Assessing Probable Causes of Death Using a Standardized Questionnaire: A Study in Rural Senegal

MICHEL GARENNE and OLIVIER Fontaine

Institut Français de Recherche Scientifique pour le Développement en Coopération (ORSTOM), Dakar, Senegal

Mortality remains strikingly high in many developing countries. According to figures for 1984 prepared by the US Bureau of Census, some 73 countries around the world appear to have a life expectancy below 60 years. Mortality is especially high in the rural areas of these countries, where the coverage of public health services is very low. Little information is available on levels of mortality and on causes of death in most remote places of Africa, Asia, and Latin America. In fact, vital registration is virtually non-existent in many places and official statistics are often unreliable. This lack of information has important implications for policy since a better knowledge of causes of death can help to direct treatments towards young children and mothers who most need them. A better knowledge of causes of death can also help evaluate the impact of programmes directed towards reducing mortality. Since no other source of information is currently available in remote places, ways for improving the knowledge of the health status of people of low-income countries seem to be an important research issue.

There have been several attempts to improve the quality and quantity of information on causes of death in places where no reliable system of registration is available. Biraud (1956) proposed the use of symptoms to help the recording and assessment of possible diagnoses of death. He suggested training non-medical personnel to record at least:

- sex and age at death
- circumstances of the death (accidents, violence, sickness)
- main symptoms, their localization and duration
- epidemic diseases prevalent.

Biraud's aim was to obtain 'community diagnoses' possibly gathered by civil servants. With a prior knowledge of the country, and of its customs and pathology, he estimated that important information on causes of death could be gathered this way. Biraud's questionnaire was simple but his approach was to focus on adults rather than on children, among whom more than 50% of deaths take place. Thirty years later one has to recognize that little has been achieved in setting up efficient systems of recording deaths or improving the assessment of causes of death in developing countries.

WHO has documented ways of improving lay reporting on causes of death and morbidity (WHO 1978). This document provides a comprehensive list of 123 diseases and 20 external causes, plus health services. Directed towards health personnel it appears, unfortunately, to be poorly adapted for research in the field. The diseases are assumed to be specified from a list of symptom associations susceptible of recognition by primary health services personnel. Some important diseases, like measles, are analysed with only one symptom, which seems too little to achieve high reliability. There are many diseases listed that occur only infrequently. Furthermore, the minimal mortality list groups together measles and chicken-pox, which can be easily separated, and it does not have categories for neonatal deaths, in particular neonatal tetanus, a very frequent cause of death. Lastly, they do not provide systematic ways of interviewing people on causes of recent deaths.

The need for more standardized procedures is particularly acute for researchers involved in projects on maternal and child health in rural places of developing countries. Other projects in developing countries have relied either on the report of the family, as in Bangladesh (D'Souza 1981), or on the constant involvement of a medical team in the field, as in Guatemala (Mata 1978) or in the Gambia (McGregor 1976), or on a combination of both as in Kenya (Van Ginneken and Muller 1984). The authors of this article are in fact two of the investigators of a research project on the relationship between nutritional status and mortality of children aged 0–5 years. The project is based on a comprehensive record of demographic events in a population of about 23,000 people in rural Senegal (Niakhar) (Garenne 1984). The assessment of causes of death in this population is of great importance for analysing the risk factors associated with nutritional status in relation to pathology.

The questionnaires devised for this study benefited from the experience of other researchers working in similar conditions. Two questionnaires for general and neonatal causes elaborated at ICDDR,B Bangladesh by Susan Zimicki as well as the RAMOS questionnaire for maternal mortality used by FHI were of great help at the beginning of this study. Four draft questionnaires were tested on more than 200 cases among people living in the rural areas of Sine-Saloum in Senegal prior to the adoption of the final version of the questionnaire that is discussed below.

