Cause of Death by Validation from Verbal Autopsy in Selected Sites of Rural South India

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ABSTRACT

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Background: Mortality data by cause of death for the entire cross-section of the population in the country is essential for informed decision making in the health sector. Information on cause of death in India is poor because, lack of data base and existing mortality record is incomplete at national level. The identification of cause of death is not feasible due to paucity of medical personnel's, complexity of datasets and health care management etc. Apart from our Practical experience, the validated verbal autopsy tool is very much important for health administrative convenience and management of medical and non-medical staffs for eliciting information on cause of death at population level. Cause-specific data on mortality form the core of any health planning strategy. The size and geographical distribution of occurrence of deaths by their causes for different age-group, sex, residence and other immense characteristics added greatest value to the public health planners, medical scientist, epidemiologists and researchers.

Methods: The Pilot based study was conducted in selected sites of Rural India, the field investigators were collected primary data sets from varied geographical location, an interviewers has visited the sites for extrapolation of accurate cause of death at population level (blinded to the hospital diagnosis it was conducted at greatest accuracy). In a nutshell, the enumerators were collected survey data sets from pretested questionnaires, consequently investigators were adopted various driven mechanisms for collecting elicited symptoms, signs of the disease conditions etc. All data sets were collected from the direct and focus group interview respectively from selected sites. The study components has derived main and pilot based, In case of main study, field Investigators were collected mortality information in the selected sites through direct interview, focus group interview and also visited door-to-door steps for gathering information pertain to cause of death by survey method. Simultaneously, the medical officers were documented cause of death on various diseases. Finally, observed and unobserved (hospital data) data sets were simulated from logit probability model to test the hypothetical statement about the population.

Results: The present study derived two components via pilot and main study, in case of pilot-based study major cause of death was pregnancy and child birth complications with predicted good sensitivity (85.7%), specificity (100%), and positive predictive value (100%) (Odd ratio 4.65; p=0.0012; CI 95%0.63-0.74). Among neonatal deaths, the major cause of death was seen in perinatal (65.0%) (Specificity 95.5% sensitivity 62.5% and PPV 87.5%) odd ratio 3.47; p=0.002; CI95% 0.55-0.71) among child mortality the major cause of death was "infectious parasitic (25.0%) with good specificity (71.0%); sensitivity (85.7%); PPV (68.0%) and odd ratio was 4.88;p=0.0001; CI 95% 0.19-0.28) As we noticed, in maternal deaths, the major cause of death was "pregnancy and child birth (36.0%) besides with specificity (86.7%), sensitivity (50.0%) and PPV (92.9%) odd ratio was 3.11; p=0.002; CI 95% 0.28-0.39). Mortality due to accidents and injuries was (9.0%) with sensitivity was (100%), specificity (95.7%), and positive predictive value was (80.0%) odd ratio was 1.98 p=0.08; CI 95% 6.33-10.19). In case of main study, among adults 204 (29.30%) p=0.018 death due to cardio vascular diseases, 96 (13.81%) p=0.00, respiratory diseases, 80 (11.5%) p=0.001, cancer, 34 (4.9%) p=0.000 and renal failure. Cardio vascular diseases rank first for both years of Potential Life Lost (PLL) and cause-specific mortality rates irrespective of gender.

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Conclusion: The verbal autopsy is the instrument, as can be used to estimate the distribution on causes of deaths in rural areas, since the vital registration is ill-defined. The death due to non-communicable diseases accounts (65.30%) on all deaths aged between 20 years and above in the selected sites: the study clearly depicted that; a strong emergency call for public health action would be needed.

Keywords: Potential Life Lost; validated Verbal Autopsy; Mortality; Cause of death

