The verbal autopsy based cause of death reporting systems in rural areas of India: A review.

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Valid and reliable statistics on cause of death is an essential input for setting of priorities in the health sector (Mahapatra, 1999). In the rural areas medical certification of cause of death is usually not feasible since many deaths occur without any prior medical attendance. Thus the country depends on a system of lay reporting of cause of death using what is called a verbal autopsy methodology. Until December 1999, cause of death data for the rural areas used to be collected under the Survey of Cause of Death (SCD) Rural scheme. SCD-Rural data used to be collected from a sample of primary health center (PHC) headquarters villages by a lay diagnosis and reporting system in accordance with guidelines issued by the Registrar General of India (1991, 1993). The SCD-Rural scheme was discontinued from beginning of 1999 (Registrar General, 1999). Instead, a cause of death component has been added to the sample registration scheme (SRS). The SRS is designed to register deaths and births in another set of sample areas in rural and urban areas. The cause of death (SRS-COD) component is also based on verbal autopsy. The verbal autopsy guidelines were developed in the 1960s when the model registration - survey of cause of death (MRS) scheme first came into existence. The MRS later came to be known as the SCD-Rural scheme. The verbal autopsy introduced by India in 1965, was the first verbal autopsy based cause of death reporting system in the world.

The concept of verbal autopsy as a source of cause of death information has been used in many developing areas have poorly developed facilities for medical certification of cause of death. It will be useful to review the content validity of the verbal autopsy-based cause of death reporting system in the light of research findings and field experiences gained over the last four decades. In this

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paper I first review the design characteristics of the SCD-Rural system and then turn to the SRS-COD component.

**SCD-Rural System in India:**

Administrative guidelines and technical methodology of this survey of cause of death (SCD) rural has been published on more than one occasion (Registrar General, 1991, 1993). A short summary of the methodology is presented below. A sample of primary health centres are selected and a system of continuous survey of deaths is done in the headquarters village. Each sampling unit covers between 3000 to 5000 rural residents. For example, the State of Andhra Pradesh had 200 sampling units as of 1998 covering a population of 0.735 million which is about 1% of the State’s population. A paramedical person from the PHC is designated as the field agent who does the primary survey. (S)he identifies key informants and maintains liaison with them. A household register is drawn up and updated half yearly. For each death occurring in the village the field agent identifies one or more persons having knowledge of the circumstances of death, interviews them and records the symptoms and circumstances of death in form 7. A structured questionnaire is used to investigate cause of death using the symptoms and circumstances of death. The structure questionnaire is supplemented by a check list. The field agent arrives at a probable cause of death by applying the structured questionnaire to symptoms and circumstances recorded in Form 7. The check list entry against the probable cause of death arrived is then tallied with the symptoms and circumstances of death. The cause of death thus arrived is reported in Form 3 (referred to as certificate of death here). The PHC statistician is designated as the recorder of events reported by the field agent. Half yearly verification of the household list is done by the recorder. Medical officer of the PHC is expected to check and certify the correctness of cause of death assignment by the field agent. Assignment of cause of death is done by the field agent based on a structured interview with a
member of concerned household. The structured questionnaire currently in use was adopted after
taking into account five years of field experience with a provisional questionnaire. The non medical
list (NML) of cause of death was last revised in 1983 to correspond to ICD 9th revision (RGI,
1991). SCD (Rural) uses verbal autopsy (VA) to arrive at cause of deaths using paramedical
personnel.

**General design features of a verbal autopsy system:**

The verbal autopsy method has since been studied and applied in many parts of the world.
The demographic surveillance system (DSS) in Matlab, Bangladesh (Nahar et al 1985; Zimicki,
1989); assessment of child mortality in Latin America (Puffer and Serrano, 1973); monitoring
endemic diseases in west Africa (Bradley and Gilles, 1984; Greenwood et al, 1987) in Kenya
(Omondi-Odhiambo et al, 1984); in Phillipines (Kalter et al, 1990) and in India (Bang et al 1992)
could be cited as of these instances. Much of the VA related work, however, remains unpublished.
For example the WHO-UNICEF (1994) memorandum on measurement of cause specific mortality
in children cites many unpublished sources.

