New challenges for verbal autopsy: Considering the ethical and social implications of verbal autopsy methods in routine health information systems

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TITLE: New challenges for verbal autopsy: considering the ethical and social implications of verbal autopsy methods in routine health information systems.

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Abstract

Verbal autopsy (VA) methods are designed to collect cause-of-death information from populations where many deaths occur outside of health facilities and where death certification is weak or absent. A VA consists of an interview with a relative or carer of a recently deceased individual in order to gather information on the signs and symptoms the decedent presented with prior to death. These details are then used to determine and assign a likely cause-of-death. At a population level this information can be invaluable to help guide prioritisation and direct health policy and services. To date VAs have largely been restricted to research contexts but many countries are now venturing to incorporate VA methods into routine civil registration and vital statistics (CRVS) systems. Given the sensitive nature of death, however, there are a number of ethical, legal and social issues that should be considered when scaling-up VAs, particularly in the cross-cultural and socio-economically disadvantaged environments in which they are typically applied. Considering each step of the VA process this paper provides a narrative review of the social context of VA methods. Harnessing the experiences of applying and rolling out VAs as part of routine CRVS systems in a number of low and middle income countries, we identify potential issues that countries and implementing institutions need to consider when incorporating VAs into CRVS systems and point to areas that could benefit from further research and deliberation.

Key Words: Verbal autopsy, ethics, civil registration and vital statistics, health information system, cause-of-death, implementation

Background

The importance of population health data to global health efforts is widely recognised and has recently been highlighted by the United Nations' call for a 'Data Revolution' and the inclusion of a data, monitoring and accountability target in the new Sustainable Development Goals (IEAG, 2014,United Nations, 2015). Cause-of-death (COD) information is some of the most basic and most essential for estimating the burden of disease, planning health services and deciding research priorities. Ideally, COD data would be garnered from routine and complete national vital registration systems in which the causes of all deaths are medically certified (Mikkelsen et al., 2014). However in many low and middle income countries (LMICs), when a death occurs outside of a health facility and/or is not certified by a medical professional, the COD goes unrecorded and any potential contribution to national statistics, or to future prevention and control strategies, is also lost (Lozano et al., 2012). In these contexts verbal autopsy (VA) methods can be used to ascertain a probable COD. A VA entails an interview with a relative or care-giver of the deceased to provide the best possible COD data in the absence of medical certification and can therefore play a key role in the data revolution.

VAs were developed and refined in research contexts, typically within Demographic and Health Surveillance Sites (DHSS) in LMICs. In some large populations in countries like China, India and Brazil, VAs have been incorporated into sample vital registration (Franca et al., 2011, Jha et al., 2006, Yang et al., 2005). Both DHSS and sample vital registration systems have typically been concerned with the production of aggregated COD statistics and not with the registration of individual deaths. More recently, international attention has focussed on the possibilities of incorporating VAs into Civil Registration and Vital Statistics (CRVS) systems in LMICs (de Savigny et al., 2017). VAs are therefore regarded as an interim measure to provide essential COD data pending the extension of health services to the point where medical certificates of cause-of-death (MCCODs) are generally available. Under these circumstances, it is tempting to treat a VA in terms of being a simple substitute for a MCCOD but the reality is more complex.

In general terms, laws in high income countries require a MCCOD both for disposal of a dead body (burial or cremation) and for registration of the death. The death will need to be registered within a set period and the registration certificate will be required for the execution of wills and insurance claims (Mikkelsen et al., 2015). This legal and regulatory framework assumes cooperation between the health sector and the office of the civil registrar not only in the issuing of MCCOD but also in public health regulations concerning the disposal of bodies. It is further assumed that all, or nearly all, deaths will be registered. A MCCOD therefore serves two purposes: it is a legal document and a basis for vital statistics which depend on the ongoing registration of births and deaths.

Laws and regulations in LMICs are likely to be modelled on those of high income countries and may be associated with comparatively heavy penalties for the non-registration of a death. Yet, despite this and despite efforts to motivate families to register deaths, the proportion of all deaths that are registered in LMICs can be very low (United Nations, 2017). Reasons for this include poor access to registries, the costs associated with registration, failure to enforce laws concerning burial, and local custom rather than law being the basis for inheritance (Huy et al., 2007). Recent attempts to improve coverage of civil registration have focussed on the notification of deaths by health services and the application of VAs to notified deaths. This has required the coordination of activities between the health sector and the office of the civil registrar. It is customary however, and courteous, to allow for a period of mourning which may take weeks or months before conducting a VA. It is therefore not possible to use a VA to initiate the process of registration of a death as is the practice with a MCCOD. The motivation for the introduction of VAs into civil registration systems, therefore, has not primarily been to register deaths but to produce vital statistics.

Incorporating VAs into civil registration systems raises important issues. There are three main areas of concern. First, the technical and methodological aspects of VAs are key to successful implementation. Ideally, for example, countries incorporating VAs into routine systems will employ a standardised and validated instrument so that results can be compared across countries and contexts (World Health Organisation, 2015). VA methods have been under development for almost half a century and a number of variations of VA instruments have been established in that time (Leitao et al., 2013). Additionally, a number of analytical approaches to interpret VAs and assign

COD have been developed (Desai et al., 2014,Murray et al., 2014). VA questionnaires can be analysed by physicians and/or by automated analytical software packages (the accuracy of VA described above was based on an analysis of automated methods). Automated VA, like SmartVA (James et al., 2011) and the InterVA Mobile Phone app (King et al., 2016), can be incorporated into android devices. VA data can be collected electronically and potentially analysed immediately after an interview. This technological advance means that quality assurance can be more easily applied, costs reduced, and time lags due to data entry, data cleaning and physician-review can be avoided (Zhao et al., 2016). It also means that the nature of interactions between the respondents and the interviewer during the VA interview may change, become shorter in duration and that VA results could potentially be disclosed at the time of the interview.

