

Verbal Autopsy - Concept and Role in Indian Scenario

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Background:

Mortality statistics plays a very important role in creating an information pool about the prevalent diseases in the community.^{1,2} Life and Death - are two universal events of life with a defined and clear outcome which is easy to understand² even for people with no medical background. Enumeration of births and deaths in the community within a defined time period helps us to have an idea about the crude birth rate and crude death rate, respectively. In absence of a well developed, reliable health information system, often, these are the only reliable health information available to us.^{3,4}

Enumerating the births and deaths in the community has a very long history - both nationally and globally. There is a tradition among Hindus - to record the death of near and dear ones while completing the religious ceremony in memory of the passed ones in Haridwar.⁵ This provides a genealogy tree of family members died. In Europe, church members used to enumerate the births and deaths in the community and usually considered as a reliable source of information.^{6,7}

However, this treasure trove of information lacks one very important aspect - cause of death. Identification of the cause of death will provide us an idea about the prevalent disease conditions in the community. This will in turn help to take preventive measures - a domain of Community Medicine/ Public Health specialists - against those fatal diseases.

One of the major barrier for such identification of cause of death was non-availability of qualified and registered medical practitioners in the community, particularly in the rural areas, at the time of the death of the individual.¹

Recognising this problem, epidemiologists identified a novel approach - asking the kith and kins of the deceased about the health conditions of the deceased immediately prior to death. This helps in identifying the most likely cause of death.

Initially, it was treated as lay reporting.^{8,9} Team of physicians visited the household of the deceased and conducted interview of the kith and kins of the deceased. This approach was tried in 1950s-'60s in Asia and Africa.^{8,9} The first documented evidence of the World Health Organization's (WHO) interest in this lay reporting could be found on a publication by Dr. Yves Biraud in 1956.⁸ With time, this lay reporting system became very popular among the epidemiologists - particularly for those communities where an effective and reliable civil registration system do not exist. Workers at the Narangwal project in India coined the term "Verbal Autopsy" to this procedure during the '60s.^{6,8,9} Since then, the term becomes popular and presently it is used globally.

Tools and Techniques of Verbal Autopsy:

Verbal autopsy could be used in different aspects of health care delivery system with different objectives. Not only could it be used for establishing the cause of death but it is also very effective in identifying lacunae in the health care delivery system.

Despite it's varied usage, the generic principle behind conduction of verbal autopsy remains same - using a

structured questionnaire, an interviewer asks certain close ended questions to the relatives of the deceased. The relative is also requested to describe the events leading to death. This narrative is recorded as spoken by the relative in their own language.

Since the initial appearance of the structured questionnaire in Matlab (Bangladesh) and Niakhar (Senegal) as the verbal autopsy tool for ascertaining cause of death, this has

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undergone many changes.¹⁰ From time to time, WHO has published newer avatar of standardised questionnaire with introduction of the recent technological improvements.¹¹ The latest one was published in 2016.¹¹

Along with this questionnaire, the other important tool for the procedure of Verbal Autopsy, is the interviewer. Initially, the interviewer was a registered physician. Later, it was found that even a person without any medical qualification, could conduct verbal autopsy almost as good as a registered medical practitioner.¹⁰⁻¹² This finding changed the verbal autopsy scenario dramatically.

Optimal use of Verbal Autopsy is possible when it is applied for all deaths in the community; rather than using it for identification of specific cause of deaths.⁶

Indian Scenario - Usage of Verbal Autopsy:

In the initial years after independence, India was lacking in number of physicians. In absence of physicians, a large number of death due to preventable causes were attributed to witchcrafts.¹³ To counter this problem, identification of proper cause of death was necessary. Recognising this, various attempts were undertaken to generate reliable death statistics and if possible, most likely cause of death. As has been already mentioned, the term "verbal autopsy" has its origin in India (Narangwal project).^{6,8,9}

Verbal Autopsy in relation to Maternal Deaths:-

One of the first usage of verbal autopsy in India was related to maternal deaths. Maternal death is defined as death of a woman while pregnant or within 42 days of termination of pregnancy, irrespective of the duration and site of the pregnancy, from any cause related to or aggravated by the pregnancy or its management but not from accidental or incidental causes.¹⁴ UNICEF recommended application of MAPEDIR (Maternal and Perinatal Death Inquiry and Response) with the objective to identify the system lacunae and scope for improvement of system rather than to assign cause of death.^{15,16} After going through a pilot testing in the Purulia district of West Bengal^{15,16} for community based review with support from UNICEF, and with evidence from few other states, it was incorporated in RCH - II (Reproductive and Child Health) as a program component.¹⁷ As the perinatal component of MAPEDIR was never implemented in India, it was named as Maternal Death Review (MDR). MDR has two components - facility based review (for maternal deaths occurring in the health facility) and community based review for all reported deaths. Verbal Autopsy is an integral part of the community based MDR.^{18,19}

During its implementation, it was observed that MDR is mostly staying as an ornamental procedure. The findings from the review are usually not considered for responses. Hence, it was further renamed to Maternal Death

Surveillance and Response (MDSR), with specific emphasis on response.¹⁸ During its use in the community, it was found that verbal autopsy was a very important tool for finding out the delays associated with maternal deaths (delay in identification of the risk factor and deciding to seek care; delay in reaching health institutes; delay in receiving appropriate care).⁶

