main/underlying cause of death.

The above assumptions need to be taken into account when trying to simplify the process underlying VAs. For example one major limitation is that lay interviewers can collect the information but are unlikely to be able to reliably assign the cause of death without a validated algorithm. This is based on the fact that even causes of death which might seem to be straightforward (e.g. accidents) might be bound to be misclassified without establishing a set of

rules that will ensure consistency. It should be also considered that even physicians using VAs have a certain degree of inconsistency in assigning the causes of death, which are likely to be magnified if lay people use their own subjective opinion.

The major problem in using the HEWs in successfully classifying the causes of death is that many of the above assumptions need to be tested. The limitations in the use of VAs, which are already existing in the resource intensive settings of the DSSs, are likely to be multiplied by many times over if the feasibility of simplifying the instrument in the context of routine settings is not carefully assessed. Major questions to be addressed include the applicability of a much shorter and simpler questionnaires and the use of reliable algorithms which are far from being well developed. Due to the almost non-existent information on the use of VAs in national routine information systems this note tries to review what criteria need to be met if HEWs were to reliably assign causes of death by using a simplified version of VAs.

RESULTS OF THE REVIEW

Objective of VAs

VAs are used in DSSs for several purposes. As a research tool VAs can be used in longitudinal studies to determine causes of death and measure the impact of interventions. VAs are used in studies to estimate the Burden of Disease to set priorities and guide policy and planning decisions. In the absence of a functioning vital registration system, VAs provide a surrogate system to record vital statistics and causes of death to monitor progress in the health sector.

The use of VAs outside the DSSs has been rare and it has been limited to resource intensive surveys. A few Demographic Health Surveys have included VA modules to interview a sub sample and India and China have conducted regular representative population surveys to collect information on the causes of death through VAs. However, it has to be noted that even in such surveys the enumerators interview the relatives of the deceased, but the final diagnosis is carried out by physicians on the basis of the information collected on the questionnaires.

Type of information

The type of information collected through VA questionnaires varies. The most common questions are related to the signs and symptoms preceding death, but they can also include risk factors, use of health care services and treatment by the deceased. For example in the case of maternal deaths, besides trying to identify the main cause of death, information is also collected on avoidable risk factors (e.g. lack of transport for complicated deliveries) to plan interventions to reduce maternal mortality (9).

Questionnaire Structure

The VA questionnaire can contain different modules according to the age of the deceased. In a review of 18 VA questionnaires (10) used at several DSSs around the world, 14 had separate modules for neonates, children and adults, while 4 had only one module for all age groups. The VA questionnaire proposed by WHO includes different modules for the signs and symptoms preceding the death within the first 4 weeks of life, between 4 weeks and 14 years, and 15 years and above (11). In a review of VA questionnaires (12), more than 90% of the questionnaires included questions on the symptoms related to fever, weight loss, oedema/swelling, cough, diarrhoea and vomiting. Between 80%-90% of the questionnaires had questions on chest pain, abdominal pain,

consciousness, fits, paralysis, headache and urine amount. Less than 80% of the questionnaires included questions on rash, pallor/jaundice, abdominal distension, swallowing, mass, neck pain, stiff neck, accidents, operations, urine colour and urine amount. Most questionnaires were similar in terms of wording and sequence of questions.

Most VA questionnaires include both open and close-ended questions. The open-ended questions allow the interviewee to give a descriptive account of the events in his/her own words while the close-ended questions are checklists of signs and symptoms which were present or absent. Open-questions leave more freedom but require more medical training, while close-ended questions are easier to administer and analyze and might reduce bias as interviewers are forced to ask all the questions, avoiding limiting themselves only to questions they have in mind. However, most questionnaires had a mix of closed and open-ended questions, which might also have the advantage of probing and increasing accuracy. The questions follow a logical sequence with more general questions being followed by more specific ones.