The current knowledge base on feasibility and validity of VA is largely restricted to
childhood mortality. The WHO-UNICEF memorandum, cited above, summarizes results of
validation studies and has tabulated sensitivity and specificity of VA for detecting major causes of
childhood death. In addition, the memorandum contains expert opinion about use of VA for
investigation of causes of childhood death. This memorandum was the result of an internal
consultation in December 1992 in which experts engaged in research and implementation of VA
participated. Bang et al (1992), for instance, have used consensus development techniques to
synthesize expert opinion on diagnostic criteria for identification of causes of childhood deaths. They
have developed questionnaire incorporating local terminologies in their study area (Gadchiroli, Maharastra) to generate the required information by verbal autopsy to satisfy the coding algorithm.

Studies about validity of VA to identify causes of adult death are being undertaken recently (Garenne and Fontaine, 1989; LSHTM, 1993). These authors in their work (1989) have reported their experience in Senegal. Similarly, The London school of hygiene and tropical medicine (LSHTM) workshop (1993) on verbal autopsy tools for adult deaths was conducted on the eve of a study currently under way in sub Saharan Africa. Proceedings of this workshop, cited above, documents a consensus of expert opinion about VA for adult deaths. Another summary and source of expert opinion is the World Bank working paper by Hayes et al. (1989). Chandramohan et al (1994) have published discussions at the LSHTM verbal autopsy workshop and have summarized all VA based studies published upto mid 1993.

I have mainly drawn upon these sources to critically examine the extent to which SCD-Rural meets the criteria of a good VA based system. Certain general design features are key to wide applicability, efficiency and validity of data generated by a VA based cause of death reporting system. Over the years some degree of consensus on major design issues have emerged. The structured questionnaires prescribed by the Registrar General of India for the SCD-Rural system was systematically examined for each of the conditions included in the non medical list. The SCD-Rural questions were examined in the light of available research results on verbal autopsy. A comparative statement of the SCD-Rural algorithm, expert opinion and findings from field studies about diagnostic algorithms and validity of verbal autopsy (VA) to assign specific cause of death, and the extent to which the SCD-Rural question satisfy expert opinion is contained in annex-1. A summary is presented in Table - 1. SCD (Rural) seems to satisfy most of these criteria except reporting of multiple causes of death. This is one area for improvement of existing SCD guidelines.
On the other hand assigning multiple causes of death creates problems for aggregation and reporting of deaths by cause. Manton and Stallard (1984) analyzed multiple cause of death patterns in the USA. Although their preferred suggestion is to use patterns of failure as the basis of analysis, it may not be a feasible alternative considering small sample sizes inherent in verbal autopsy based statistics. To the extent certain deaths are assigned to combination of causes there will be reduction in number of deaths reported under the respective component causes (LSHTM, 1993). A compromise may be to restrict the number of multiple causes of death to a manageable number and develop algorithms to distribute these to their component causes. Manton and Stallard’s (1984) study suggests that recording up to three multiple causes would include more than two thirds of deaths. Choosing the top three most probable causes contributing to death may help improve the accuracy of estimates and keep it manageable.

The trade off between open ended interview and structured questionnaire needs further elaboration at this stage. Although open ended interview format allows pursuit of unusual diagnostic clues not covered by structured questionnaire, it requires more skilled interviewers. For example comparatively lower assignment to unknown category has been achieved with physicians acting as interviewer (Greenwood et al 1987). Open ended interviews and coding of cause based on judgment of the interviewer reduces the inter regional and inter temporal comparability of cause of death statistics.
No Multiple causes of death should be permitted (WHO-UNICEF, 1994, LSHTM 1993).

Recording multiple causes

Yes

At the LSHTM workshop (1993) most participants preferred the checklist with filters to one without. Symptom based filtered modules (e.g. cough module) were preferred to disease specific filters. Zimicki (1990) reports that the respondents in Matlab, Bangladesh were asked a list of 16 questions. If the answer was yes, auxiliary questions specific to each symptom was asked. This was found superior to a large checklist of symptoms.

Filter questions

Yes

At the LSHTM workshop (1993) most participants preferred the check list with filters to one without. Symptom based filtered modules (e.g. cough module) were preferred to disease specific filters. Zimicki (1990) reports that the respondents in Matlab, Bangladesh were asked a list of 16 questions. If the answer was yes, auxiliary questions specific to each symptom was asked. This was found superior to a large checklist of symptoms.

