

ASSESSING PROBABLE CAUSES OF DEATHS

USING A STANDARDIZED QUESTIONNAIRE

A STUDY IN RURAL SENEGAL

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# ABSTRACT

A study has been conducted in rural Senegal (Niakhar) on 808 deaths of all ages. Probable causes of death have been assessed using a standardized questionnaire and well trained enumerators. Physicians are needed only for the reading of the questionnaires and the assessment of "probable causes of death".

Results of a survey over 2 years in a population of 23000 people indicate that deaths of neonates, deaths of children below the age of 5 years as well as maternal deaths can be assessed a probable cause with a reasonable degree of confidence. Deaths of older children and young adults are more difficult to assess; reports on deaths of the elderly were too poor to be of statistical significance. The quality of answers was better when close relatives answered the questionnaire and when the interview took place not too early and not too late after death; the optimal delay seemed to be between 3 and 9 months after the death. A classification of causes into "probable main cause", "probable immediate cause" and "probable associated cause" added only little information to the general picture.

Mortality remains high in many developing countries. According to the US Bureau of Census, some 73 countries around the world appear to have a life expectancy below 60 years (1984 figures). 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 or 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 their mothers who most need them. A better knowledge of causes of death can also help evaluating 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 seems to be an important research issue.

There have been several attempts to improve the quality and the quantity of information on causes of death in places where no reliable system of registration is available. Biraud (1954) proposes to use symptoms to help the recording and the assessment of possible diagnoses of death. Biraud suggested to train 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' aim was to obtain "community diagnoses" possibly gathered by civil servants. With a prior knowledge of the country, of its customs and its pathology, he estimated that important information on causes of death could be gathered this way. Biraud's questionnaire was simple. His approach was focusing on adults rather than on children whereas more than 50 % of deaths occur below age 5 years in most areas of tropical countries. 30 years later one has to recognize that little has been achieved to have efficient systems of recording deaths or to improve the assessment of causes of deaths in developing countries.

WHO has documented ways of improving the lay reporting on causes of death and morbidity (WHO, 1978). This document provides a comprehensive list of 123 disease plus 20 external causes and health services. Directed towards health personnel it appears unfortunately as 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 only with one symptom, which seems too little for a good reliability. They are many diseases listed that are of poor statistical value. Furthermore, the minimal mortality list groups together measles and chickenpox which can be easily separated with value and it does not have categories for neonatal deaths, in

particular neonatal tetanus, a very frequent cause of death. Last they do not provide systematic ways of interviewing people on causes of recent deaths.

This 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 a constant involvement of a medical team in the field, as in Guatemala (Mata, 1978) or in the Gambia (McGregor, 1976) or 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 on the relationship between nutritional status and mortality of children age 0 to 5 years. The project is based on a comprehensive record of demographic events in a population of about 23000 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 with 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 (Family

Health International) have been of great help at the beginning of this study. Four draft questionnaires have been 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.

#### 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 produced any such injuries" (WHO, 1975, p. 763). This definition includes all the complex processes through which the patient goes prior to death. Of course it is out of question to analyse all these processes through retrospective interview of people and only careful necropsies conducted by well trained people can allow one to assess scientifically all the causes of death. The ICD classification of causes of death includes some 931 categories (3 digits codes, not counting E and V codes) and for each death there can be 3 to 4 "diseases or morbid conditions or injuries" which makes an enormous amount of possibilities for the coding of exact causes of death.

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 can be gathered if it is possible to tackle these most common causes. And in fact in high mortality populations, especially for children deaths, the most common causes of deaths are infectious, with typical clinical signs that people are able to notice. For instance main killers of children in Senegal are diarrhoea 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 as extremely valuable.

The approach to the constructing of a questionnaire for assessing causes of deaths 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 groups of age and sex. Then, a series of symptoms associated with each of the common causes is elaborated. Symptoms to be kept for the study have to be sufficiently specific to pinpoint a probable cause as well as to exclude the other possible causes already listed. This approach allows one to elaborate a classification of probable causes of deaths with a category of "undetermined" that are assumed to be different from the specified causes. This aspect is of particular importance for the validity of the classification. As it will be seen below the questionnaire produces more information than expected, sometimes from additional evidence provided by health personnel. These diseases can be either rare diseases or more frequent ones that were considered as impossible

to be identified from retrospective interviews. They should not be included in the final results since their statistical value is questionable. This is the case for instance for tuberculosis which can sometimes be identified from the questionnaire but which is likely to be missed in a retrospective investigation.

Of course, this type of questionnaire is depending 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 on speaking about deaths. Furthermore some ethnic groups do use classifications of symptoms that are far away from those of westerners and it is sometimes difficult to have people make a distinction between similar symptoms that they consider as 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 this way in many instances.

