Social Science & Medicine 184 (2017) 65–74

Contents lists available at ScienceDirect

Social Science & Medicine

journal homepage: www.elsevier.com/locate/socscimed

Review article

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

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ARTICLE INFO

Article history:
Received 12 August 2016
Received in revised form
27 April 2017
Accepted 1 May 2017
Available online 3 May 2017

Keywords:
Verbal autopsy
Ethics
Civil registration and vital statistics
Health information system
Cause-of-death
Implementation

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.

1. 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.

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http://dx.doi.org/10.1016/j.socscimed.2017.05.002
0277-9536/

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., 2015a,b). 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.

2. 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