Table 1: General design features of a good VA system and the SCD (Rural) scheme in India.

<table>
<thead>
<tr>
<th>Criteria / Expert opinion</th>
<th>SCD (Rural)</th>
</tr>
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<tbody>
<tr>
<td>Identification of respondents</td>
<td>Yes. The recorder does an independent survey of households once every six months and tallies with report of field agent. Specific review of field agents choice of respondent is not made. SCD guidelines do not contain recommendations on choice of respondent as is done by Garene and Fontaine (1990).</td>
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<tr>
<td>Recall period</td>
<td>Yes. The field agent maintains regular contact with suitable informants from the village on a weekly or fortnightly basis. The recorder does an independent survey half yearly. The VA interview would take place between 2 weeks to 7 months after the date of death.</td>
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<tr>
<td>Structured questionnaire and diagnostic algorithm.</td>
<td>Yes</td>
</tr>
<tr>
<td>Standardized pre-coded questionnaire and predefined algorithm is to be preferred (WHO-UNICEF, 1994). Participants at LSHTM workshop (1993) preferred a check list as opposed to an open format of interview and a predefined algorithm for coding.</td>
<td>Yes</td>
</tr>
<tr>
<td>Filter questions</td>
<td>Yes</td>
</tr>
<tr>
<td>At the LSHTM workshop (1993) most participants preferred the check list with filters to one without. Symptom based filtered modules (e.g. cough module) were preferred to disease specific filters. Zimicki (1990) reports that the respondents in Matlab, Bangladesh were asked a list of 16 questions. If the answer was yes, auxiliary questions specific to each symptom was asked. This was found superior to a large checklist of symptoms.</td>
<td>Yes</td>
</tr>
<tr>
<td>Recording multiple causes</td>
<td>No</td>
</tr>
<tr>
<td>Multiple causes of death should be permitted (WHO-UNICEF, 1994, LSHTM 1993).</td>
<td>No</td>
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</table>
Since SCD (Rural) satisfies most of the general design criteria for VA does it mean that the statistics generated by it would be valid? Not necessarily. Although the design features shown in Table - 2 are necessary for efficiency and validity they are not sufficient. Validity of classification of deaths to particular causes will depend on characteristics of the cause of death per se, content of the questionnaire and algorithm used for specific disease entities. Contents of questionnaire and coding algorithms are discussed below.

**Validity of SCD-Rural disease specific algorithms:**

As the WHO-UNICEF (1994) consultation noted, VA is suitable only for causes that have clear and unambiguous set of symptoms at the time of death. The symptoms and signs chosen to code deaths to a particular disease should result in most of the deaths truly due to the cause concerned to be coded as such (sensitivity) and exclude other causes that may have related symptoms. In addition, the choice of symptoms and signs must be parsimonious to reduce interviewer and interviewee fatigue. At the least, questions and coding algorithms should have face and content validity. In other words they should be based on expert judgment about their usefulness to identify and exclude specific causes. In addition validity with respect to a criterion will be desirable. Criterion validity of an instrument is assessed by comparing its result with some reference standard. Thus choice of a reference standard is the key to empirical validation of VA algorithms.

The gold standard reference for assignment of cause of death has been the autopsy. As the LSHTM (1993) workshop has noted, this is not a practicable solution to validate VA since the later alternative to medical certification of cause of death is considered only in areas with scarce medical facilities. Two other references have been proposed (LSHTM, 1993) and used, namely (a) hospital diagnosis and (b) clinical diagnosis. To validate VA with respect to hospital diagnoses, deaths in a community are coded using the VA instrument under testing. If the deceased happened to have been hospitalized, the medical records from hospital are retrieved. The reference cause of death is
assigned on the basis of the person's medical record in hospital. Alternatively, patients discharged from a hospital may be followed up after a lapse of time and deaths if any may be coded by VA. The hospital based reference diagnosis and the VA based code are then compared. Major shortcoming of the hospital based reference is selection bias. The LSHTM workshop discussed possible ways of reducing selection bias. An example of hospital diagnosis based reference is the study in Kenya by Snow et al (1992). In this study, hospital diagnosis was used as a reference to check validity of cause of death coded by physicians from verbal autopsy data. On the other hand, clinical diagnosis in the community has less of a selection bias. This would require a lot of medical manpower, which may not be available in an area for which VA is considered. It may, however, be possible to temporarily mobilize physicians for purposes of a validation study, since methodological lessons learnt from it would be useful for wider application. Kalter et al (1990) used physician diagnosis as the reference to estimate validity of different verbal autopsy based algorithms. Zimicki (1990) compared interviews by lay reporters with in-depth interview by physicians.