Second, the processes, resources and capacity necessary to scale up VA applications and to incorporate and integrate VA data into CRVS systems need to be carefully planned. Countries need to consider how to coordinate the training and supervision of large numbers of interviewers, the incorporation of data into national systems and developing appropriate analytical approaches to the new data require addition attention. Though this is beyond the scope of this paper, further guidance on these aspects will be of value to countries as they build their VA capacity while simultaneously strengthening and developing vital registration systems (de Savigny et al., 2017).

Lastly, the ethical, social and legal concerns that arise from VA approaches also present new challenges. These concerns are the topic of the present deliberation. Death and disease are sensitive matters everywhere. Furthermore, VA is typically conducted in areas where infrastructure and health systems are weak and people are socio-economically disadvantaged. Unsurprisingly, therefore, there are significant concerns surrounding the implementation of VAs in certain settings. Local culture, custom, beliefs and sensitivities can influence the acceptability of VAs by different communities and individuals. Consequently, careful consideration of each new and unique socio-cultural setting and local capacity for VA roll-out is required by VA implementing technicians and their partners.

Some of the aforementioned concerns involving the application of VAs have been previously explored (Aborigo et al., 2013,Chandramohan et al., 2005). Most, if not all, have been scholarly investigations addressing VA integration in low-resource settings. However, the application of VAs in routine systems of data collection – as promoted by the Sustainable Development Goal agenda and its Data Revolution - will involve new actors and institutions (outside of academia) and raise new challenges.

In this review of current practices we explore each step of the VA process, from the design of the VA instrument to reporting results, and identify the most pressing ethical, social and legal issues for those involved in VA implementation to consider. Choosing appropriate responses to many of these issues is likely to be highly context specific. We aim, however, to help practitioners identify where challenges may need deliberation and help to identify areas that require further research. This paper is based upon both the current literature on VAs and our own recent experience in the early introduction of VA into CRVS, in particular in Asia and the Pacific.

METHODS

Firstly, a review of the VA literature was conducted to identify analyses, guidelines and commentaries on the ethical, legal, social, and cultural implications and considerations for quality VA practice. We examined the literature employing a narrative review approach (Mays et al., 2005), iteratively and reflexively discussing emergent findings among the research team. Several of the authors are members of the Bloomberg CRVS Data for Health Initiative and are currently working closely with countries to incorporate VA into their routine systems.

Next, based in part on the sections outlined in the WHO Verbal Autopsy Standards (World Health Organisation, 2015), we identified and considered six stages of VA implementation in conjunction with the literature. These six VA implementation stages included: (i) the questionnaire; (ii) the interviewers; (iii) sampling; (iv) the interview; (v) the VA data; and (vi) the VA results. In the case of (iii) sampling, routine systems 'sampling' was not considered relevant, however, and instead we included a category of 'systems design' to refer to issues that arise in the process of incorporating VA into CRVS. Otherwise, we considered the relevant issues in each of these stages for the implementation of VA in routine systems. Terms were chosen to represent these issues and these stages for our search strategy.

Search strategy

Two databases were used to conduct our literature search: Scopus (which incorporates both PubMed and EMBASE content from 1996 onwards) and Web of Science. The searches were conducted in March 2016 and updated over six months later in early November 2016. Search terms were chosen based on the six stages of VA implementation and a seventh category of generic terms of interest. These are presented in Table 1.

Inclusion and Exclusion

Inclusion was not restricted by date of publication, study design and both quantitative and qualitative approaches were accepted. As editorials, letters and commentaries also commonly contain normative discussion of ethics and real-world perspectives on research methods, these were also included. Articles written in languages other than English were excluded. Articles were also excluded if they did not contribute significantly to the topic of this paper, i.e. the social, cultural, ethical or legal aspects of VA applications. For example quantitative papers that only briefly noted the ethical procedures employed in their study were excluded

Narrative synthesis

Literature identified through the searches was used to explore the current state of knowledge within each of the VA processes and to identify any issues that should be considered when scaling-up VAs and incorporating them into CRVS. Along with findings from the literature searches, however, broader literature, including findings from the grey literature searches using Google and Trove, and authors' experience was called upon to provide context, analysis, and recommendations around emergent themes.

RESULTS/DISCUSSION

A total of 839 papers published from 1988 onwards were retrieved from the literature search (Figure 1). After the removal of duplicates and articles in languages other than English, as well as exclusion of articles that did not engage substantially with the ethical, social, cultural or legal aspects surrounding VA methodology, 61 papers remained [INSERT LINK TO ONLINE FILE HERE]. A further 11 articles that did not appear in the searches or were present in the grey literature were identified, either through online searches or by recommendation by one or more of the authors.

In this section we identify the potential challenges associated with the integration of VA into routine systems at each stage of the VA process and provide a discussion of possible ways forward (summarised in Table 2).

