

Death Audit by Verbal Autopsy and Social Autopsy: Potential Yet Unutilized Tool

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INTRODUCTION

In the quest for robust, reliable, and representative methods for filling health information gaps, mortality measurement plays a pivotal role. As a stepping stone towards Universal Health Coverage and bridge the health inequalities across a nation, mortality statistics help to monitor trends of health conditions of the population, detect new epidemics, find out proportion of avoidable causes of death, aid in budgetary allocation of disease control programs or in other words, play an immense role in strengthening nation's health system.

The three systems that measure mortality in India are the Civil Registration System, Medically Certified Causes of Death and the Sample Registration System (SRS). It is a well known fact that the coverage of Civil Registration System is currently inadequate due to gross under-registration. Around three quarters of deaths occur out of hospital in India and without medical attention and more than half of these do not have a certification at the time of death [1]. In this scenario, Verbal Autopsy (VA) is a stepping stone to increase the coverage of the functioning civil registration and death certification system to estimate cause-specific mortality. As defined by WHO, VA is a method used to ascertain the cause of death based on an interview by a trained, (usually) non-medical fieldworker with next of kin or other caregivers in order to gather information on the signs and symptoms that occurred prior to death and is applied for deaths where there is non-availability of certification of medical causes [2]. These details are then interpreted by trained physicians who assign likely cause-of-death according to ICD 10 Classification with the assumption that majority of cause of deaths have distinct recognisable symptoms and signs.

GENESIS AND USES OF VERBAL AUTOPSY

Existing even before 19th century in Europe when the modern system of death registration was not in vogue, designated death searchers were sent to households where deaths had occurred to ascertain the nature of death. With passing decades, modifications and refinements in methodology were done by various countries predominantly in Africa and Asia, which actively used this method for investigating maternal and child deaths. The potentiality of this method of investigation in contributing meaningful information towards improvement of health system is also well recognised in India where this technique was labeled as "verbal autopsy" at the Narangwal project at Ludhiana, Punjab in the year 1972 [3]. VA was used extensively in The Million Death Study (MDS) in India (1998-2014), one of the largest studies of premature mortality in the world and finally has been incorporated as a part of official mortality data collection system in SRS since 2002 [4]. Apart from India, where VA is officially used as a part of SRS since 2002, countries like Brazil, Bangladesh and Sri Lanka have also included this system in their official mortality data collection system [1].

CONCEPT OF SOCIAL AUTOPSY

Social Autopsy (SA) is another relatively novel approach which aims at identifying the non-biological causes of death, encompassing social, behavioural and intrinsic health system contributors. The history of SA dates back to the year 1952 in the United Kingdom of Great Britain and Northern Ireland as a part of hospital based

confidential enquiry into maternal deaths [5]. In order to qualify a community/household level enquiry as social autopsy, following answers need to be obtained:[6]

- Eight essential components of care-seeking process should be enquired: recognition of illness, adequacy of home-care, type of care given outside home; delays to formal health care seeking and related barriers; and the respondent's perspective on quality of care.
- Factors at household and community level as well as health system factors contributing to the death should be explored.
- Data obtained should be concrete and in large scale in order to support health programme or policy development or for community empowerment.

POTENTIALITY OF VERBAL AUTOPSY AND SOCIAL AUTOPSY (VASA)

Social Autopsy in combination with Verbal Autopsy, i.e., VASA (Verbal Autopsy and Social Autopsy) is not only used to ascertain cause of death, it can also obtain a holistic view of the social and health systems determinants contributing to the death as well as obstacles faced by the decedent in seeking, reaching and receiving essential healthcare. At population level, these information can be invaluable to help prioritisation in agenda setting of health policy and services. VASA has been conducted in countries like Bangladesh (as part of the Maternal and Perinatal Death Surveillance and Response (MPDSR) system, Malawi, Niger and Nigeria, using retrospective surveys for data collection for investigating maternal, neonatal, stillbirths, and under five deaths [4]. This tool has also been adapted by researchers to investigate adult deaths due to all causes, deaths due to communicable diseases like dengue, Kalazar, HIV/AIDS and non communicable diseases like road traffic accidents as revealed from review of published literature.