1. The Approach

According to WHO guidelines, causes of death are defined as 'all those diseases, morbid conditions or injuries which either resulted in or contributed to death and the circumstances of the accident or violence which
Assessing Causes of Death in Senegal

Michel Gareinne and Olivier Fontaine

produced any such injuries' (WHO 1975: 763). This definition includes all the complex processes experienced by the patient prior to death. Of course it is out of question to analyse all these processes through retrospective interviews and only careful autopsies conducted by well-trained personnel can allow one to assess scientifically all the causes of death. The ICD classification of causes of death includes some 931 categories (three-digit codes, not counting E and V codes) and for each death there can be three to four 'diseases or morbid conditions or injuries'. This multiplies the possible coding or assignment of exact causes of death beyond the boundaries of feasibility of any lay classificatory system.

However, in high-mortality populations a very small number of diseases account for a very large number of deaths, and, furthermore, most of them are simple infectious diseases, usually caused by one or few pathogenic agents. Hence, an important amount of information on mortality could be gathered if it were possible to identify these most common causes. And in fact in high-mortality populations and especially for childhood deaths, the most common causes of death are infectious, with typical clinical signs that people are able to notice and remember. For instance, the main killers of children in Senegal are diarrhea and pneumonia—bronchopneumonia—bronchitis whose symptoms are fairly easy to describe. As these two diseases already account for half of the deaths of children between 1 month and 5 years of age, the possibility of identifying them appears extremely valuable.

The approach to the construction of a questionnaire for assessing causes of death from lay reporting is first to list a series of causes that are likely to occur frequently in the population. This will be done for various age groups and both sexes. Then, a series of symptoms associated with each of the common causes is elaborated. Symptoms that will be kept have to be sufficiently specific to pin-point a probable cause as well as to exclude the other possible causes already listed. The classification of causes of death includes a category of 'undetermined' causes that are assumed to be different from the specified causes. This aspect is of particular importance for the validity of the classification. As will be seen below, the questionnaire produces more information on certain diseases than expected, sometimes from additional evidence provided by health personnel. These diseases are either rare diseases or more frequent ones that were assumed to be difficult to identify from retrospective interviews. They should not be included in the final results since their statistical value is questionable. This is the case, for instance, with tuberculosis, which can sometimes be identified from the questionnaire but which is likely to be missed in a retrospective investigation.

Of course, the results that are obtained with this type of questionnaire depend on the ability and willingness of people to talk about recent deaths in their families. In various ethnic groups in Africa for instance this investigation is extremely difficult due to taboos and general reluctance to speak about deaths. Furthermore, some ethnic groups classify symptoms in ways that only remotely relate to Western classifications and it is sometimes difficult to have people make a distinction between similar symptoms that they consider equivalent. Our experience in Sine-Saloum, however, as well as the experience of others in various countries indicates that a large body of information can be gathered using this procedure.

2. The Questionnaire

The main guideline to the elaboration of the questionnaire developed in Senegal is to make use of all the information available that appears to be relevant for assessing the probable cause of death. The main items of information are the following:

- the age at death, particularly for neonates;
- the duration of illness, needed for standardization of the coding and also relevant for many causes such as malaria or maternal deaths;
- the symptoms: these are the basis for the diagnosis;
- the history of the disease: this item is particularly rich in information, although rarely sufficient for diagnosis. It summarizes the main symptoms that have caught the family's attention and provides the sequence of events between the first symptom and death. In addition, the open question that probes into the history of the disease often gives some evidence of contamination for communicable diseases.
- the treatments: this is important for assessing causes of death such as malaria. For instance, cases of acute fever among children who took quinine or chloroquine could not be attributed to malaria;
- any evidence of contamination: this can be a determining factor for assessing causes of deaths from communicable diseases such as measles, whooping cough, and cholera. In some cases symptoms are not always as unequivocal as required for diagnosis, but clear evidence of contamination in addition to a few symptoms can make the assessment of a probable cause of death less problematic.

Since symptoms selected for diagnosis vary widely according to the type of disease under investigation, four types of questionnaire have been designed:

- for neonates, i.e. children who died within the first four weeks of life;
- for children, i.e. children who died between 28 days and 14 years;
- for maternal deaths, i.e. women who died within the first six weeks after delivery;
- for other adult deaths, i.e. men or women above 15 years of age.