(i) The Questionnaire

VA questionnaire design has been evolving rapidly over recent years. Analytical work has focused on reducing the bias and improving the accuracy of questions (King et al., 2010). From a social, cultural and potentially ethical perspective, however, it is the nature of the questions and how they are posed that is perhaps more relevant. Survey questions can be closed or open-ended, and VA questionnaires are typically made up of a combination (Soleman et al., 2006). A thorough discussion of the necessary considerations surrounding choices between open-ended questions versus structured questions in VA has been provided by Fottrell et al and more recently by King et al (Fottrell & Byass, 2010,King et al., 2016). Different approaches bring about different forms of memory, open-ended requiring the recollection of details while closed question require the respondent to recognise specifics (Bennett AE & K., 1975).

Open-ended questions are often considered a more natural way of conducting an interview and can be more comfortable for respondents (Lerer et al., 1995). In the Population Health Metrics Research Consortium (PHMRC) questionnaire the open-ended section follows a series of closed-questions. This design provided the basis for the development of automated methods for the assignment of cause-of-death it was necessary to ensure that responses to question items were consistent and not influenced by the narrative response. However, in both Andhra Pradesh, India and Papua New Guinea (PNG) respondents and interviewers have commented that starting with the open-ended section may help make the conversation more relaxed. They also asked why, if the COD was obvious in the case, say of drowning, it was necessary to ask a list of symptom questions. In SmartVA the order of questions was altered so that if the COD could be established early in the interview, direct questioning could be terminated at that point and the asking of unnecessary questions avoided. There is no direct evidence, however, about whether the sequence of closed and open questioning has any effect on the accuracy of diagnosis (Kumar et al., 2006,Lee et al., 2008).

There is little doubt that the open-ended narrative can establish a sequence of events and provide additional context to closed questions and is thus particularly important to a physician's diagnosis of VAs (Joshi et al., 2009,Soleman et al., 2006). The approach taken in the development of automated analysis of the PHMRC instrument was data text mining which relied on the analysis of text items extracted from open narrative (Murray et al., 2014). Difficulties arose when it was found necessary to translate the entire narrative from other languages into English. It was recognised, however, that respondents may find expressing the story in their own terms emotionally beneficial (Bird et al., 2013,Gouda et al., 2016). As part of the process of shortening the length of the instrument for routine application in CRVS systems, the open-ended section of the questionnaire was replaced in

SmartVA by a check list of key words and phrases extracted from the open narrative at the time of interview.

The open-ended narrative can also be useful in that it can sometimes capture the non-medical context of a death. Understanding the local beliefs and practices surrounding deaths can provide essential information for public health action (Allotey & Reidpath, 2001,Borse et al., 2011,Gutschow, 2016,Hussain-Alkhateeb et al., 2015,Jat et al., 2015,Kamat, 2008). Some have suggested that VAs could be extended to include a deeper qualitative approach in order to capture information about the health services and cultural explanations of death (D'Ambruoso et al., 2016,D'Ambruoso et al., 2008, D'Ambruoso et al., 2010, D'Ambruoso et al., 2010b, Gutschow, 2016, Houston et al., 2015, Reyes, et al., 1998, Parkar et al., 2009). Some issues to consider: firstly, although some authors have suggested that VA results have led to significant policy changes in some contexts (For example see: (Setel, 2012)) limited evidence is available to directly describe the impact of VAs, or similar data, on driving subsequent action in policy or practice. Secondly, information provided by respondents about government health services or health workers may be false or inaccurate, and if so, this is usually motivated by the respondent’s fear of being critical of the authorities.

Nonetheless, recording open-ended narratives tend to take time. Before the advent of hand-held electronic devices, the interviewer would record the open-ended narrative on paper (Bird et al., 2013). In the CRVS context this is no longer likely to be possible. The record of interview has lost its earlier richness. This needs to be acknowledged and, if such areas of inquiry are seen to be of fundamental importance, some form of survey will need to be added formally, possibly to a sample of all VAs. For example, once identified through VA and MCCOD, maternal deaths could be followed up with a qualitative interview or a social autopsy questionnaire which has been used to study the social and health system circumstances surrounding a death and to investigate the reasons for delayed contact with health care (Iyer et al., 2013,Kallander et al., 2011,Kalter et al., 2011,Webber & Chirangi, 2014, Njuki et al., 2014, Nonyane et al., 2016, Sikder et al., 2012, Storeng et al., 2012). The use of social autopsy can itself act as a social intervention helping communities to identify and work on health problems (Biswas et al., 2016). D'Ambrouso et al (D'Ambruoso et al., 2016), for instance, have incorporated questions about the recognition of severity, access to, and quality of health services into the VA. The strengthened CRVS with COD informed by VAs provides a necessary frame from which researchers can sample and select cases for this more in-depth analysis.

(ii) The Interviewer: Qualifications and Training

There is much of importance that is implicit in the research environment and involved in the training and background of the interviewers that can influence the practice of verbal autopsies. AS such, there is much that may be lost in the scale-up of operations required for the administration of VAs in the civil registration context. Issues to be considered include 1) the training of interviewers and the need for counselling of informants, 2) the professional background and qualifications of VA interviewers, 3) the provision of support for VA interviewers and 4)here, and elsewhere, the relationship between interviewers and the local health services is likely to prove critical.

