

# A Qualitative Inquiry into the Application of Verbal Autopsy for a Mortality Surveillance System in a Rural Community of Southern India

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## **Abstract**

The aim of this investigation was to identify operational and ethical issues encountered in the application of verbal autopsy (VA) in a rural community in south India. A qualitative study involving semi-structured interviews was conducted with 183 bereaved caregivers in rural Andhra Pradesh, India. Simple descriptive analysis was undertaken. Only 16% of adult deaths and 27% of child deaths occurred in healthcare settings. Healthcare utilization for the terminal illness was reported in two thirds of medical (non-injury) causes of death. Supporting medical evidence was available in <10% of cases to supplement the interpretation of verbal autopsies. About 14% of bereaved caregivers refused to give written consent but provided oral consent. Additional ethical concerns included inability to ensure privacy in 15% of interviews and unsolicited information from unauthorized neighbours in 5% of cases. Such methodological, logistical and ethical issues operate to impact on the quality of VAs. Consideration of these issues would strengthen ongoing efforts in the harmonization of VA procedures.

## Introduction

Knowledge about the distribution of causes of death in populations is critical for public health planning, resource allocation and impact evaluations. Such information is, however, inadequate for developing countries because of weak civil registration systems and hospital-based death certification systems. Hence, verbal autopsy (VA), an indirect method of ascertaining the cause of death based on information on illnesses or circumstances preceding death obtained from bereaved caregivers, offers an interim strategy to generate cause-specific mortality data in such settings (Jha et al. 2001; Setel et al. 2005; World Health Organization [WHO] 1978). Currently, VA is routinely employed in over 20 developing countries – the Million Death Study within the Sample Registration System (SRS) in India, the Disease Surveillance Point (DSP) system in China and over 35 other small demographic surveillance system (DSS) sites spread across 18 other countries (WHO 2005). In parallel with the increasing use of VA are efforts to validate and harmonize VA methodologies globally (Chandramohan et al. 2001; Setel et al. 2006; WHO 2005). While issues such as cause-specific mortality fractions and their validity have been reported extensively, there is minimal documentation on process issues encountered while employing VAs for mortality surveillance. The aim of this study was to document the operational and ethical issues pertaining to the application of verbal autopsy in a rural community for a local mortality surveillance system and to study the local after-death practices relating to mourning and death registration.

## Materials and Methods

### Study Setting

The study site was at Palamaner, located in Chittoor district in the south Indian state of Andhra Pradesh. Chittoor district is predominantly rural – 78% (Registrar General of India [RGI] 2005). The study area comprised five administrative regions, called *mandals* (Palamaner, Baireddipalli, Gangavaram, Ramakuppam and V. Kota), forming the erstwhile Palamaner *taluk* (sub-district), with a total population of about 252,020 (2004 survey).

Our study population was the rural population of 208,630 within Palamaner *taluk* (excluding Palamaner town, population of 43,390). Agriculture was the mainstay of the local economy, but, because of low and erratic rainfall, the income levels of the people were low. About 47% of the population was estimated as below the poverty line (Society for Elimination of Rural Poverty 2004).

### Study Design and Instruments

A qualitative study involving face-to-face interviews was undertaken. Study respondents were interviewed using a semi-structured questionnaire designed to obtain information on respondent details (relationship to deceased, willingness to be interviewed), details of deceased (socio-demographic information, location of residence, healthcare sought for terminal illness and a verbal autopsy for cause-of-death) and after-death practices (death registration, last rites and mourning practices).

For the verbal autopsies, we used the four different age-specific questionnaires from the Indian SRS study of causes of death (<http://cghr.org>) – neonatal death form (0 to 28 days), child death form (29 days to 14 years), adult death form ( $\geq 15$  years) and maternal death form (15 to 49 years; females suspected or known to be pregnant or to have delivered within the last six weeks). Briefly, all these questionnaires were of a hybrid format – that is, a combination of a closed-ended, structured component for key disease symptoms/exposures and an open-ended narrative component to obtain the respondent's history, verbatim. The adult questionnaire had, in addition, a symptom list to aid in the collection of a good narrative (<http://cghr.org>). All questionnaires were in English, but interviews were conducted in the local language, Telugu. A key modification we made was the instruction given to field interviewers to also collect medical reports (e.g., prescription slips or discharge summaries) to aid in subsequent physician reviews. In addition to attempting to obtain a biomedical cause of death by physician review, we tried to obtain the cause of death as perceived by the respondent ("natural" vs. "supernatural" cause). Fieldworkers graded the cooperation or willingness of study respondents, using a Likert semantic grading scale (1 = uncooperative, 2 = reluctant, 3 = average, 4 = willing,

5 = very cooperative). If a fieldworker was not able to contact a caregiver after three visits to a household, he or she moved on to the next household with an available respondent.