For convenience maternal-deaths questionnaires were included in the adult questionnaire for women and questionnaires for men were printed separately. The four types of questionnaire have the same structure:

- a first page, with all the information to be coded, including identification, age, and sex of respondent. the date of death. place of death. a
Assessing Causes of Death in Senegal

summarizing the treatments, and the cause the family thought to be responsible for the death. A separate part is for final assessment of probable causes of death:
- the history of the diseases leading to death and the treatments;
- a list of main symptoms or conditions. For each symptom follows a series of questions probing into its nature. These include the duration of illness, the dates of onset and termination, and the treatments for the symptom;
- other symptoms or conditions that may add useful information, as well as chronic diseases and other regular treatments;
- a check-list for establishing the diagnosis.

2.1 Questionnaires for Neonates

Questionnaires for neonates were designed to assess five main causes: neonatal tetanus, pneumonia of the new-born, birth trauma, congenital defects, and a composite group of causes that were impossible to separate: prematurity and low birth weight. The diagnosis of neonatal tetanus was made according to the following criteria:
- death from three to 20 days after birth;
- evidence of tetanus symptoms: refusal of the breast, tetanic crisis, rictus, infection of the umbilical cord;
- no evidence of vaccine against tetanus.

A good indication was also the family's recognition of a magical cause, referred to as kumaalass in Serer. The fact that tetanus is often attributed to magic created some difficulties in eliciting response to the questions. In several instances the investigators had to return to the family for checking purposes to attempt to obtain a better description of the symptoms.

Pneumonia of the new-born was diagnosed from:
- fever until death;
- symptoms of pneumonia within at least one day prior to death, such as: rapid breathing, difficult breathing, palpitating nostrils.

Birth trauma and congenital defects were assessed from the mother's report of the history of delivery and the child's aspect after birth. ...

2.2. Questionnaires for Children

These were designed to assess the role of a series of infectious diseases thought to be important; diarrhoea, pneumonia-bronchopneumonia-bronchitis, measles, whooping cough, meningitis, tetanus, malaria, epilepsy. Additional questions were directed towards malnutrition. ...

Michel Garenne and Olivier Fontaine

2.3 Maternal Deaths

Maternal deaths were divided into two categories: antepartum, i.e. during pregnancy, and postpartum, i.e. within six weeks of delivery. Questions concerning maternal deaths were directed towards identifying eclampsia, obstructed labour, severe bleeding, infections, and pulmonary embolism. ...

2.4. Other Adult Deaths

Adult deaths other than maternal deaths were the most difficult to identify from the questionnaires. The only diseases that were possible to assess with a reasonable degree of confidence were cholera, tuberculosis, leprosy, epilepsy, and accidents. ...

In some cases it was possible to ascribe death to cardiovascular diseases. But, as will be explained later, the distribution of causes of adult deaths is not as reliable as those for infants and children. ...

3. Importance of the Enumerator and of the Respondent

In remote parts of developing countries a constant obstacle to surveys and inquiries is communication with people who have a different value system. The choice and training of enumerators is fundamental to the quality of the answers. Enumerators should be of the same ethnic group as the people who are surveyed, if possible of the same village or the same region, since words that designate diseases or symptoms may vary from place to place even within the same ethnic group. Enumerators also need to be able to translate the answers into a more widely used language, usually a European language. Enumerators working at the Senegalese Project have at least four years of secondary schooling and one of them has seven years. All have received intensive training to carry out this type of survey. Special care is placed on the translation of answers given in Serer. Enumerators are also asked to write down Serer names of diseases as often as possible for checking purposes. The training also involves the clear identification of morbid symptoms as well as preparation in the approach to those who are surveyed.

The relationship between the enumerator and the interviewee is determinant for the quality of the answers. In-depth knowledge of the customs and taboos of the people under investigation is also required for good reporting.