In the research environment interviewers are commonly recruited from the ranks of nurses and other health professionals who, it could be assumed, are experienced in dealing with issues arising from severe illness and death. It has been argued that VA interviewers should be trained in counselling skills in order to minimise and mitigate emotional distress potentially caused by VA interviews (Chandramohan et al., 2005,Soleman et al., 2006). A study of the ethical and social issues that arose using VAs in a research site in PNG concluded that experienced interviewers were not simply working from the VA instrument but were responding to the emotional needs of the grieving respondent (Gouda et al., 2016). They had not received training in counselling but were able to provide comfort in culturally specific ways. Counselling is not a common service in many LMIC cultural contexts and the ways in which it is implemented would need to carefully consider local beliefs and customs surrounding death, disease and bereavement (Schieffelin, 1985). Here, guidance from the participating community would be both prudent and necessary

VA field sites have used both medical and non-medical staff to conduct VA interviews. Medical field staff are usually health care workers or nurses. Although a few studies have investigated the possibility of employing non-physicians to ascribe the COD in the cases of maternal and perinatal death (Araya et al., 2004,Dongre et al., 2008,Engmann et al., 2011,Engmann et al., 2009), to our knowledge very little literature exists on the effects of professional background on either the effectiveness of the VA interview (does the VA reveal the right COD?) or the acceptability of the interview by the respondent or community (do respondents find it more acceptable to be interviewed by medical professionals? Are medically trained interviewers better at counselling respondents through their distress?).

Qualitative studies in Indonesia and Vietnam have suggested that community members are more comfortable with healthcare workers administering VA questionnaires (Dawkins et al., 2009, Jennaway et al., 2009). On the other hand, in some contexts employing lay persons may alleviate fears about sharing sensitive information with those seen to be associated with state authorities. Employing lay persons to conduct VAs is also likely to be a significant cost-cutting strategy. Empirical evidence is currently lacking to guide these decisions, however. One major ethical consideration in this context is concerned with the potential misallocation of limited resources. Health care workers in many of LMICs are likely to be in short supply. It could be argued that in such cases skilled health care workers would be better employed working to prevent death and ill-health. Another important reason employing lay interviewers should be considered.

In a number of different ways VA interviewers need to be supported by the implementing institutions, such as research institutions or Ministries of Health. First, VA interviewers are faced with many social and ethical decisions when interacting with family respondents (Gouda et al., 2016). How VA interviewers relate to the community and the relatives of the deceased may have an impact on how they respond to being interviewed. Interviewers may also be obliged to abide by local mourning protocols, which may include bringing an offering to the family or even helping with the funeral arrangements (Brolan et al., 2014, Gouda et al., 2016). In many cases VA interviewers may come from the community they work in and therefore issues around privacy and confidentiality (as well as security) must be carefully considered to ensure protection to all concerned.

Second, VAs can be emotionally draining for both the respondent and the interviewer. Given the nature of VA work the interviewer will interview many sad people and hear tragic and traumatic stories of death. Interviewers have subsequently noted the emotional pressure this work can place upon them (Gouda et al., 2016). Some institutions provide opportunities for peer-counselling for their fieldworkers and build a network of support as a team (in conversation with Partners in Health Rwanda).

Lastly, VA interviewers are privy to sensitive information and this may put the interviewer in a vulnerable position. Family members may disagree with the VA process or be unhappy that the respondent has revealed particular information. Culturally-specific threats should also be considered. For example, in PNG deaths blamed on witchcraft or sorcery can be problematic for VA interviewers and, in that context, VA interviewers have felt vulnerable to the spiritual forces involved in these kinds of deaths or feared repercussions from sorcery (Gouda et al., 2016).

In conclusion, it is important that these issues be considered in the evaluation of VAs in CRVS. An implementing institution should consider their ethical responsibility to protect the VA interviewers from emotional and physical harm as important as the protection of the VA respondents.

Training needs to be reviewed and revised in response to evaluation, especially as methods and applications evolve (Bird et al., 2013). It must go beyond assessing the accuracy of responses and should be culture- and site-specific. Regular debriefing of interviewers should be maintained and if interviewers are not drawn from local health departments then relationships with those departments should be strengthened so the program can learn from the skills and experience of local health workers.

(iii) Systems Design: Considering Coverage and Equity

CRVS coverage can be a major limitation for equity analysis and ensuring that populations are represented is a key challenge. Incorporating VAs of disadvantaged populations into CRVS systems presents the opportunity to collect and track important data on health inequalities. Universal VA coverage is unlikely to be realistic or cost-effective however. Therefore, sample registration systems and a 'mixed-methods' approach bringing together all sources of data from death certification and VAs in order to provide a cause-specific mortality fraction population estimate for public health purposes needs to be carefully considered in some contexts (Byass, 2007).

Even where VAs are not feasible, notification of deaths disaggregated by age and sex is invaluable for public health planning. Those deaths that most need a VA are those that occur outside of health facilities. These decedents were likely to have faced either financial, geographic or cultural barriers to accessing health facilities; factors related to health equity which should ideally be taken into account in both VA implementation and VA analysis (D'Ambrouso, 2012). These concerns require carefully developed technical guidance as well as ongoing deliberation (de Savigny et al., 2017).