In India, Dead Woman Talking Initiative, a collaborative civil society initiative, is one such example where over 200 maternal deaths in 10 states during January 2012 to December 2013 were investigated by SA using SSSR Framework-Science (or technical aspects), Systems (health systems related factors), Social (individual, family, community factors), and Rights (Human Rights, Right to health, Reproductive and Sexual rights) [7]. After a maternal death was reported in a community and verified by trained staff of the organisation by making a house visit, SA was conducted on family members by a team of 2-5 trained investigators, after the mourning period (usually 4 weeks) was over. Interviews were also conducted with other community members as well as frontline health workers to find out the "missed opportunity" which if addressed would have probably saved another maternal death. Eventually this method was taken up at programmatic level to investigate maternal deaths by MAPEDIR and later on by MDSR using Three Delays Model. Furthermore, based on the findings, vital interventions have been taken up to effectively fill up the gap of missed opportunity e.g. in Dholpur, Rajasthan, taxi union, local NGO, and district health society collaborated in planning and running an obstetric help line and referral transport system [6]. In Maternal and Perinatal Death Surveillance and Response (MPDSR) system in Bangladesh,

a facilitator trained in SA initiates dialogue with a group of 30-50 community members including family members of the deceased and explores the social factors, avoidable issues and barriers surrounding the death. Here social autopsy is also used as a health promotion tool, whereby the facilitator also presents information, education and communication materials to show the community what they need to do if similar maternal or neonatal complications arise again [8]. Effectively conducted SA can help the community in knowledge building, community/self empowerment and commitment generation. Reflections of such potentiality was also reported by a case-study in Bangladesh, where these sessions resulted in an increase in health-care seeking among women in pregnancy and after childbirth [8].

Another format adopted for analysing SA data is the Pathway to Survival model, which is utilised in many countries in Asia, Africa, and Latin America to explore the care seeking pathway for childhood illnesses and deaths. The first analysis of child deaths following the Pathway model was a survey conducted in 1995 for 271 child deaths in El Alto, Bolivia [6]. Since then, efforts have been put forth for refining the tool, most notable amongst which are WHO/UNICEF-supported Child Health Epidemiology Reference Group (CHERG) the International Network for the Demographic Evaluation of Populations and Their Health (INDEPTH) [9]. To review and update the Pathway Analysis social autopsy format. Initiatives have also been taken to include the inquiry questions in electronic data collection systems in various Low Middle Income Countries (LMICs) e.g. 'Smart Care' in Zambia [10]. More recently, community-led approach to inquiry on Ebola outbreak, the 'Ebola Response Anthropology Platform' revealed how social and cultural norms became barriers to access care and the findings helped to design and test supportive programmes for survivors and families [4].

CHALLENGES IN VASA INQUIRY

Despite the huge potential of VASA method for providing information in order to strengthen health care delivery system, various methodological differences need to be addressed for comparability of data across countries. Most notable amongst them is the variability of recall period for obtaining VA data wherein published studies report wide variability ranging from 2 weeks to 2 years in case of maternal deaths and 4-6 weeks to 5 years for child deaths; thus possibility of recall bias may lower the strength of evidence gathered. Development of standardised tools which are simple and less time consuming for collection of SA data, in similar lines to standard WHO VA formats is also another challenge that needs to be addressed in order to encourage the use of social autopsy, as a method for routinely informing policymakers and planners [2]. Some studies have reported use of qualitative methods, while some had developed integrated VASA tool; but variability of data collection techniques have led to variable data analysis hampering cross country comparison and thus limiting its utility. Last but not the least, unless standard tools are developed, field worker training will be a major challenge, as questions related to death inquiry are always sensitive in nature and at times stigmatising to the family members. Ethical challenges related to the protection of individuals in terms of data confidentiality and mental distress, are especially pertinent. Therefore internationally validated methodology for combining

or sequencing the verbal and social autopsy interviews through standardised questionnaires is the need of the hour. Consensus on standardised formats of SA and computer-aided data analysis plans will further enhance the quality of social autopsy data.

WAY FORWARD

In Indian context, though VA is being widely used, SA and combination of VA and SA for prioritising health problems and informing policymakers for providing targeted interventions has not yet gained much foothold except its limited usage in Maternal Death Surveillance and Response. In 2014, Government of India had initiated the program MINERVA (Mortality in India Established through Verbal Autopsy) for assigning cause of death through verbal autopsies performed under Sample Registration System and coordinated by the Office of Registrar General of India [11]. As of August 2019, the MINERVA network with 25 reputed government and private medical colleges in its network along with 804 physician coders are working to strengthen the mortality surveillance system in India [12]. As an integral component of this robust platform, SA can be added in the next step for understanding barriers to care seeking pathway for fatal diseases with preventable potential but with high prevalence like malaria, tuberculosis, road traffic accidents, and other non communicable diseases like stroke. Recognising the fact that SA is a powerful tool, rigorous research is also needed to explore the cost effectiveness of social autopsy to act as a powerful tool for community empowerment.

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