### **Sample Size**

A sample of 180 deaths amounting to 10% of expected total deaths ( $n = 1670$ ) in a year (the crude death rate for rural Andhra Pradesh is 8 per 1000) (RGI 2005) was chosen on a convenience basis for exploring the feasibility of instituting a mortality surveillance system using locally trained fieldworkers and medical officers.

### **Study Personnel**

Eight multipurpose health workers/research assistants with about 10 to 12 years of formal education were the field interviewers. More than 80% were male; this meant that several female respondents had to be interviewed by male fieldworkers. Both experienced ( $n = 6$ ) and newly appointed workers ( $n = 2$ ) underwent a standardized sandwich VA training program that covered VA procedures as well as relevant medical terminology training, practice field interviews and revision training. The order of preference for choosing a respondent was determined a priori to follow a uniform methodology (<http://cghr.org>) (Jha et al. 2006). Training emphasized positive and negative symptom elicitation, with a focus on the terminal illness and repeated reminders not to pursue for any specific medical diagnosis. New workers were also given brief training in counselling skills to aid in handling grief and bereavement.

Four medical officers underwent a standardized training program to assign a probable cause of death (<http://cghr.org>); the focus was on identifying the “underlying cause of death” (WHO 2003).

### **Cause of Death Assignment, Re-sampling and Ethical Approval**

All interviews were to be held in private after written consent had been given. Each VA report was reviewed independently by two physicians, and disagreements were subsequently adjudicated by a third physician. All diagnoses were coded using the ICD-10 classification system. For quality assurance purposes, 30 of 183 deaths (16%) were re-sampled for a repeat home visit, questionnaire re-administration and cause of death assignment by one of the authors (PKM). The study protocol was approved by the St. John's Institutional Review Board.

## **Results**

### **Geographical Spread**

Median (range) distances of the study villages from a district road, state highway and the national highway were 0.5 (0–12), 3.0 (0–23) and 6.0 (0–29) km, respectively.

### **Demographic Characteristics of the Deceased**

Of the 183 deaths studied, 17 (9%) were neonatal deaths, 13 (7%) were child deaths and 153 (84%) were adult deaths. Ninety-three percent of the deceased were Hindu and 7% were Muslim. Socio-demographic details of the 153 adult deaths are shown in Table 1. The mean reported age at death was 65 (range = 15–99) years. Literacy rate was 35%.

### **Informed Consent**

In accordance with the ethical committee approval, we sought written informed consent from the relatives of the deceased. In about 25 (14%) cases, this was problematic because family members were unwilling to affix their signature or thumbprint to a document, even though they understood the purpose of the study and wished to participate. These 25 interviews were subsequently conducted after only verbal consent was obtained, and the institutional review board was informed about this protocol deviation.

In about 15% of interviews, privacy could not be maintained. In spite of repeated requests by the interviewer, the respondent and/or the neighbour(s) saw no reason for a private interview, and the neighbour was also present during a part or whole of the interview. In addition, in another 5% of

cases, fieldworkers came back with two often conflicting narratives from two sources for a particular death — one from a relative/associate of the deceased and another unsolicited version of the terminal illness from a neighbour who volunteered the information to the fieldworker. Examples were cases of vague fevers reported by relatives but a history of HIV/AIDS related by neighbours, and history of vague somatic complaints reported by relatives but a history of suicide related by neighbours.

**Table 1. Socio-demographic characteristics of deceased adults, cooperation of respondents and causes of death**

Socio-demographic characteristics ( <i>n</i> = 153)	No. (%)
Sex	
• Male	91 (59%)
• Female	62 (41%)
Marital status	
• Never married	4 (2.5%)
• Currently married	112 (73.5%)
• Widowed	36 (23.0%)
• Divorced/separated	1 (0.5%)
Completed years of school	
• < 8 years	124 (81%)
• ≥ 8 years	29 (19%)
Occupational category	
• Daily wage labourer	76 (49.5%)
• Cultivator	29 (19.0%)
• Salaried/ business	10 (6.5%)
• Non-worker	38 (25.0%)
<b>Cooperation of study respondents (<i>n</i> = 183)</b>	<b>No. (%)</b>
Uncooperative	26 (14%)
Reluctant	17 (9%)
Average	38 (21%)
Willing	38 (21%)
Very cooperative	64 (35%)
<b>Causes of deaths (<i>n</i> = 183)</b>	<b>No. (%)</b>
Cardiovascular/endocrine system (I00 to I99)	44 (24%)
Infectious diseases (A00 to B99)	33 (18%)
Neoplasms (C00 to D48)	20 (11%)
Injuries (V00 to Y98)	20 (11%)
Respiratory system (J00 to J99)	13 (7%)
Digestive system (K00 to K93)	7 (4%)
Perinatal conditions	6 (3%)
Ill-defined conditions (R00 to R99)	33 (18%)
Other organ systems	7 (4%)