A CRVS system can also provide a platform from which to help facilitate reaching disadvantaged groups and addressing their needs. Take for example the work conducted by Data2X which highlights the unequal gender representation of CRVS systems and ways in which this can have ongoing effects on gender inequality (Knowles, 2016). Verbal, as well as social autopsy data have a potentially important role in strengthening health systems and strengthening equity in health systems. While social autopsy can identify those for whom the health system has failed, developing VA methods that are embedded in local community knowledge and practices through participatory processes can help to ensure community ownership of knowledge and ultimately to instigate community-based solutions and local action (D'Ambruoso et al., 2016, Prata et al., 2012).

(iv) The Interview

Informed consent and confidentiality are often highlighted as key ethical principles in health research and survey work. The relevance of individual autonomy in global health ethics however has recently been brought into question (Carrel & Rennie, 2008,Kingori, 2013,Osamor & Kass, 2012). It has been argued, for example, that informed consent is often conducted to safeguard the research process and provide written documentation rather than to ensure that participants fully understand their role in the research process and what they can expect to benefit from it (Bhutta, 2004). Outside the research context, consent is not always obtained. Public health surveillance, for example, is seen to be in the interest of the collective and is often conducted without explicit informed consent (O'Neill, 2004).

The authors argue, however, that in the case of VAs, compulsion is unlikely to lead to compliance. The accurate assignment of COD from VA depends on accurate data collection which, in turn, depends on the active and willing cooperation of the respondent. There is little to be gained by overriding individual autonomy (such as threatening legal sanction) in this respect. To open an interview by explaining its purpose and processes and by obtaining the willing cooperation (written or otherwise) of the respondent is a matter of both courtesy and common-sense. Our practice has been to instruct interviewers to curtail the interview if the informants become overly distressed and/or if they say they are unable to continue. It is not our allotted task to punish those in distress.

If an informant requests privacy, the interviewer should accede to the request. It is not unusual however for a number of people to attend the interview. In some cultural contexts the head of the family would be expected to accompany others during an interview or it may also be that several members of the community were involved in the care of the decedent and with some having access to knowledge that others lack. On such occasions the informants may seek to achieve consensus in their account of the terminal illness. Interviewers can and should ask the main respondent if they mind others being present during the interview but often there can be more than one person present at an interview (Mony & Vaz, 2011).

Informed consent is often obtained from the main respondent or for example in India, the head of the household. In cases where there is more than one respondent, however, the concern surrounding 'who should provide consent?' may require negotiation with the family or community.

One study looked at the potential of using birth attendants, instead of grieving mothers, as VA respondents in perinatal deaths (Engmann et al., 2012). If this is deemed appropriate, consent should still be sought from the mother, and potentially the head of the household.

Another ethical concern is the timing of the VA interview. A VA interview can be an emotional experience for the bereaved, perhaps particularly when the death occurred recently and/or was due to traumatic circumstances. There is a general consensus that interviewing a bereaved individual too soon after a death could cause unnecessary emotional harm to the respondent and should be avoided. Deciding what the appropriate amount of time after a death is will require a careful consideration of a number of factors such as local cultures, the nature of the death and who is to be interviewed (Allotey et al., 2015,Chandramohan et al., 2005). Typically two weeks is considered a reasonable time to wait after the death, but in some cultures, like in Vietnam for example, waiting six months may sometimes be seen to be appropriate (Brolan et al., 2014). Although neonatal deaths may pose specific challenges, evidence suggests that VAs can be conducted up to 12 months after a death without loss in accuracy (Hussain-Alkhateeb et al., 2016,Serina, 2016). In certain situations, for instance when a person is dead on arrival at a health facility, it may be appropriate to conduct the VA at the time when the death is identified. The appropriate period of mourning should be established according to local culture and the delay in conducting the interview built into CRVS procedures. Again, community guidance is both prudent and necessary.

The duration of an interview may also matter. There is a general move to reduce the length of a VA interview (Serina et al., 2015). Some evidence, however, has suggested that respondents, at least in some contexts, may prefer a relaxed experience where they have time to recall the details of the death (Gouda et al., 2016). Where possible, therefore, interviewers should be given some flexibility with regards to timing and duration of interviews; this is particularly true for those that may not have previously had much contact with health services and may need more time to appreciate the relevance of the questions or may want to learn about their relative’s condition or how to help prevent similar types of deaths in their community (Asuzu et al., 1996). Again this is where embedding the development of these systems in communities and in partnership with the community may see long term benefits (D'Ambruoso et al., 2016).

(v) VA Data

We have considered privacy in terms of persons other than the primary respondent being present during a VA interview. We will consider confidentiality in terms of access to written information. This may comprise 1) the record of interview; 2) the COD assigned to the decedent; and 3) de-identified data.

Access to information about individual deaths can vary substantially by country and indeed within countries (Dimick, 2009). We suggest that the right of access to the assigned COD be on the same legal basis as access to a MCCOD within countries. This might, for example, be based on the relationship of the applicant to the decedent and evidence that the information was required for some legal right or entitlement. A situation can be envisaged, for example, where suicide is assigned as the COD. This might lead to the denial of an insurance claim and consequently persons not present at interview wishing to take legal action against those who were present. We suggest that under those circumstances access to the VA assigned COD could be made available to the claiming party as a consequence of a court order (for instance).

When the circumstances surrounding a death pose potential harm to others, however, confidentiality can be at odds with reporting requirements (Lee et al., 2012). In the case of HIV reporting, for example, it is generally recognised that the importance of complete and unbiased reporting outweighs individual rights to confidentiality (Melchert & Patterson, 1999). Having said this, we must make clear that the legal status of COD assigned on the basis of a VA has, to the best of our knowledge, never been established.