The choice of the respondent is as important as the choice of the enumerator. In most cases when the death of a child is to be investigated, the best respondent: will be the mother if she is alive and present. When the mother is reluctant to answer, or absent, or unable to answer for a variety of reasons, the father may give reliable answers. In cases of fostering, i.e. when the child is not living with his parents, good answers can also be obtained from the person who takes care of the child, usually the grandmother or the mother's sister. Reports from mothers are usually very detailed and accurate, especially when the disease is recognized by the population.
Assessing Causes of Death in Senegal

Michel Garenne and Olivier Fontaine

Mothers notice with precision the symptoms that occur in a child as well as changes in the child’s health status that are often not noticeable to a foreign observer. Accurate and detailed reports of mothers are a valuable source of information when barriers of taboos and shyness are overcome.

Deaths of adults are far more difficult to investigate, since nobody pays as much attention to other adults as a mother to her child. Among adults maternal deaths appeared to be the easiest to investigate since at delivery women are taken care of by other women in the family and by traditional or modern midwives. Other women who have taken part in the delivery are usually a reliable source of information for maternal deaths. Deaths of young adults due to other causes often result from long-lasting sicknesses that have prompted individuals to visit a physician or a nurse and to receive treatment. For diseases other than those easily recognized by the population (epilepsy, leprosy, or cholera), empty boxes of drugs and prescriptions are probably the best source of information. The most serious problems in the investigation of deaths occur among the elderly. Among the Sereer, old people who feel sick often hide their disease, do not go to dispensaries, refuse to take drugs, and declare they want to die within the village like their ancestors. ...

The choice of the respondent also has an impact on the quality of the answers. Respondents have been divided into only two groups, close relatives and others, since there was no evidence of any difference between close relatives. Close relatives are defined as mother or father for children, grandmother for foster-children, and as spouse, parents, or children for adults. The quality of answers is always better when close relatives have answered the questionnaire, whatever the age at death (see Table 8.2). Results are statistically significant when all age groups are considered together. Close relatives rarely refuse to give details of the death (6.7% against 25.4% for other relatives) and on average the questions are better answered, since a diagnosis can be made in 69.8% of cases when close relatives answer rather than in only 50.3% when other relatives answer.

4. Delay in Answering

The delay in answering the questionnaires also has an impact on the quality of the answers. People interviewed too early after a death may be more reluctant to talk about it. On the other hand, if the visit occurs too long after the event, people may have already forgotten some of the details of the sequence of events that are necessary for assessing the cause of death. ...

5. Coding

The questionnaires used in this study are considered by the authors to be a minimum for assessing causes of deaths with a reasonable degree of confidence. However, they lead to more information than a single probable cause of death. They allow us to understand the sequence of the diseases that resulted in the death of a child. For instance, cases of measles followed by acute diarrhoea or pneumonia are usually well reported. This raises an important problem for coding answers. Is the recorded death to be attributed to measles or to diarrhoea? Does one need to code all the diseases leading to death as recommended by WHO?

In the pilot study, we preferred to follow exactly the sequence of morbid episodes that resulted in death. For instance, a sequence of measles followed by diarrhoea could be coded as having measles as the first disease and diarrhoea as the second but without assigning priority to either of the two. However, as we show below, the information on the exact sequence of diseases obtained from this type of questionnaire is rather poor and, except in common cases involving sequences such as measles and diarrhoea, there was virtually no information on conditions other than those related to the main cause. We later adopted a hierarchical classification of ‘probable main cause’, ‘probable immediate cause’, and ‘probable associated cause’. The definition of ‘probable main cause’ is not equivalent to that of the underlying cause defined by WHO; however, both classifications appear as equivalent in many instances, since most cases are simply attributed to one cause. This hierarchical classification proved to be far more useful for tabulations and comparisons with other sources, since only the main cause is usually published in mortality data.

Selection rules for considering the main cause, the immediate cause, and the associated cause were adopted. These rules are applied only in a small number of diseases, in particular measles, whooping cough, diarrhoea, and pneumonia. ...

6. Results

Depending upon the age at death and the type of questionnaire a number of causes were assessed with a reasonable degree of confidence.