Sometimes empirical validity of VA tools are assessed indirectly by checking consistency of VA based statistics with known epidemiological patterns. One approach has used known efficacy of vaccination to reduce mortality due to the disease concerned. Validity of a VA tool measuring mortality due to that disease may be indirectly inferred from the time trend of estimates generated by it and vaccination coverage. For instance, Stephens (1990) studied measles related morbidity and mortality data collected by nonmedical field interviewers in a rural area in Senegal. Data on measles incidence and cause specific mortality was aggregated by hamlets. Stephens examined the movement of measles epidemic from hamlet to hamlet implied by the verbal autopsy data, consistent with known epidemiologic pattern of measles and vaccination coverage in respective hamlets.
SCD (Rural) algorithm organizes all causes, at the highest level, into ten modules based on obvious age-sex-major symptom complex (Table-2). An answer to the first round of questions about applicability of these modules leads the interviewer into the detailed questions under that module. It will be fairly obvious to determine if the death was due to say accidents and injuries (SCD module-1), maternity (module-2) or was of an infant less than one year old. There is a problem about the last module on senility. There are no further expansion of causes under senility. Criteria for inclusion under senility is that the person was extremely old and apparently not sick. The person should be above 60 years and none of the specific causes in SCD list be traced. The age criteria of more than 60 years would tend to put more deaths under this category.

Table-2 SCD (Rural) cause groups, availability of expert opinion or validity information on each cause and concordance of SCD questions with expert opinion.

<table>
<thead>
<tr>
<th>Category</th>
<th>Not Available</th>
<th>Availability and Concordance</th>
</tr>
</thead>
<tbody>
<tr>
<td>Fevers (3)</td>
<td>Influenza, Typhoid</td>
<td>Malaria</td>
</tr>
<tr>
<td>Digestive disorders (6)</td>
<td>Food poisoning, Peptic ulcer, Acute abdomen</td>
<td>Gastroenteritis (diarrhoea), Cholera, Dysentery</td>
</tr>
<tr>
<td>Coughs (5)</td>
<td></td>
<td>Tuberculosis of lungs, Bronchitis, Asthma, Pneumonia, Whooping cough</td>
</tr>
<tr>
<td>CNS disorders (3)</td>
<td></td>
<td>Stroke, Meningitis, Convulsions</td>
</tr>
<tr>
<td>Diseases of the Circulatory System (3)</td>
<td>Anaemia</td>
<td>Congestive heart failure, Ischaemic heart disease</td>
</tr>
<tr>
<td>Other clear symptoms (13)</td>
<td>Cirrhosis and chronic liver diseases, Chicken pox, Leprosy, Poliomyelitis, Mental disease, Diabetes, Hyperplasia of prostate, Uraemia, Obstructed hernia</td>
<td>Jaundice, Measles, Tetanus, Cancer</td>
</tr>
</tbody>
</table>
Figures in parentheses are the number of conditions within the group. For 12 causes under Accident and Injuries expert opinion is not available by specific cause. However, there is general agreement that these causes are obvious to lay reporters and hence verbal autopsy is considered to accurately assign deaths due to these causes. For similar reasons, the six causes under maternal deaths is not shown. Senility and other residual codes are not shown.

Expert opinion and SCD questions for the underlined causes of death listed under this column do not agree.

The SCD structured questions, and check list were compared with currently available expert opinion or validity information for respective causes of death in the SCD non medical list.

Table-2 gives a summary of SCD non medical list causes of death for which at least some expert opinion or validation information is available and if the SCD questions are in accordance with them.