BACKGROUND

The comprehensive assessment of disease burden will help the policy makers to identify the leading causes of deaths in the community level and we can plan necessary health sector interventions [1]. Since, the burden of disease has been quantified by combining information on morbidity and mortality [1-5]. Information on morbidity in India has been obtained from existing disease surveillance system (incomplete and inadequate). The special rounds of National Sample Survey Organization (NSSO) [6,7] and National Family Health Surveys (NFHS) [1,2] provide information on mortality and reported morbidity but they are not the routine on-going activities. Though, registration of births and deaths act is promulgated, information on mortality through the Civil Registration System in India is inadequate and incomplete to say the least [3]. Under the registration of births and deaths act, Government of India enforced the scheme of Medical Certification of Cause of Death (MCCD) in all major states and Union Territories except Jammu and Kashmir of India in which the physician attending the deceased during his or her terminal illness is expected to ascertain the cause of deaths [5]. At present, the scheme of MCCD is in operation only in some urban areas [6]. In case of rural areas many literatures cited, the paucity of medical personnel and facilities, the system of MCCD is virtually not operational [7]. To bridge this gap, survey on cause of death was initiated way back in 1968 under the Model Registration System (MRS). The MRS was renamed in 1982 as 'survey of cause of death - rural scheme' in which cause of death for the rural areas are being collected from a sample of villages by lay-diagnosis using medical auxiliaries [9]. This scheme has been in operation since 1999 under the SRS-COD component [10]. In developing countries like India, identification of cause of death for the entire country by medical professionals is not a feasible proposition with limited resources in terms of money and manpower [11]. There is a need for trained non-medical staff to determine the cause of death by administering VA [12]. The validity of cause of death data generated by medical auxiliaries or non-medical staff using VA has to be evaluated. It is worthwhile, in short to elicit the causes of death in larger community level or population. The causes of death at the population level will help in identifying the leading cause's death in practice by the community level [10]. In this present study we discussed the validation of VA findings by real data sets as compared to that of hospital diagnosis. The verbal Autopsy instrument was employed with accelerating reasonable estimation of various kinds of distributions of cause of death at the population level , In case of all types of deaths in order to establish frequentisitc priorities for needful action taken by the local population. Finally, this paper also attempts to present various findings of verbal autopsy instrument for eliciting different causes of death in selected sites of South India.

METHODS

Validation of study area: The field technical service personnel's collected the information pertaining to cause of death through visual basis (field practice area for National Institute of Epidemiology)

while, they covered a total of 148 village panchayath (rural administrative units) comprising of 264 contiguous villages and a total of 2,90000 people were selected from the Sriperumbudur and Kancheepuram taluk of Chingleput district, Tamil Nadu, south India. However, the diseases has predominately affected in all the selected sites and mortality rate was significantly higher as compared to that of other areas (NHFW, 2014).

Verbal Autopsy: The verbal autopsy instrument was adopted for collecting cause of deaths from the testes questionnaires (structured based on English and local languages for child collecting paediatric and adult deaths used by various researchers in India (unpublished) was considered). Structured questionnaires were divided into four parts viz Schedule- 0; identification and socioeconomic data of the household; Schedule 1-Stillbirths; Schedule 2- Neonatal deaths (0-28 days); Schedule 3 Child deaths (29 days to 5 years); Schedule 4- Adult deaths (above 5 years) including maternal deaths etc. The VA instrument has been translated into local language Tamil, and it was modified to a suitable format for the local community. Two non-medical Senior Research Fellows (SRF) having post-graduate qualification and two field investigators (FI) having graduate qualification from the local area (Tamilnadu) was recruited and trained in collecting the permissible information from the local community. During the field training, the interviews of each SRF were carefully monitored and supervised by Medical Officers. Periodic feedback sessions were held to appraise the quality of information collected, based on symptoms and signs for assigning the cause of death etc. A team consisting of a Medical Officer and one field investigator collected the information on age, sex, address, type and cause of death from the local hospital records. The field investigator identified the household in the community where the death was occurred. The SRF was blinded to the hospital cause of death for fair comparison with the VA diagnosis. The interview was carried out by SRF in their local language after explaining fully the objectives of the study and obtaining the consent from the respondents. In each interview we built rapport with the respondents by administering the module consisting of demographic and socio-economic particulars of the household. Although, we collected verbatim of the unprompted history of the deceased. Later, the interviewer probed the respondent in terms of open-ended questions. A series of highly sensitive questions were asked for the respondents. The positive response directed the interviewer to the appropriate disease-specific module in which more probing questions were asked about the illness and its severity. On the basis of the symptoms and signs and the corresponding algorithms, the Medical Officer identified the cause of deaths. Thus, cause of death was elicited for each type of event selected from the pilot based study. Nevertheless, the corresponding cause of death given in the hospital diagnosis was compared with field data. The number of deaths for each cause of death is too small to compute sensitivity or specificity analysis. Besides, the list of causes of deaths becomes unwieldy for presentation form. While, presentation point of view, we adopted standard procedures for eliciting information, the cause of death was obtained through VA