Among neonates, 26 deaths were attributed to neonatal tetanus, 32 to prematurity or hypotropia, 10 to pneumonia of the new-born, and two to congenital defects. No analysis of immediate cause was made. Associated causes were mostly due to the death of the mother, which often implies the death of the child. In rural places orphans have little chance of survival. They can receive assistance from charitable organizations, which exist and are efficient in the country, but in many cases the child has to survive on cows’ milk for the first few weeks of life after which he might be breast-fed by his grandmother or his mother’s sister.

Among deaths of children less than 5 years old, 132 were attributed to diarrhoea and 68 to pneumonia–bronchopneumonia–bronchitis, the two leading causes of deaths. Thirty-nine were attributed to measles, 19 to whooping cough, 38 to malaria, and 13 to malnutrition. Among rarer
Assessing Causes of Death in Senegal

causes of death there was one case of food poisoning, one case of meningitis, one case of tetanus, two cases of septicaemia, three cases of chickenpox, two cases of hepatitis, one case of anaemia, two cases of epilepsy, one case of late effect of meningitis, one case of hydrocephalus, and one case of intestinal obstruction. In addition there were two accidents.

Among deaths of children of 5–14 years there were four cases of diarrhoea, three cases of meningitis, one case of measles, six cases of malaria, three cases of pneumonia, and two accidents.

Six out of the 14 maternal deaths recorded were possible to attribute to a cause directly from the report in the questionnaire. Furthermore, in seven cases there was a visit by a physician since maternal deaths often occur in a hospital. Among antepartum deaths one was an extrauterine pregnancy with haemorrhage, one was due to pre-eclampsia, and one had no report from the family since it occurred outside the village and the case was not found at the hospital. Among the 11 postpartum deaths, two were due to pulmonary embolism, two to postpartum haemorrhagia, one to placenta praevia, one to eclampsia, one to postpartum infection, and one to uterine failure.

Among deaths of young adults, two were attributed to tuberculosis, one to septicaemia, two to epilepsy, two to pneumonia, one to nephrotic syndrome, and three to accidents.

Among the elderly, only few probable causes of death were specified: one case of diarrhoea, one food poisoning, four tuberculosis, one leprosy, one septicaemia, one hemiplegia, three hypertensive heart diseases, one myocardial infarction, one intracerebral haemorrhage, four pneumonia, one asthma. In addition there were three accidents.

The analysis of immediate causes of death adds only little to our knowledge of the main causes (see Table 8.4). Diarrhoea was found to be followed by pneumonia in seven instances among 137 cases. Whooping cough was followed in five instances by diarrhoea, in two by pneumonia, and in one case by measles. Among 40 cases of measles, six were followed by diarrhoea, three by pneumonia, and one by whooping cough. Of 13 deaths attributable to malnutrition as a main cause three were followed by diarrhoea and two by pneumonia. Finally, of 77 cases of pneumonia–bronchitis three were followed by diarrhoea. All in all, among 494 probable causes of death assessed from the questionnaire, only in 50 (10%) has a probable immediate cause of death been added.

Associated causes also added little to the probable main cause (see Table 8.5). Diarrhoea was associated in 22 instances (one with whooping cough, nine with measles, one with malaria, and nine with pneumonia). Malnutrition was also found to be often associated with other causes of death: in 11 cases with diarrhoea, in one case with whooping cough, and in one case with pneumonia. In our project at least the main purpose of using associated causes is to allow evaluation of routinely recorded late effects of measles, whooping cough, and malnutrition on mortality. The fact that the child has had a history of chronic diarrhoea is more difficult to interpret since there is no record of this disease in the population as a whole. However, it should be noted that many cases of deaths associated with several diseases or symptoms have resulted in an ‘undetermined’ cause.

Michel Garenne and Olivier Fontaine

7. Discussion

This type of standardized questionnaire has an advantage over unstructured interviews: it does not require a well-qualified physician to conduct the interviews as is done in some research projects. The expertise of a physician is required only for reading the completed questionnaire and for checking in the field when needed.