Access to de-identified mortality data – particularly for the development of public health policy and planning interventions - has already been the subject of much discussion (Brolan et al., 2017). Access to information gathered is crucial to coordinate public health action, to monitor progress and to guarantee accountability. Chandramohan et al (2005) have previously called for mortality data from demographic surveillance sites be made available through public domains and the use of the UK Freedom of Information Act to help develop guidelines on the provision of primary data. In the spirit of open-access to information, in 2014 INDEPTH made the largest mortality database freely available online (Wellcome Trust, 2014). Similarly, health information systems need to consider how information can and should be shared with policy-makers, researchers, civil society and the public. In a 2005 special edition of the Bulletin of the WHO on Health Information Systems (HIS), McGrail and Black (McGrail & Black, 2005) raised a number of important questions about HIS data including; who owns the data, who is responsible for the data, what will data be used for and how will the use of data be controlled? The authors go on to argue that LMICs now have the opportunity to learn from the experiences of developed countries and incorporate policies at the early stages of system development to address some of these concerns. In the US, for example, guidelines have been developed to help identify the issues that arise in the context of registry data (Gliklich et al., 2014). Even in this case, however, the authors urge that legal counsel be sought to ensure that actions abide by domestic and international law.

Access to identifiable data must be restricted but even de-identified data, when disaggregated, could potentially stigmatise small communities. It has been noted, however, that the emphasis on privacy and confidentiality in COD notification to National Statistics Offices can impede public health research. In South Africa, for example, a new Births and Deaths Registration Act in 2014 means that restrictions placed upon notification in the name of confidentiality has made the use of data for public health purposes challenging or impossible (Groenewald et al., 2015). The authors point to the

UK National Public Health Act of 2006 (Parliament of the United Kingdom, 2006) as an example of successful collaboration between the National Health System and the CRVS. As routine VA is in its infancy, we therefore urge all involved to consider these issues carefully and to not rush domestic VA-related legislation without adequate and well-considered inter-disciplinary research, experience and insight.

(vi) VA Results

At the population level, VA information is very effective at estimating the distribution of different causes of death and has been shown to be a valid basis for the production of vital statistics (Hernández et al., 2011,Murray et al., 2014). The accuracy with which VAs assign a cause of death to a specific individual, however, is less than 50% accurate (Murray et al., 2014). An individual VA-assigned COD is, of course, a concern of the immediate family but the results cannot possibly carry the same legal weight as those obtained from MCCOD.

Although VA respondents have also expressed a desire to know the outcome of analyses in some instances (Aborigo et al., 2013,Gouda et al., 2016), we are not aware of this having been established practice in research sites. Nevertheless, we consider that, having contributed to the information contained in the VA, and ensuring appropriate levels of confidentiality are upheld as we have discussed above, the informant and the family of the decedent have a right to know the outcome of the interview. This will require an appropriate legal framework. Although it may eventually be technically possible using automated diagnostic methods to provide respondents with a probable COD at the conclusion of the interview we strongly recommend against this. Firstly, as noted above, VA results at the individual level are highly uncertain. Secondly, the VA results need to be imparted in a considered way and in an appropriate environment. A MCCOD is usually written after the physician has had a period of contact with the family and has had opportunity to discuss the diagnosis with them. We recommend therefore that if a family requests information about the cause-of-death that an appointment is made for them to meet with a health professional in privacy in the local health facility. This implies high degree of coordination from the implementing institution as individual VA results will need to be communicated with the relevant health professionals and these health professionals will need be trained in the interpretation of the VA outcomes and in counselling families. It also assumes that countries will be able to provide disadvantaged and rural, or remote living, individuals help to access said local health professionals. We must point out that thus far we have no experience of this in practice. Where there is a suspected infectious disease, such as HIV, involved in a death family members should be counselled to attend a health clinic and receive testing.

Legislation in most countries maintains that only a registered medical practitioner can authorise a death certificate. The legal status of COD assigned by automated VA is yet to be established in nearly all jurisdictions. Not only is there uncertainty surrounding the accuracy of the assigned COD but this has been based on information provided by third parties who may have a vested interest in determining that outcome. This is a very different situation from that of a physician who is expected to have first-hand knowledge of the decedent. We therefore counsel caution in relying on the outcome of a VA without full consideration of the evidence upon which that outcome has been based. This would include due caution in relying on COD assigned by VA in the context of social insurance schemes which may restrict payments for particular causes (such as suicide) or may potentially alter premium rates based upon risk of disease to those surviving relatives (World Health Organization, 2013).

Special cases occur, in the Philippines for example, when the decedent has contact with health services, a VA has been used to supplement the physician’s knowledge of a case and the physician is expected to sign a MCCOD incorporating this information (Knowledge Management and Information Technology Service, 2015).

Another potentially problematic legal concern is the VA interviewer’s responsibility to report crimes. VA interviews can reveal details about a death that may implicate someone in a criminal activity or direct blame to an individual or institution. Guidance for research investigators in these cases is lacking (Johns Hopkins School of Public Health Institutional Review Board, 2010). Some specific issues may need to be considered. Where an alleged perpetrator of a homicide is identified during the VA, for example, local cultural understandings of causality may also need to be considered (Sibley et al., 2009). Beliefs about witchcraft, for instance, may point blame on an innocent individual (Fottrell et al., 2012). Secondly reporting allegations may put VA interviewers in danger of retaliation from those accused. Lastly, while on one hand reporting to the police or authorities may threaten the trust between the public and CRVS authorities, on the other, failing to report guilty perpetrators of crimes could break it completely.