and from selected community hospital records. The data sets were classified and identified according to different categories in the International Classification of Diseases, 10th revision (ICD-10) [5]. Overwhelmingly cause of death collected data was categorised based on the standard operating protocol, finally the data sets was presented through verbal autopsy, finally it was compared with the cause of death datum available in the hospital records (considered as the gold standard). The validation of cause of death was done by computing of sensitivity analysis the misclassification of cause of death was obtained in terms of false positive (FPV) and false negative rates (FNR) by using standard formulae. The frequency distributions of COD by VA and hospital diagnoses on five types of deaths were compared by using Kolmogorov-Smirnov two-sample non-parametric test statistics [6]. In case of main we conducted a Study on the basis of realistic approach. One district from each of the four zones in Tamilnadu state via north, south, central and western region respectively. Thirty areas (villages and towns) were selected from each of the selected districts. A total of 30 geographical areas are being covered to elicit cause of death occurred during first six months from the date of survey. The field investigators were visited door-to-door step survey in the selected sites or villages or town to enumerate all the deaths that occurred during the last six months from the date of survey. Field teams were likely revisited later to the selected areas to get information on cause of death occurred during the latter part of the year to ensure completeness of death statistics, we collected information on the number and type of deaths independently from village administrative Officer, village or municipal president and panchayath assistants updated. The same SRF who elicited information on symptoms and signs of the disease condition in the pilot study was employed for this study. The medical officer identified the cause of death based on this information from verbal autopsy. The survey in one district is completed. Cause of death by the type of death for the selected district was also presented. Simultaneously, we constructed life tables separately for males and females. For each deceased we computed and termed the differences between the age at death and the corresponding expectation of life as the Years of Potential Life Lost (YPLL). We computed and presented the sum of all YPLL's. The proportionate mortality and estimated Years of Potential Life Lost (YPLL) after the age of 5 years by the cause of death in selected and was analysed (district in south India, 2002-2003 were compared).

RESULTS

Study validation: The recall period of eliciting information on cause of death for 13 (9.70%) stillbirths, (30%) neonatal deaths, 20 (22.38%) child deaths, 17 (12.31%) maternal deaths and 54 (39.13%) adults' deaths were available in the local hospitals and was occurred in six months for validation study. We identified as caused by obstructed labour observed -O (O 66.0; odd 2.83, p=0.0012; CI95%-0.58-0.69) (3 cases odds 2.69, p=0.008; CI95% 0.88-1.25), 2 each by ante-partum haemorrhage (O46.9; odds 6.33 p=0.002 CI 95% 0.42-0.49) and macerated, 1 each by prematurity (PO 7.3), low birth weight (PO 7.1), eclampsia (O15.9; odds 2.21 p=0.0018;CI 95% 0.10-0.19), severe anaemia, premature rupture of membrane (O 42.9; odds 3.68 p=0.021 CI 95% 0.36-0.45) & undetermined (R69). In neonates, asphyxia 9 (13.84%) deaths; odds 2.17 p=0.08 CI95% 0.12-0.86) was the major cause of death followed by prematurely 8 (12.30%) deaths odds, p=0.0017 CI 95% 0.15-0.88), followed by low birth weight 6 deaths (9.23%) odds 1.98, p=0.185; CI 95% 0.12-0.36 congenital defect 4 (6.15%) deaths odds 0.98, p=0.133; CI95% 0.12-0.38), acute

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LRI (2 deaths odds 0.22 p=0.86 CI95% 0.13-0.26) and one due to birth trauma. Diarrhoea or Dehydration 7 (10.76%) deaths, odds 2.84, p=0.021; CI95% 0.22-0.46) was found to be the major cause among post-neonates and 1 or 2 (1.58%) deaths each due to pneumonia, congenital defects, meninges encephalitis, bronchitis, sarcoma, whooping cough, epilepsy, tubercular meningitis, and tetanus etc. Of the 17 (26.15%) (odd 3.49 p=0.002; CI 95%