Interviewers

The level of education of the interviewers varies across DSSs with about half of the sites using medically trained people (e.g. nurses) and half using high school graduates (10). Medically trained interviewers are considered to be more accurate in identifying signs and symptoms preceding death, but they might be biased towards certain causes of death with which they are more familiar. The respondents are usually relatives who assisted the deceased and are therefore familiar with the signs and symptoms that preceded death. An acceptable recall period is between one and 12 months, and interviews within the first month are discouraged because they interfere with the bereavement process.

Causes of death

VAs use a short list of causes of death, which are frequently separated for children and adults, with the number of causes in the list varying considerably across sites. In a review of DSSs (10) the number of causes of death ranged between 4 and 120 causes for children, and from 53 to 142 for adults, with a few DSSs having a common short list of causes for both children and adults with a number of causes of death ranging between 32 and 57. Also the structure of the causes of death varied between free listing without subgrouping and grouping by organ systems or other type (e.g. communicable vs. non communicable diseases).

Notwithstanding the above mentioned relatively long list of causes of death, the potential diagnostic capacity of VAs is generally limited to a few single causes and a few main groups of causes. This is due to the fact that a reliable diagnosis on the main cause of death depends on several assumptions. Each investigated cause of death must have a set of features that can be recalled during the interview and can be distinguished from other similar causes of death. For example, deaths from injuries have distinctive features that can be distinguished from other forms of deaths, although it is not always easy to distinguish between different types of injuries (e.g. accidents vs. suicides). Some important diseases such as malaria (4) are not considered suitable for VAs because they have less distinctive symptoms which might not be distinguishable from other infectious diseases.

If possible one main underlying cause of death should be selected so that the total number of causes of death is the same as the total number of deaths, allowing to estimate proportional mortality by cause. This is important to establish priorities and to inform decisions on strategies to reduce the burden of mortality. However many deaths, especially among children, result from many causes,

such as a child which at the time of death might have been malnourished, but might also have been suffering from measles and acute respiratory infections. In these cases it might be difficult to decide if one or the other cause was more important in causing death and multiple causes of death are allowed in some DSSs. This has the advantage of reflecting the interaction of different causes which might not be easy to disentangle in terms of which was the leading cause of death, but allowing multiple causes complicates the estimation of the proportional mortality by cause.

Assigning the causes of death

The assignment of the causes of death is by physician review or by pre-defined algorithms. The most common experience with VAs is that physicians assign the causes of death by reviewing the data collected by the interviewers (17-19). The diagnoses assigned by doctors by reviewing the information recorded on the VA questionnaires have been validated mainly against hospital records (13-16) and have been found to have reasonable sensitivity and specificity for selected causes of death although with a certain degree of inter-observer variation which vary across studies.

Pre-defined algorithms have the advantage of decreasing inter-observer variability and allow automation of cause of death assignment. Algorithms are based on the concept of distilling the process of physicians' review into standardised rules. This allows the automatic assignment of the cause of death in the presence of a combination of symptoms which according to physicians are supportive of the most likely cause of death. Compared with a physician reviews of VA questionnaires, algorithms are less accurate in assigning individual causes of death, but if properly validated they have the advantage of being repeatable, ensuring reliability (20).

However, the validation of standardized algorithms to assign the causes of death has been limited. Anker et al (2) reviewed the diagnostic accuracy of algorithms used in several studies to assign neonatal and childhood deaths. Although there was a high variation across studies, it appeared that the diagnosis was more satisfactory for neonatal tetanus, measles, malnutrition, and accidents and less satisfactory for diarrhoea, acute lower respiratory infections and malaria. The reference from Anker et al. is a useful source providing the symptoms used to diagnose a given cause of death and their sensitivity and specificity.
(http://www.who.int/csr/resources/publications/surveillance/whocdscsrisr994.pdf)

Validation of algorithms for adult causes of deaths has been less documented. One of the few validations was conducted by Chandramohan et al (21) in a multicentre study in hospitals in Tanzania, Ethiopia and Ghana. A VA questionnaire was developed to interview relatives of patients who died in hospital and computerized algorithms for key causes of death were designed on the basis of symptoms reported on the questionnaire. The cause of death assigned by a panel of physicians who reviewed a given questionnaire and the cause of death which was assigned by the computerized algorithms was validated against the cause of death recorded on the medical record. Physicians performed better in diagnosing the causes of death than the algorithms and their validity was high[1] for acute febrile illness, direct maternal causes, TB/AIDS, tetanus, rabies and injuries; while validity was low for malaria, pneumonia, diarrhoea and non communicable diseases. For the causes of death assigned through the computerized algorithms, validity was high for rabies, injuries and direct maternal causes, and it was low for other causes of death.