## Respondents

In our study, the respondents for all neonatal and child deaths were the parents. For adult deaths, details are shown in Table 2.

The median recall period was four months (range = 0–24). Nearly 90% of interviews were conducted after a gap of four weeks following the date of death in order to give time for mourning.

The average time taken to fill out the questionnaire was 35 to 45 minutes (25 to 35 minutes for verbal autopsy and 10 to 15 minutes for the qualitative questionnaire). There were few missing items (3.6%) in the questionnaires.

Nearly four fifths (77%) of respondents were cooperative and willing to narrate details about the deceased (Table 1). The median score was 3.5 out of 5.0 (25th to 75th centile = 3–5). This did not vary by type of consent given (written or oral).

Table 2. Sex and relationship of respondents for adult death interviews

Relationship to deceased	Sex of respondent		Total
	Male No.	Female No.	No. (%)
Son/daughter	45	15	60 (39%)
Spouse	5	25	30 (20%)
Son-in-law/daughter-in-law	1	23	24 (16%)
Parent	5	9	14 (9%)
Sibling	8	1	9 (6%)
Other relatives	8	8	16 (10%)
Total	72 (47%)	81 (53%)	153 (100%)

### Healthcare Utilization and Evidence

At least some healthcare was sought during the illness preceding death in about 65% of medical (excluding injuries) causes of death among both children and adults. Most of this (65%) was from a private medical practitioner, 20% was from a government health centre, 5% from a non-profit health clinic and the remainder from traditional practitioners. Among care classified as provided by private medical practitioners, respondents could not differentiate between licensed and unlicensed medical practitioners.

Supporting medical evidence (e.g., prescriptions or hospital discharge summaries) was obtained in less than 10% (17/183) of cases. Further, the quality of the evidence was found to be very inadequate – most often, handwritten sheets containing investigation/medicine names were illegible. In three households, the deceased's medical records were reportedly buried or cremated along with the body. Limited availability of medical information also meant that the certainty of diagnoses graded subjectively by the physicians as high, medium or low was 21%, 55% and 24%, respectively.

### Details of Death

Only about 16% (24/153) of adult deaths and 27% of newborn/child deaths (8/30) were in health-care settings. However, there was a significant difference between the mean age (standard deviation; SD) of adults who died in hospital (mean = 45.1 years; SD = 20.1) compared to those who died at home (61.6 years; SD = 19.5 years);  $P < .01$ .

A supernatural cause of death (e.g., spirits) was attributed in less than 2% of deaths, using the approach of getting respondents' perceived cause of death.

According to physician review based on VA reports, circulatory system disorders and infectious diseases were the most common causes of death (Table 1). Agreement between two physicians was 56% at the initial coding stage and reached 79% after the reconciliation stage; 21% of records were adjudicated by a third physician.

### Mourning Practices – Last Rites, Grieving and Death Registration

The interval between death (at home or outside the home) and burial/cremation was about 12 to 36 hours. Almost always, the burial/cremation was conducted the same or the next evening. In most households, a male member of the household (the son, wherever possible) was to be present for the last rites. It was not essential for any temple priest (e.g., *poojary*) to be present for the last rites/burial. Last rites performed included washing of the dead body and performance of a *pooja* (religious ritual). Disposal of body was most often by burial (86%) and less often by cremation (14%) among Hindus; it was by burial (100%) among Muslims.

Of all deaths, 55% were reported to have been “registered”; however, only 10% of respondents had a death certificate in hand. Further enquiry revealed that “registration” meant the family had notified the village secretary, but a death certificate was handed to the family only in few instances (e.g., injury deaths) to facilitate receipt of welfare payments such as pensions or *solatia* (compensation paid for solace by governments in India, usually for tragic injury deaths); otherwise no death certificate was issued to the relatives. Among those who had not registered the deaths, reasons for non-registration were as follows: 82% did not know about death registration, 7% did not see any benefit in registration, 7% did not see the utility of reporting deaths in older persons specifically and 4% reported being too preoccupied with their mourning.