Verbal Autopsy in relation to Universal Immunisation Programme (UIP):-

Verbal Autopsy has been utilised in identifying problems associated with another vulnerable group - children. In the Universal Immunisation Programme (UIP), verbal autopsy is used during the investigation of AEFI (Adverse Events Following Immunisation). This is also expected in identifying the problems associated with system and adopting corrective measures.²⁰

Verbal Autopsy in relation to Sample Registration Survey (SRS):-

Office of Registrar General (ORGI), Government of India was entrusted with the responsibility to generate reliable birth and death statistics. Along with census, they maintain various sampling units across the country.²¹ These sampling units are used to generate reliable information on various demographic parameters.^{21,22} They were pilot tested in 1964-65 and fully functional since 1969-70.²² This is known as Sample Registration Survey (SRS). Each SRS unit has a designated SRS supervisor, a permanent employee of the ORGI, and a Part Time Enumerator (PTE), a local community member. PTEs continuously enumerate the births and deaths in the community. SRS supervisors visit the units twice in a year and do the enumeration for last 6 months independent to the PTEs. During this visit, SRS supervisors visit every household of the unit and inquire if any birth or death had taken place since last visit. As PTEs and supervisors are working independent to each other, this is considered as independent dual survey. Through this independent dual survey, a final list of births and deaths are prepared. Initially this huge network was used for enumeration of birth and deaths only; identification of cause of death was not done by the SRS supervisors.²²

With the entry to this millennium, Center for Global Health and Research (CGHR), Canada signed a Memorandum of Understanding (MoU) with ORGI for utilising this huge network of supervisors for conduction of verbal autopsy. There were four different verbal autopsy forms - 10A (for neonates), 10B (for individuals with age between 28 days to 14 completed years), 10C (for the adults) and 10D (to be filled up for maternal deaths in association with 10C). These filled up verbal autopsy forms were then shared with physician coders for assignment of most likely cause of death. This collaboration continued till 2014. ORGI published articles

enumerating the prevalent causes of death based on this process. These findings were representative upto state level and not below that level due to the sampling criteria.^{21,23,24}

In 2014, Government of India decided to nationalise this process. Due to lack of medical professionals within the hierarchy of ORGI, ORGI decided to rope in All India Institute of Medical Sciences, New Delhi - one of the premier medical institutes of the country - as Technical Support Unit. Initially, a technical advisory group was formed with the responsibility of making policy and strategy decisions. AIIMS-New Delhi decided to include other premier medical colleges across the country for covering the length and breadth of the country as Network Partner Institutes (NPIs). Presently, twenty-five NPIs are included in this activity. It is named as MINerVA (Mortality in India Established through Verbal Autopsy). For the state of West Bengal and Sikkim, Department of Community Medicine, Burdwan Medical College is identified as NPI.²⁵⁻²⁷

Limitations:

The biggest limitation of 'Verbal Autopsy' probably lies in its name. Though verbal autopsy is small and very simple to utter, it is likely to provide a false idea about its usage; particularly among medical fraternity. The term 'Autopsy' carries a legal weightage. It helps to identify the exact cause of death. Thus autopsy has a definitive legal value. However, 'Verbal Autopsy' does not have any legal value; in spite of having 'Autopsy' in its name. This has an epidemiological value but as it could not identify the exact cause of death, this could not be used legally.

In case of community based MDSR, findings from verbal autopsy are sometimes being used to punish the health care workers; rather than filling the lacunae of the health care delivery system. The 'No Name, No Blame' policy mentioned in the MDSR guideline are often overlooked by the administrators.¹⁸ It is creating a barrier in the identification of the health system lacunae and thus causing difficulty in combating maternal deaths.

Although, the process of verbal autopsy reduced the required number of physicians for identifying the most likely cause of death, the requirement for skilled manpower still exists. The interviewers need to be trained in the process of verbal autopsy, which is a resource consuming process. These interviewers are going to act as eyes and ears of the physician coders in the field. Unless they are properly trained, the quality of the narrative will be poor and will act as a hindrance in identifying the cause of death.

Presently, the narratives are available in the language of the relatives of the deceased. Unless a physician with that language proficiency is identified, identification of the most likely cause of death for that individual will not be possible to make. So, even with all these methods, most likely causes of deaths among the lingual minorities are likely to be under estimated.

Way Forward

With the availability of machine learning (ML), artificial intelligence (AI) and massive computer resources, steps are now being taken to transfer the responsibility of identifying the most likely cause of death from physicians to computer algorithms. These smart algorithms improve themselves with usage. Ultimately, this will help to release the physician coders from the mundane task of coding to taking care of patients.^{6,8}

Identifying the opportunity, World Health Organisation has made certain changes in the verbal autopsy form and made them more structured. The latest version was released on 2016. An OCR compatible software will go through these forms and made them appropriate for the algorithms. The algorithms will then identify the most likely cause of death from the scanned forms. Out of the various algorithms available, InterVA and SmartVA are the most popular. However, these are currently not being used in India.

Conclusion:

Despite its use in different parts of the health care delivery system in India, verbal autopsy remains an under utilised and often misunderstood epidemiological tool. In case of community based MDSR, a proper evaluation of verbal autopsy as a tool for combating maternal deaths is due for a long time. Verbal Autopsy could not be a long term measure for assigning the causes of death. In the long run, every citizen should have access to a physician at the time of death. This will help in identification of the actual cause of death; rather than the most likely cause of death. It is the responsibility of the government to take measure in this regard. When Medical Certification of Cause of Death (MCCD) will be universally functional, probably verbal autopsy will no longer exist as tool for ascertaining cause of death.

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