[1] Positive Predictive value >70% (probability that the cause of death assigned by physician was the same as in the medical record)

In another study Quigly et al (22) validated the use of algorithms for four specific adult causes of death in Ghana and Tanzania. The causes of death derived from the computerized algorithms were consistent with the cause of death assigned by physicians for injuries and meningitis while less consistency was found for TB/AIDS and diarrhoea. Compared to physicians the computerized algorithms underestimated the number of deaths due to diarrhoeal diseases and overestimated the number of deaths due to TB/AIDS.

The above results suggest that further work is needed before algorithms can be widely used by lay people to assign causes of death. Algorithms increase reliability, and thus ensure comparability across time period and sites, allowing VAs to be used by trained people without medical background. However, because of the limited experience in validating algorithms they cannot be presently used as an alternative to physicians in assigning the causes of death. Therefore, one priority area for operational research is to developed local algorithms that can be tested and validated before they can be used by HEWs.

Experience with lay reporters in Ethiopia

There has been an attempt to simplify VAs in a rural area of Ethiopia. Lulu and Berhane (23) have tested a simplified questionnaire which was used by lay workers to collect information on all deaths which occurred in the age group 15-49 in nine rural and one urban kebeles covered by the Butajira DSS. The questionnaire was a simplified version of the WHO questionnaires on VAs, took about 20 minutes to administer and was designed to be used by high school graduates to interview illiterate rural people. The data collected through the questionnaire were entered into a computerized expert algorithm that according to signs and symptoms assigned the causes of deaths (Table 1). The first drawback of simplifying the VA questionnaire was that it allowed to assign a few specific causes and a few broader causes of deaths compared with more individual causes which are identified by more lengthy questionnaires. On the other hand broader categories increase the reliability of the instrument and thus its applicability to wider settings.

Table 1 Algorithm used by Lulu and Berhane (published in Ref 23)

Computerized Algorithms	**Causes of death**
Duration of illness < 30 days + Accidents (intentional or unintentional)	Injuries
Pregnant or in labor or in the puerperal period	Maternal causes
Duration of illness > 30 days + Cough + Weight loss + (Bloody Sputum or Fever or Ascites) + no diarrhoea	TB
Duration of illness > 30 days + Cough + Diarrhoea + Fever + Weight Loss	AIDS
Duration of illness > 15 days + (Oedema of legs or Ascites) + Jaundice	Liver diseases
Duration of illness < 15 days + Abdominal swelling + Repeated vomiting + No diarrhoea	Acute abdomen
Duration of illness > 30 days + cough + Dyspnea + Wheezing + No bloody sputum	Chronic obstructive lung diseases
Duration of illness < 30 days + Diarrhoea + No cough	Diarrhoeal Diseases
Duration of illness < 15 days + Fever + Headache	Acute febrile illness
Duration of illness < 15 days + Fever + Headache + Neck stiffness	Meningitis
Duration of illness < 30 days + Cough + Fever + (Dyspnoea or Chest pain)	Pneumonia
Duration of illness < 30 days + Dyspnoea + Palpitation + (Oedema of legs or Ascites)	Cardio Vascular diseases

The study carried out by Lule and Berhane showed the feasibility of applying a simplified method of VA but has its own limitations. Also in this case, the interviewers were not using the algorithms to assign the causes of death which were automated through a computer. Furthermore, the causes of death assigned by the algorithms were not validated against the causes of death assigned by physicians or against the causes of death recorded on the medical records. This did not allow to check the extent of misclassification.