This type of questionnaire also produces multiple types of evidence for assessing causes of death. In fact, the procedure relies on several articulate layers of evidence. The first is derived from the declaration of the family. The second step is the use of a systematic questionnaire aimed at assessing a probable cause. A third is the clinical examination by a physician prior to death. A fourth is the in-depth study of the case prior to death, with biochemical examinations. A fifth and final level is the autopsy, which is probably the only rigorous way of assessing causes of death. ...

For children less than 5 years old (see Table 8.7), diarrhoea is reported by the population (117 out of 132 cases are correctly identified). Probable diagnosis of measles and whooping cough are, by definition, closely linked to spontaneous reports of parents since the probable cause assessed from the questionnaire relies upon parents’ declaration of the disease. Discrepancies occur mostly from a confusion between main and immediate cause and, sometimes, from poor reporting of cough or crises for pertussis and of fever for measles. Cough, chest-aches, and cold, along with malaria–fever–hot body are the most confusing categories where the benefits of the questionnaire are the greatest. Malaria would have been misdiagnosed in 70% of cases and pneumonia–bronchitis in 30% of cases if only spontaneous reports of the family had been taken into account. Not surprisingly, accidents are consistently reported in both cases. Although the case of meningitis among children less than 5 years old would have been missed, cases of death due to meningitis among older children are properly reported by the family.

If correspondences can be established for diseases in children, little can be done for adults, due to the poor performance of the questionnaire. With respect to maternal death no comparisons were done since relatives do not report on these deaths. ...
Assessing Causes of Death in Senegal

The reading and interpretation of the questionnaire involves subjectivity and judgement. Although there were strict guidelines, questionnaires analysed by two different persons rarely end up with the same diagnosis. This leads to an inflation of the category 'undetermined cause'.

It would be extremely valuable to compare results of such a study with autopsies. Naturally, there would be certain discrepancies, if only because clinical signs do not always signal the disease. However, Van Ginneken and Muller (1984) found that clinical signs were at least as good as most sophisticated biochemical examinations for measles and whooping cough. On the other hand, whatever the discrepancies, the distribution of the deaths according to main probable cause is still a valuable tool. ...

8. Conclusion

The results of retrospective interviews recorded with a standardized questionnaire in rural West Africa suggest that very valuable information can be gathered with a simple methodology and adequately trained enumerators. Physicians are needed only to read the questionnaires and assess 'probable causes of death'. Results of surveys applied over a two-year period on a population of 23,000 people indicate that causes of deaths of neonates, of children below the age of 5 years, as well as of maternal deaths can be assessed with a reasonable degree of confidence. Causes of deaths of older children and of young adults are more difficult to assess, and reports on deaths of the elderly were too poor to be of any use.

For all ages combined, 87.7% of questionnaires were properly filled in and a cause could be identified in 64.9% of those cases. The report and assessment was better for neonate, young children, and maternal deaths. The quality of answers was better when close relatives answered the questionnaire and when the interview took place not too soon and not too long after death; the optimal delay seemed to be between three and nine months after the death.

Among the causes of death that were identified from the questionnaires the most common were: diarrhoea and dysentery, pneumonia–bronchopneumonia–bronchitis, malaria, measles, whooping cough, malnutrition, tetanus, and a composite category of prematurity–low birth weight–hypotropia for neonates. Among other infectious diseases meningitis, septicaemia, chicken-pox, hepatitis, tuberculosis, and leprosy were identified. Among other diseases (other than maternal deaths) epilepsy, hemiplegia, hypertension, myocardial infarction, intracerebral haemorrhage, asthma, and anaemia were identified. It should be noted that some of these causes have been assessed from physicians and found either in health centre registers or in prescription records.

A classification of causes into 'probable main cause', 'probable immediate cause', and 'probable associated cause' added little information to the general picture. Major associations were found between diarrhoea, pneumonia, measles, whooping cough, and malnutrition.

Michel Garenne and Olivier Fontaine

Although the reliability of this approach can always be questioned in the context of low levels of modern education the results we obtained seem to be in line with other investigations. The use of a standardized questionnaire does provide at least some evidence supporting an assessment of probable causes of death. Its limitations are a function of the list of causes of death under investigation.

References