20.11-28.56) maternal deaths 4 (6.15%) odds 1.22 p=0.168 CI 95% 0.22-0.86 cases were seen due to post-partum haemorrhage, 3 (4.61%) cases death due to eclampsia, and 2 (3.07%) cases each were due to indirect obstetrical and abortion and 1 (1.53%) case each obstructed labour and congenital heart disease. Among the 9 (1.384%) adult cases deaths were due to accidents and CVD (MI+ Stroke + CCF), 8 (12.30%) cases were acute abdominal pain, 6 (9.23%) cases were senility and 3 (4.61%) cases were diarrhoea with dehydration, rest of the 2 (8.69%) cases death due to renal failure (RF) etc. The frequency distribution of deaths caused from the verbal autopsy compared with hospital records for stillbirths, neonatal, child, maternal and adult deaths was similar for most disease categories. However, there were 7 (10.76%) cases that were caused due to belonging of the 'undetermined' category by the VA which did not appear in the hospital diagnosis. There was no statistically significant difference between the two distributions (P > 0.01). Still births, included mostly pregnancy and childbirths related disease conditions. Neonatal deaths were mainly caused due to perinatal diseases while infectious and parasitic diseases caused most child deaths. Most maternal deaths were caused by pregnancy, child birth and puerperium related diseases. Among adults, (28%) of the deaths were due to cardiovascular diseases, 8 (15%) due to 'external: accidents and injuries', 7 (13%) each were due to 'cancers' and 'digestive' diseases. Among the 7 hospital cases (still births) of 'pregnancy, child birth and puerperium' disease category, sensitivity, specificity and PPV of the COD by VA were (87.5%), (100.0%) and (100.0%), respectively. High sensitivity of COD by VA was observed for 'perinatal' diseases in neonates (95.5%) while specificity was low at (62.5%). For child deaths, the sensitivity of COD by VA was (85.7%). The sensitivity of COD by VA was (86.7%) for maternal deaths while the specificity was low at (50%) (The numbers were small). Among adults, the sensitivity of the COD by VA for cardio vascular diseases was (73.3%). However, the specificity and PPV were the highest at (100.0%). For other non-communicable disease category, such as cancers, the sensitivity was (71.4%) while specificity and PPV was (97.9%) and (83.3%) respectively.

Main Study: Pregnancy and child birth (48%) odds 6.33 p=0.002 CI 95 % 0.39-0.51 have the main cause among stillbirths. The next major cause (32%) odds 4.81 p=0.03 CI95 % 0.28-0.36 among stillbirths was due to prematurity. Out of 42 neonatal deaths, 15 (35.7%) odds 3.38 p=0.001 CI95 % 0.32-0.36 was due to asphyxia, 13 (31%) odds 4.82 p=0.001 CI95 % 0.28-0.35 was due to prematurity. Five (17.9%) cases each out of 28 child deaths were due diarrhoea and CHD. Four child deaths each were due to 'accidents and neurological related problems. Out of 697 adult deaths, 204 (29.3%) odds 10.26 p=0.001; CI95% 24.22-32.66 were due to cardio vascular diseases (CVD), 96(13.8%) odds 3.17 p=0.003 CI95% 10.22-14.56 due to respiratory diseases, 80 (11.5%) odds 6.18 p=0.001 CI 95% 8.56-14.52 due to accidents, 65 (9.3%) odds 5.02 p=0.002 CI 95% 7.45-12.22 due to senility, 64 (9.2%) odds 3.48 p=0.001 CI 95% 5.55-7.45 due to gastro-intestinal tract conditions, 60 (8.6%) odds 4.88 p=0.008 ,CI 95% 6.33-10.25 due to cancer, 34 (4.9%) odds 1.86 p=0.001 CI 95% 2.22-5.28 due

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to renal failure, 28 (4.0%) odds 4.74 p=0.002 CI95% 2.3-5.55 due to suicides, 6 cases death due to AIDS and the rest were due to other causes shows ranking of causes of death by estimated YPLL and mortality rates by cause of death separately for both males and females. CVD ranks first by both YPLL and cause-specific mortality rates for both males and females. However, by cause-specific mortality rates senility ranked fourth among males but by YPLL it ranked fourteen. Similarly, in case of females by cause-specific mortality rates senility ranked second but by YPLL itranked thirteenth.