Criminal deaths are likely to be relatively sensitive. Non-disclosure for fear of reprimand, or because of trauma could mean that VAs are not easily interpreted (Matzopoulos et al., 2015). In India, for instance, deaths by fire amongst women between 15 and 34 are prevalent and are not readily reported to the police. Many of these deaths are likely to be the result of domestic violence but will not be identified as such on death certificates (Sanghavi et al., 2009) or VAs. For fear of their own safety, a VA interviewer may feel they are in a vulnerable position and need to cover up murder (Wardlow, 2006).

Disclosure of details gained during interviews should abide by similar guidelines as those applied to patient’s rights to confidentiality. Doctor-patient privilege is a central tenant of medical ethics (Agyapong et al., 2009). This principle is not considered to be breached when disclosure is in the public interest. We recommend therefore that respondents should be made aware that information revealed during the interview will remain confidential except in the case that interviewer discovers; 1) that someone is a danger to themselves or others; 2) that a child (under the age of 18) has been subjected to abuse or neglect; or 3) that a crime has been committed or will be committed and the authorities have not been made aware. Going forward, we suggest a robust but sensitive discussion be had between population health practitioners, appropriate legal advisers and development agencies, Department of Health staff, and community members to locate potential, context-specific solutions to legally or otherwise safeguard the VA interviewer is necessary.

CONCLUSION

Today, more than two thirds of deaths that occur globally are still not captured by civil registration systems (Mikkelsen et al., 2015). In these cases, VA can provide crucial data to inform national decisions about disease prioritisation and health service provision. To date, significant efforts have been employed to ensure that the analytical potential of VAs has been comprehensively explored. Current guidelines and standards for VA implementation, however, were developed with research settings in mind and indeed may not have had sufficient impact upon practice (Joshi et al., 2009).

The challenges involved in incorporating VAs into registration systems should not be underestimated. Technological advances can help ensure cost-effectiveness and ultimately the quality of data (Joshi et al., 2015). Now, it is necessary to consider the implementation of VAs in routine (non-research) settings is conducted effectively, ethically, and in a socially acceptable manner in accordance with local custom and contexts and ensuring community participation and ownership by fostering an environment of responsive VA practice. To achieve this, concerted effort and committed leadership will be necessary to scale up human resources and provide adequate training to the VA workforce and to envisage and prepare for potential consequences of VA methods.

Indeed, the VA process brings up many issues outside the technical and scientific discourse within which it has largely been embedded (Brolan et al., 2017). Countries and their partner agencies should ensure that a diverse range of perspectives are taken into account by making available forums to include voices from the community as well as from other local institutions such as those representing religious, legal, anthropological and of course medical perspectives and interests. To date the operational aspects of routine VA in CRVS are novel experiences and monitoring and evaluation should be included as part of the implementation plan to better understand how to ensure quality implementation and the acceptability of VA methods by diverse communities. Legislation and regulation, in respect to access to data in particular, should not be rushed without first accumulating sufficient country-experience of incorporating VA into CRVS. Incorporating VA into CRVS systems is a major step forward for the data revolution, and such a step should be preceded with careful consideration and caution.

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Table 1 Search terms

	Search terms: (verbal autopsy OR verbal autopsies) AND…
1 The Questionnaire	Open narrative OR qualitative OR survey design OR questionnaire design

2 The Interviewer: Qualifications and Training	Layperson OR training OR qualifications
3 Systems Design	Equity OR equitable OR justice OR inequality
4 The Interview	Consent OR confidentiality OR autonomy OR privacy
5 VA Data	Data access OR access to data OR access to information
6 VA Results	Crime OR criminal OR murder OR homicide
7 General Terms	Social OR cultural OR community OR ethical OR ethics OR acceptability OR legal OR law OR implementation OR routine