Validation of the Ethiopian Algorithm

The algorithm used by Lulu and Berhane in Ethiopia was instead validated in a district in India (24). Lay interviewers with 15 years of education used a local VA questionnaire and assigned a single cause of death through the algorithm used in Ethiopia. The diagnosis from the lay interviewer was compared with an independent diagnosis done by a physician (gold standard) on the basis of the same VA questionnaire. The validity of the algorithm was based on the level of agreement between the cause of death assigned by the lay interviewer and by the physician. Validity was good (according to selected cut off points for sensitivity) for injuries, diarrhoeal diseases, TB and and was less satisfactory for the rest of the other causes of death.

Limitations of algorithms

Although algorithms give the opportunity to use lay interviewers to assign the cause of death they are still affected by several problems. Diagnostic accuracy of algorithms is limited to a few causes of death and thus the statistics that might be derived is limited. Validation studies are very few and their results are not always consistent with some causes of death coming out as validly classified in one study but not in another one. For example the Indian validation found that the Ethiopian algorithm was satisfactory in identifying diarrhoea as cause of death while another study carried out in Tanzania found that diarrhoea was frequently misclassified as a cause of death by using algorithms.

DISCUSSION

The first issue to be considered when proposing to collect causes of deaths through the HEWs is to keep in mind the objective of collecting the causes of death and the minimum requirements to ensure that the objective is met. The objective of collecting such information is to quantify the burden of mortality in the population to decide priority interventions, monitor trends and measure the impact of policies and interventions. This objective can be met if the information collected through a simplified version of the VA method has sufficient reliability in consistently assigning causes of death to confidently measure the variation in mortality patterns across geographic areas and time periods. If reliability is not ensured any comparison among time periods and geographic areas becomes meaningless because changes in mortality might be due to misclassification and vagaries of reporting.

To maintain reliability and thus achieve the above mentioned objective, minimum criteria need to be met. The criteria are as follows:

- Ensure through careful validation that any simplification of the VA tools would not compromise the minimum amount of information required to arrive at a reliable cause of death;
- Test such approach in areas were physicians are available to validate the causes of death assigned by the HEWs. The real issue is not the simplification of the questionnaire but the insufficient experience about validating the assignment of the causes of death by lay persons;
- Set up a strong system of training and supervision in administering the questionnaire (however simplified it might be); and
- Limit the recording to the few causes of death which have been found to have a reasonable validity and which at the moment seem to include neonatal tetanus, measles, injuries, meningitis and direct maternal causes.

The above criteria are not academic exercises and ignoring them is likely to produce misleading results. This means that a strategy to develop, test and validate the use of algorithms by HEWs can only be done in pilot areas where a more traditional system of VAs could run in parallel to validate the use of algorithms by the HEWs.

Any attempt to collect data on the causes of death can only proceed in gradual steps ensuring that the above mentioned minimum criteria are met. The first step would be to test the feasibility of carrying out VAs outside the Ethiopian DSS of Butajiura by selecting sentinel pilot kebeles in the catchment areas of health facilities where doctors are available to review the VA questionnaires. In these pilot kebeles, the HEWs should produce a baseline census of all households in the area, to be renewed at the beginning of each year. Any death should be communicated by the HEWs to a VA interviewer who will be trained in administering an adapted version of the International standard WHO verbal autopsy questionnaires (11) which should be pre-tested. Each VA interviewer, to be stationed in the area to cover a certain number of pilot kebeles, should visit the households where a death has occurred to conduct the VA interview. The filled VA questionnaires should be forwarded by the VA interviewer to the health facility serving the pilot area where available doctors will be trained in assigning the causes of death by reviewing the questionnaires. Possibly each questionnaire should be reviewed by two doctors who should come to a consistent diagnosis on the main cause of death.