Altogether there are 57 specific causes in the SCD non medical list, excluding the residual categories. Accidents and injuries account for 12 of these. Consensus about validity of VA to code deaths due to accidents and injuries is quite strong, since most of these are easily recognized by lay persons. Cause specific discussions of VA on accidents and injuries are not available in the literature. So is the case with deaths due to maternal causes under which SCD non medical list contains 7 causes. Excluding these 19 causes under accidents, injuries and maternal deaths there are 38 specific codes in the rest of the SCD non medical list. At least some expert opinion or validity information is available for 24 out of these 38 causes. As can be seen in Table-2 most of the causes for which some expert opinion is available are infant deaths, respiratory and diarrhoeal diseases. For 21 out of these 24 causes the SCD questions appear to be in accordance with expert opinion and validity information available in the literature.

The three causes for which there is major discrepancy are (a) cord infection, (b) prematurity, and (c) cancer. Most experts agree and validation studies show that verbal autopsy is
good at detecting neonatal tetanus. In SCD neonatal tetanus is included under cord infection and thereby misses an opportunity for accurate estimation of deaths due to a cause which is very important from public health point of view. Experts opine that it is usually difficult to distinguish between pre maturity and low birth weight (Garene and Fontaine, 1989; Gray, 1989). Hence they ought to be lumped together for accuracy of VA based statistics. The SCD list does not include low birth weight in its list. It can be added to pre maturity without any disturbance to the structure of the rest of the questionnaire. The SCD list lumps all cancers into one cause. Some expert opinion is usually available by site of cancer. More over, some cancers would have symptoms which may be confused with the filter questions for other modules. For example stomach cancer cases may be investigated as deaths due to digestive diseases. In that case the field agent may get to consider cancer of stomach at all since there is no mention of it in the digestive causes module. So is the case for lung cancer.

Non availability of expert opinion or validity information in the literature for other causes in the SCD non medical list does not imply that they are prima-facie not valid. The SCD design was based on expert opinion obtained at the time of drawing up the scheme and revision of manuals. The SCD design process included a phase of field testing of provisional questionnaires and finalisation by expert consultation. Considering the large extent to which questions for specific causes are in accord with expert opinion and information from VA validity studies, the SCD questionnaire appears to be prima facie valid.

Prima-facie, validity of SCD questionnaire is reassuring in the sense that the scheme design is largely in accord with current knowledge about verbal autopsy. But it does not assure us that the cause of death statistics are accurate for all causes. In case of causes for which VA is known to be highly sensitive and specific (say more than 75% for each) the SCD statistics can be mapped to
medical causes directly. For other causes more detailed algorithms for mapping of SCD statistics onto the desired set of medical causes will have to take into account available knowledge about sensitivity and specificity of VA in general and specific peculiarities of SCD implementation as well.

**SRS-COD Component:**

From January 1999, survey of cause of death was integrated with the SRS (RGI, 1999). It is understood that the SCD-Rural guidelines have been extended to the SRS-COD component. Although formal communication regarding this is yet to be available, I was able to obtain a copy of the RGI instructions on "Collection of data on causes of death" (Director of Census Operations, Andhra Pradesh, 1999). Two more columns have been added to SRS Form 5 (Columns 16-17) and Form-10 (columns 12-13). The SRS part time enumerator (PTE) records cause of death in column 16 and the code in column 17 of the revised Form-5. The SRS supervisor records similar information in columns 12 and 13 of the revised Form-10. A major departure from the SCD-Rural design is doing away with the symptom record (SCD-Rural Form-7). The SCD-Rural symptom record was similar in its information content to the WHO cause of death report format, which requires information about underlying causes of death. The SRS-COD component asks field agents to record the code to which cause of death is assigned. No further information about symptoms and circumstances of death need be reported. This later information is required for systematic screening and coding of cause of death reports. Another departure from the SCD-Rural is doing away with the structured questionnaire. Instead the instructions contain a list of causes, related symptoms for some, and the corresponding ICD10 code. For some causes, no description of expected symptoms is given. However, it is too early to make a judgment on the new system. It will be helpful if specific research studies are taken up to evaluate the performance of the new cause of death reporting system in rural areas.
The SRS-COD component will generate verbal autopsy based cause of death information for urban and rural areas, since SRS is operates both in rural and urban areas. Thus there will be two sources of cause of death data from urban areas, namely the (a) SRS-COD component, and (b) the Medical Certification of Cause of Death (MCCD) reports. It is claimed that this will allow for comprehensive statistics on cause of death for all areas of India. While availability of verbal autopsy based cause of death data for urban areas will allow for some plausibility checks and comparisons with the MCCD based data, the later source is definitely more preferable, since it is based on medical certification. The problem for urban areas is poor compliance by hospitals and medical attendants. This is mainly due to the fact that there is no effort, at all, by municipal authorities to ask for compliance with provisions of the Registration of BD Act. about reporting of cause of death.