Almost all families also reported an extended mourning period varying from three to 12 months. This fell under two broad categories: (i) not attending any “auspicious” ceremonies (such as marriages) in other households and consuming only vegetarian food for three months, and (ii) not scheduling any “auspicious” ceremonies in their own households for 12 months.

## Discussion

### Operational Issues

#### Study Design

The outcome of a cause-of-death investigation in a region would depend on the choice of study design pursued by the investigator, that is, whether the perspective was from an “epidemiological” approach of obtaining a biomedical cause of death, or from an “anthropological” approach of obtaining a cause of death as perceived by the caregiver (Allotey and Reidpath 2001; Boerma et al. 1997). In our study, attribution to a supernatural cause of death (e.g., spirits), at less than 2%, was much lower than the level of 15% noted in Africa (Allotey and Reidpath 2001). This could be attributed to the predominantly biomedical approach in study design undertaken in our investigation. It could also be due to a “social desirability bias” (Paulhus and Reid 1991) on the part of respondents because the interviewers were identified as belonging to the local allopathic hospital.

Cause-of-death assignment by physician review as undertaken by us is the method used widely in India, unlike other methodologies such as expert algorithm or data-derived algorithm tried out in other settings (Baqui et al. 2001; Byass et al. 2003; Lulu and Berhane 2005; Quigley et al. 1999). The high diagnostic accuracy at the population level of the method we used for attribution of death has been noted, compared to the latter methods (Quigley et al. 1999).

According to physician review based on full VA reports, circulatory system disorders were found to be the commonest (26%) cause of adult deaths in our sample. Non-communicable diseases, along with infectious diseases and injuries, constitute a “triple burden” that has been documented in other studies, from the northern part of the state of Andhra Pradesh (Joshi et al. 2006) and from the non-poor states of India (RGI–Centre for Global Health Research and Collaborators 2009). Agreement between two physicians was 56% at the initial coding stage and reached 79% after the reconciliation stage, with most of the mismatch between the two diagnoses due to differences within the same ICD chapter (e.g., chronic obstructive pulmonary disease [J44] vs. asthma [J45]) or to equivalence codes (e.g., pneumonia [J18] vs. acute lower respiratory infection [J22]); this was comparable to a national-level study (Bassani et al. 2010).

#### Study Personnel

A key limitation to the widespread adaptation of VA tools in mortality surveillance systems could be the availability of skilled personnel – trained fieldworkers to record evidence, data managers to enter and analyze data and physicians to assign a cause of death. This has been noted earlier by others (Garenne and Faveau 2006). Multipurpose health workers or research assistants are typical of fieldworkers likely to be available in most settings in the country (Gajalakshmi et al. 2003; Joshi et al. 2006). Exigencies of fieldwork may also determine the number and timing of visits to households to interview potential respondents. This also has a bearing on deployment of fieldworkers for VA work exclusively or in parallel with other community outreach work.

Age, sex and relationship of respondent have not previously been found to affect accuracy of the VA, but presence of the caregiver during the terminal stage of illness was found to increase the accuracy of the diagnosis (WHO 2005).

### **Study Instrument**

Hybrid VA questionnaires incorporating structured and open-ended components are used less often in India than the open-ended narrative alone. Of late, their use has been shown to be as good as or even better than either component alone in both children (Soleman et al. 2006) and adults (<http://cghr.org>). Availability of supporting medical evidence could theoretically impact the quality of cause-of-death assignment. In our area, reported healthcare utilization before death was reasonably high; however, such contextual information was not found to impact physician reviews. This could be due to three reasons: (i) low availability of medical reports from households with deaths, (ii) poor quality of available medical evidence (due to illegible, incomplete or irrelevant records), and (iii) inaccessibility of medical reports because of prevailing local mourning practices such as burning/burial of medical records along with the body of the deceased. While the first two have been documented earlier (Mahapatra and Chalapati Rao 2001), the last is a new finding. While it may impact assignment of cause of death at the individual level, because of the low prevalence of the practice in our setting it may not have impacted population estimates. However, there is a need to look more closely at the prevalence of such practices in a larger population under prospective follow-up to determine its impact.