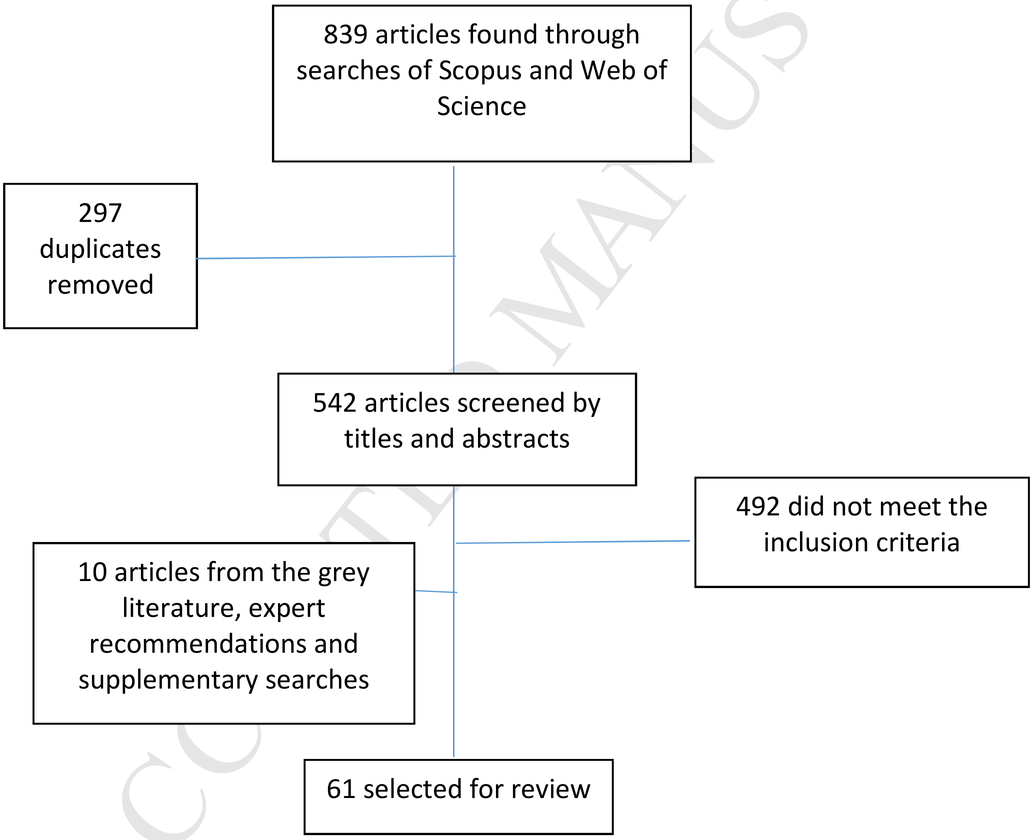

Figure 1 Flowchart of literature search and paper selection

Table 2 Summary of recommendations and issues raised

Stage of VA process	Recommendations and Issues Raised
The Questionnaire	• Qualitative approaches may bring to the fore important cultural aspects of the death or provide insights into the health systems role in the death. This must be weighed up against the time and efficiency

	needs. Ultimately the VA as a proxy for MCCOD is intended to inform vital statistics or to provide public health information. It is unlikely that routine VA will be able to accommodate a significant qualitative component. However, data collected by routine VA could be used to help develop a sampling frame from which researchers could develop studies to investigate health systems and other issues related to mortality and public health • Perhaps more feasible is the inclusion of a limited number of questions about access and quality of health services, though again the extent of this questioning will have to be weighed against the time needed to complete the survey and the demands placed on the routine system.
The Interviewer	• It has been recommended that VA interviewers be trained in bereavement counselling. This could be very valuable but a careful understanding of the cultural contexts in which the interviewers are working will be necessary. Implementing institutions should consider working with local psychologists or medical anthropologists. • VA studies have used health care workers as well as lay persons to conduct VA interviews. The evidence on the acceptability by the community of different qualifications and levels of education is currently limited and inconclusive. Further research in this area would be of value. • Due to the sensitive nature of their work VA interviewers may face the potential for emotional (and in some rare occasions physical) harm. It will be important for implementing institutions to be aware of their interviewers needs and provide the necessary support.
Systems Design	• Ensuring equitable representation in civil registration needs strong technical guidance and countries should invest time and resources in developing appropriate strategies. • Encouraging the active participation of communities in the development of VA approaches can be an invaluable process to ensure local ownership of processes, knowledge transfer and ultimately action to improve health outcomes.
The Interview	• VAs should not be made compulsory by implementing institutions. Informed consent should be obtained and the emphasis must be on *informing* respondents and communities about the role VAs play. • The acceptable or preferred timing and duration of VA interviews are likely to be culturally specific and procedures around these factors should be decided with the community of interest where possible.
VA Data	• With regards to confidentiality, individual VA data should be considered to be of the same legal status as a medically certified cause of death which would typically be restricted to immediate family. • Routine VA is still in its infancy. Countries should not be too quick to secure rigid legal frameworks around the use and access of VA data.
VA Results	• VA results are typically characterised by some degree of uncertainty. Even where the cause of death seems obvious, such as in the case of drownings, the information is garnered from an individual who may be driven by their own perceptions, emotions and motives. The possibility that the VA contains wrong information cannot be discounted. We recommend therefore that individual VA results

	should not be disclosed at the time of interview. If a family wants more information an appointment should be planned with trained health service provider. - During a VA interview, it may become apparent to the VA interviewer that a crime has, or possibly has, occurred. There is insufficient guidance on the rights and responsibilities of interviewers and research institutions in these situations. We suggest that sensitive discussion be had between population health practitioners, appropriate legal advisers and development agencies, Department of Health staff, and community members to locate potential, context-specific solutions to potentially invidious positions the VA interviewer may find him/herself in.
Overall	- Where possible, when developing implementation plans, forums should be made available to a wide variety of voices from the community as well as from other local institutions such as those representing religious, ethical, legal and medical perspectives and interests. - Monitoring and evaluation should be included as part of the implementation plan to better understand how to ensure quality implementation and the acceptability of VA methods by diverse communities. - Legislation and regulation should not be rushed without first accumulating sufficient experience of incorporating VA into CRVS.

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- Countries require cause-of-death (COD) statistics for effective public health planning
- Verbal autopsy (VA) can provide COD where medical death certification is absent or weak
- VA methods are currently being incorporated into Civil Registration and Vital Statistics systems
- Presents a number of social, cultural, legal and ethical issues that should be considered when scaling-up VA
- Countries must carefully consider the regulatory structures necessary for VA in routine systems