DISCUSSION

The study demonstrated that, the non-medical staff with reasonable training could elicit symptoms and signs reliably from the kith and kin of the deceased to ascertain the causes of death by VA. Medical professionals has feasible can confirm the already elicited causes of death. Another important finding of this study is the similarity of the distribution of cause of death by VA with that of the hospital records similar study reported by [12]. Though the state health authorities have conducted mass immunization campaigns, study documented child deaths due to whooping cough, tetanus and tubercular meningitis etc. Deaths due to accidents and injuries were very frequent. The sensitivity of the COD by VA for 'accidents and injuries' was the highest at (100%) in this study as compared to (97%) in other validation studies done by Geneva, WHO [13,14]. This may be true particularly when deaths are sudden and unexpected and there is no difficulty in reporting COD by VA. The sensitivity of non-communicable diseases such as CVD and cancers are generally lower than for accidents and injuries. This was expected as few of these disease conditions having unique features, as demonstrated for cardiovascular diseases [9-15]. Among adult deaths, lower sensitivities and higher specificities and moderate PPV for CVD and Cancers determined in this study were consistent with those obtained elsewhere [16-20]. Similar findings were observed for digestive disorders and infectious and parasitic disease conditions. As regards to maternal deaths high sensitivity and high PPV were found for pregnancy and childbirth related causes and they were consistent with the study done in elsewhere [21-25]. The findings of this study can be compared with those of other studies. Many researchers employed verbal autopsy technique to determine causes of death among infants, children and adults [26,27]. However, multiple factors such as (i) The community in which the information on COD is obtained (ii) type of questionnaire used (iii) Field procedures and (iv) The analytic process influence the outcome of a VA study. Literature review suggests that there were only a few validation studies on VA [1-7] [22-28]. Validation of causes of Infant deaths was done in the community of one district of Haryana and two districts of Orissa [29]. The validation studies on causes of death by verbal autopsy among children were hospital based and was done in Kenya and Philippines. Validation studies on adult deaths and on maternal deaths were hospital based and was carried out in African countries. All the studies assessed the validity of the verbal autopsy (VA) using the hospital diagnosis as a 'gold standards. All the studies used lay interviewers for collection of symptoms and signs and professionals (Medical personnel) for ascertaining the cause of death. The study conducted in Haryana included validation of causes for neonatal deaths and post-neonatal deaths. The recall period in these studies varied from 1 to 52 weeks. The study done in Kenya did not employ algorithms to arrive at the diagnoses. The reported validity of verbal autopsy varied between studies and the sensitivity and specificity of verbal autopsy (VA) varied between different causes of death. The relatively high sensitivity and high

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specificity of the tool obtained for stillbirths were consistent with those determined elsewhere [18,19]. Perinatal causes among neonatal deaths achieved higher sensitivity in this study (96%) than that of the study conducted in Haryana state of India (83.8%) [30]. Infectious and parasitic diseases among the children were the main causes that attained higher sensitivity (86%) in the study than the study in Kilifi, Kenya (36%) [31] were comparable with those in Cebu, Philippines (78%). In this report hospital diagnoses were used as the 'gold standard'. It may be admitted here that there could be problem in this assumption. For example, hospital deaths do not represent all deaths in the community as against accidents and injuries. It cannot be generalized to the entire community, as the data sets used for validation are not representative samples from the community. However, this should not affect the general picture of sensitivity and specificity of causes of death investigated. The quality of information reported may be better following the respondents' exposures to modern medical care [32] and knowledge of symptoms and signs of various diseases. The main study demonstrated that the findings through VA instrument could be effectively used in developing countries like India with deficient vital registration systems, to prioritise public health problems, identify the major cause-groups of deaths and suggest resource allocations for effective health planning. By international agreement, deaths are coded according to the underlying cause. Underlying cause of death is defined as "the disease or injury which initiated the train of morbid events leading directly or indirectly to death or the circumstances of the accident or violence which produces the fatal injury [33]. This study demonstrates an attempt to develop measures to study burden of disease so that appropriate interventions can be developed. YPLL recognizes that death occurring in the same person at a younger age clearly involves a greater loss of future productive years than were it to occur at an older age [34]. YPLL helped in ranking causes of death rather than cause-specific mortality. For example, by cause-specific mortality rates, suicide ranked eighth among males but by YPLL it ranked fourth. Similarly, for females by cause-specific mortality rates suicide ranked sixth but by YPLL it ranked second a reflection of the fact that (74%) of the suicide-related deaths are in the agegroup 10-30 years [35]. An interesting and valuable use of current mortality from disease will be to study the burden of disease. For example, five of the leading causes belong to non-communicable disease (NCD) conditions; in both males and females (65.3%) of PYLL are due to NCD [36-38]. With the ageing of the population worldwide, an 'epidemiological transition' is taking place so that by the year 2020 non-communicable diseases are likely to account for (70%) of all deaths in developing countries: clearly a strong call for public health action.

CONCLUSION

The cause of mortality in the above driven life data sets summarizes and concludes that the newer VA tool would be needed to formulate public health programmes. Often, validation of verbal Autopsy instrument was employed through trained non-medical staff is very feasible. Instrument provided reasonable estimates of cause of deaths on various types of deaths and it can be introduced as a routine tool in the Sample Registration System for mortality record. Deaths due to non-communicable diseases account for (65.3%) in all deaths aged 20 years and above by suggesting a need for alarming public health action in defined time intervals. Driven mechanism is very useful to prioritize the public health needs for managing effective health care system at national and global level and also planning the predictive health care programmes if healthemergency declared.

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CONFLICT OF INTEREST

The authors declare that they have no conflict of interests.

AUTHORS CONTRIBUTIONS

All the authors contributed equally to this work.

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