A low rate of missing items in the questionnaires suggests that the workers and respondents did not have difficulties with the construct of the questionnaire or the specific questions. The short, 2-page hybrid VA questionnaires may have increased compliance and accuracy of reporting compared to the lengthy, symptom-based modular questionnaires, but this was not directly tested in this study. Shorter questionnaires may generally be more acceptable because of efficient use of the interviewer/interviewee's time, reduced chance of "acquiescing responses," reduced fatigue and less chance of social desirability bias (Paulhus and Reid 1991).

### **Dual Narratives**

In those cases with dual versions of the circumstances of death, practical difficulties faced by the fieldworkers in emphasizing/documenting verbatim reports and by the physician reviewers in assigning the cause of death remain unknown. This is an area that could be explored further.

Availability of dual versions of the circumstances of death such as was seen in our study could also impact the estimates of cause-specific mortality fractions in a region depending on the relative importance given to the narrative by the fieldworker and/or the physician coder, as well as the type and proportion of total deaths with such dual reports.

### **Implications of Grieving and Other after-Death Practices on Ascertaining Death**

Culture-specific rituals and mourning practices, while serving to assist the bereaved in the completion of their "task of grieving process" (Hagman 1995; Kagawa-Singer 1998) also have several implications for studies on cause-of-death estimates in a community. First, the interval between death and burial/cremation essentially offers a short window of opportunity for clinical investigators and other researchers attempting to validate pre-mortem clinical diagnosis or VA-derived cause-of-death against an autopsy (limited, partial or complete clinical autopsy). Second, confusion or lack of awareness about the process and purpose of death registration appears to continue to keep the civil vital registration at sub-optimal levels (Jewkes and Wood 1998; Mony et al. 2011). Third, evidence relating to healthcare utilization prior to death when available may be inaccessible because of local practices such as disposal by burning/burial along with the body in some households, as noted above.

### **Ethical Issues**

Some authors have insisted on written as opposed to verbal consent prior to interviews (Chandramohan et al. 2005). While such formal consenting procedures may be followed in research settings, they

tend to be less formal when the verbal autopsy process is employed routinely for mortality surveillance on a large scale, such as in India's Sample Registration System (Jha et al. 2006). In addition, insisting on written instead of verbal consent may pose concern for some participants. This might be because of an inherent suspicion of being associated with any formal document relating to death. Hence a proportion of individuals are likely to feel comfortable giving verbal instead of written consent. Further, there may also be bias if only written consents are included in studies; medico-legal deaths (under investigation by forensic and law enforcement agencies), or deaths that are seen as socially unacceptable – like suicides or HIV/AIDS – are more likely to be missed, as written consents are less likely to be obtained.

Orientation training given to new fieldworkers on handling grief, and also taking care to conduct interviews after a 4-week grieving period, may have boosted comfort levels of fieldworkers in handling field interviews and also minimized "interview friction," as evidenced by a reasonably high level of cooperation in this study.

Despite the best efforts by fieldworkers to ensure privacy, it was not possible for some interviews in our setting. The respondent and/or the neighbour(s) did not see the need for a confidential interview of the family of the deceased. From our study it was not possible to conclude whether privacy was not considered an issue by such individuals in a rural community or whether the respondent caregivers felt insecure about demanding privacy during interviews.

In instances when two conflicting narratives were obtained, the narrative from the non-family respondent seemed a more plausible alternative with regard to chronology and medical symptomatology, as compared to the version obtained from the family respondent; but this also presented an ethical dilemma. The relatives had not consented to accepting the others as additional respondents, and also the fieldworkers were receiving unauthorized histories that were not originally intended. The impact on the trust and well-being of the caregivers, neighbours or fieldworkers is not known.

Our study has some limitations. First, the sampling of participants was purposive and hence the quantitative findings are likely to be indicative and may not be completely generalizable. However, the purpose of the study was not to arrive at quantitative estimates of cause-specific mortality estimates of the population but rather to obtain a range of qualitative information related to the circumstances surrounding death. Second, the analysis was performed only by the authors and so may have been biased to some extent by their own preconceptions in the design of the study approach and study instruments.

In summary, operational issues (pertaining to methodology and logistics) and ethical issues and their attendant implications are likely to be faced during the application of verbal autopsy in a given setting. It may not be possible to address all of these concerns, and hence choices may have to be made by the investigator so as to maintain "research rigour" (Ratcliffe and Gonzales-del-Valle 1988) while working with realities at the field level. The synthesis of such qualitative research together with quantitative research (Mays et al. 2005), rather than either alone, will also help in the process of strengthening the application of the verbal autopsy as a tool for increased mortality surveillance in many developing countries. Making vital registration and mortality surveillance systems more robust in the light of these considerations may also help build trust in the workings of public health.

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