The above first step should be followed by a second step in which a simplified algorithm to be used by the HEWs should be developed, tested and validated. The algorithm could be similar to the one developed by Lulu and Berhane in Butajira and the HEWs should be trained by the VA interviewer to use the algorithm to assign the causes of death. The parallel system based on the interviewers and the physicians should continue to operate allowing to validate the causes of death assigned by the HEWs, which should be compared with the causes of death assigned by the physicians. In this context the researchers of Butajira could be involved to design, test and validate the algorithms, train the HEWs and validate their diagnoses against the causes of death assigned by the physicians. Once the algorithms used by the HEWs are validated they need to be further refined and the feasibility of assigning the causes of death through the HEWs need to be documented.
The pilot sites could constitute an embryonic Mortality Surveillance System (MSS) which should be fine tuned as experience develops. At the beginning, the pilot areas could be selected according to practical criteria, such as availability of health facilities where physicians are willing to provide support in assigning the causes of death. The first stage should be spent in testing and evaluating the data collection strategy and once enough experience will be built up, the MSS could be

gradually expanded. As experience develops in the initial sentinel sites, it should be possible to set up a plan to select areas which are more representative of the regions. This step by step process is in line with Quigly et al (20) "a validation study may need to be conducted as part of an initial stage of surveillance, in order to obtain data for validating and modifying the algorithms". Without such gradual "stepping stones" any short-cuts to use HEWs to assign the causes of death is unrealistic and bound to produce misleading information.

Outside the pilot areas involved in the above mentioned MSS, the role of the HEWs should be to ensure vital registration only, providing a demographic surveillance system (DSS) on vital events. It will be already a big achievement if the HEWs will be able to record the number of births and deaths by sex and age groups and if the HMIS will be able to aggregate these data. It is unrealistic to expect all the HEWs to be able to assign the causes of death outside the pilot sentinel sites.

The above mentioned strategy is in line with the Sample Vital Registration with Verbal Autopsy (SAVVY). SAVVY methods are integrated into the Health Metrics Network's vision of "stepping stones" to improve vital events monitoring. SAVVY revolves around the following systems:

- Demographic surveillance system (DSS) — DSS is a complete and continuous enumeration of births, deaths, and migration in a geographically defined population.
- Mortality surveillance system (MSS) — MSS consists of the active reporting of deaths in a geographically defined population. Verbal autopsy (VA) interviews are used to determine the probable causes of death.
- Death Certification and ICD Coding — This involves application of the tenth revision of the International Classification of Diseases (ICD-10) and WHO-approved procedures to certify deaths from verbal autopsy interviews and assign a probable cause of death.
- Nested surveys — Nested surveys consist of focused sets of questions and are included in the census update rounds. Examples include surveys on poverty monitoring, reproductive health, health service coverage, and environmental and behavioural risk factors.

SAVVY has developed several materials that can be downloaded from their web site http://www.cpc.unc.edu/measure/tools/monitoring-evaluation-systems/savvy and could be used by the proposed pilot sites.

CONCLUSIONS

The next steps should be to set up a plan on how to implement the sentinel pilot system for MSS. This could begin in a few sites to test the feasibility of the data collection strategy and to validate the use of the algorithms by the HEWs. In setting up the strategy of the MSS it will be helpful to involve the professionals of Butajira, who have built substantial experience in VAs, to provide critical inputs in terms of tools, training, supervision and validation.

Involving the HEWs in assigning the causes of death require careful testing of the data collection strategy, which has to be designed upon the knowledge which has accumulated in the last few decades. The use of standardized algorithms is limited and the diagnosis in most sites using VA is still carried out by physicians. No developing country has yet succeeded in integrating simplified data collection systems on the causes of death at the most peripheral level through the use of lay personnel to assign causes of deaths. VAs as commonly known today have not yet been applied on a wider scale outside the DSSs or a few surveys and the use of the HEWs in assigning the causes of

death is presently unfeasible on a routine basis for the reasons that have been discussed in this note and careful testing and validation is required.

Considering the objectives to be achieved and the experience that has been developed on VAs in developing countries, any widespread routine use of simpler questionnaires and algorithms to assign the causes of death must consider the minimum feasibility criteria mentioned in this note. The only way forward is to recognize the present role of the HEWs in monitoring vital events and to pilot test an expansion of the VAs in areas where the HEWs could interact with trained interviewers who will liaise with high level staff at the nearest health facility. The above strategy is the only feasible one in expanding the data collection on the causes of death to the peripheral level.

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