**Summary and conclusion:**

Valid and reliable statistics on cause of death is an essential input for setting up of priorities in the health sector. Developing countries like India are making efforts to operate cause of death reporting systems that are feasible within the given constraints of partially developed registration of vital events, and poor availability of medical facilities. In the rural areas medical certification of cause of death is usually not feasible since a lot of deaths happen without any prior medical attendance. So India depends on a system of lay reporting of cause of death using what is called a verbal autopsy methodology. Until December 1999 cause of death data for the rural areas used to be collected under the Survey of Cause of Death (SCD) Rural scheme, from a sample of primary health center (PHC) headquarters villages by a lay diagnosis and reporting system. From January 1999 the a cause of death component has been added to the SRS (SRS-COD component). Certain general design features are key to wide applicability, efficiency and validity of data generated by a VA
based cause of death reporting system. Over the years some degree of consensus on major design issues have emerged. The structured questionnaires prescribed by the Registrar General of India for the SCD-Rural system was systematically examined for each of the conditions included in the non medical list. The SCD-Rural questions were examined in the light of available research results on verbal autopsy. SCD-Rural system appeared to satisfy most of the general design criteria for a good Verbal Autopsy system. The SCD structured questions, and check list were compared with currently available expert opinion or validity information for respective causes of death in the SCD non medical list. Altogether there are 57 specific causes in the SCD non medical list, excluding the residual categories. Accidents and injuries account for 12 of these. Consensus about validity of VA to code deaths due to accidents and injuries is quite strong, since most of these are easily recognized by lay persons. Cause specific discussions of VA on accidents and injuries are not available in the literature. So is the case with deaths due to maternal causes under which SCD non medical list contains 7 causes. Excluding these 19 causes under accidents, injuries and maternal deaths there are 38 specific codes in the rest of the SCD non medical list. At least some expert opinion or validity information is available for 24 out of these 38 causes. For 21 out of these 24 causes the SCD questions appear to be in accordance with expert opinion and validity information available in the literature. The three causes for which there is major discrepancy are (a) cord infection, (b) pre maturity, and (c) cancer. Most experts agree and validation studies show that verbal autopsy is good at detecting neonatal tetanus. In SCD neonatal tetanus is included under cord infection and thereby misses an opportunity for accurate estimation of deaths due to a cause which is very important from public health point of view. Experts opine that it is usually difficult to distinguish between pre maturity and low birth weight (Garene and Fontaine, 1989; Gray, 1989). Hence they ought to be lumped together for accuracy of VA based statistics. The SCD list does not include low
birth weight in its list. It can be added to pre maturity without any disturbance to the structure of the rest of the questionnaire. The SCD list lumps all cancers into one cause. Some expert opinion is usually available by site of cancer. Moreover, some cancers would have symptoms which may be confused with the filter questions for other modules. For example stomach cancer cases may be investigated as deaths due to digestive diseases. In that case the field agent may not get to consider cancer of stomach at all since there is no mention of it in the digestive causes module. So is the case for lung cancer. In terms of its design and verbal autopsy guidelines, the SCD-Rural system was reasonably valid. It appears to have been discontinued mainly on account of poor coverage and poor compliance at different levels of the cause of the reporting system.

The SRS-COD component relies on verbal autopsy to determine cause of death. However, major departures from the SCD-Rural design are (a) doing away with the structured questionnaire approach, and (b) lack of a symptom record. The SCD-Rural symptom record (SCD-Rural Form-7) was similar in its information content to the WHO cause of death report format, which requires information about underlying causes of death. The SRS-COD component asks the field agents to record the code to which cause of death is assigned. No further information about symptoms and circumstances of death need be reported. This later information is required for systematic screening and coding of cause of death reports. However, it is too early to make a judgment on the new system. It will be helpful if specific research studies are taken up to evaluate the performance of the new cause of death reporting system in rural areas.

References:


21. Director of Census Operations, Andhra Pradesh; Collection of data on causes of death”; *Official communication to the SRS staff, 1999, obtained by the author on July 06, 2000.*