#### THE QUESTIONNAIRE

The main guide to the elaboration of the questionnaire that has been developed in Senegal has been to make use of all the information available that can be relevant for assessing the probable cause of death:

- the age at death, particularly important for neonates.
- the duration of illness, at least needed for standardization of the coding and also relevant for many causes such as malaria or maternal deaths.

- the symptoms, that are the basis for the diagnosis.
- the history of the disease. This part is particularly rich in information, although rarely sufficient for diagnosis; it summarizes the main symptoms that have struck the family's attention and gives the sequence of the events between the first symptom and the death. In addition, this open question often gives some evidence of contamination for communicable diseases.
- the treatments. This also appeared to be important to assess causes such as malaria. For instance cases of acute fever for no other causes 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 or cholera. In some cases symptoms are not always as clear as it is required for diagnosis, but clear evidence of contamination plus one or a few symptoms can make the decision to assess a probable cause of death.

Since symptoms selected for diagnosis strongly vary according to the type of disease under investigation, 4 types of questionnaires have been devised:

- neonates, i.e. children who died within the first 4 weeks of life.
- children, i.e. children who died between 28 days and 14 years.
- maternal deaths, i.e. women who died within the first 6 weeks after delivery.

- other adult deaths, for men or women above 15 years of age, outside of maternal deaths.

For convenience maternal deaths questionnaires were included into the adult questionnaire for women and men questionnaires were printed separately.

All of the 4 types of questionnaires have the same structure:

- a first page, with all the information to be coded, including identification, age, sex, the respondent, the date of death, place of death, a summary of the treatments, 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 related to this symptom, including the duration of illness, date of beginning and end, the treatments for this symptom. These questions are asked only if the symptom is present.
- 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.

#### NEONATES QUESTIONNAIRES

Questionnaires for neonates were designed to assess 5 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 on the following criteria:

- death from 3 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 assent to a magical cause, called "Kumalass" in Sereer. The fact that tetanus is often attributed to magic created difficulties in asking the question, and in several instances the investigators had to return to the family for checking purposes. In these cases the family always agreed to describe the symptoms more clearly the second time.

Pneumonia of the new born was diagnosed from :

- fever until death
- symptoms of pneumonia within at least 1 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.

Prematurity and low birth weight were assessed from either mother's report of marked prematurity (low number of weeks of pregnancy), or report that the child was markedly small or report of cases of twin births or triplets. Deaths among these children usually occurred within 3 days after birth.

## CHILDREN QUESTIONNAIRES

Children questionnaires were designed to assess the role of a series of infectious diseases that were assumed to be important, mainly: diarrhoea, pneumonia-bronchopneumonia-bronchitis, measles, whooping cough, meningitis, tetanus, malaria, epilepsy. Additional questions were directed towards malnutrition.

Diarrhoea and dysentery are probably the easiest category to determine. The main difficulty in attributing a cause to diarrhoeal diseases stays in eliminating the other possible causes that can be associated with diarrhoea, such as malaria or measles. Criteria that were retained for classifying diarrhoea as the main cause were:

- declaration of diarrhoea
- evidence of abundant stools until death
- no evidence of other disease mentioned in the check list
- signs of dehydration such as thirst, sunken eyes or sunken fontanelles.

Pneumonia, bronchopneumonia and bronchitis diagnoses were based on the evidence of fever until death and of the following symptoms: rapid breathing, breathing like a little dog difficult breathing, palpitating nostrils, insuccion, acute cough; the symptom reported should have lasted at least 24 hours prior to death to avoid confusion with signs of agony.

Measles deaths were also easy to determine since people recognize accurately the disease. Criteria were :

- declaration of measles by the parents
- death within 6 weeks after the beginning of the fever and rash.
- evidence of an epidemic in the village, or evidence of contamination outside of the village.
- symptoms in the following sequence: fever, running nose, red eyes, rash starting on the face, rash inside the mouth (Koplik spots), rash all over the body, peeling of the skin.
- no evidence of excluding symptom, such as water in the pimples.

Whooping cough is also easily recognized by the people.

In addition to the declaration by the family, criteria were:

- death during the period of cough (100 days after the start)
- evidence of an epidemic in the village, or evidence of contamination outside the village.
- at least long lasting cough together with symptoms such as whoop, vomiting, red eyes.

Malaria is one of the most difficult disease to evaluate from this type of questionnaire. Criteria that were used were:

- high fever with sweat or chills
- death within 3 days after the beginning of fever
- no evidence of adequate prevention or treatment at least 12 hours prior to death, such as chloroquine or quinine.

The fact that the death occurred to a healthy child and that it surprised the parents or that the death occurred during the rainy season were considered as additional evidence, but were not taken as a criteria.

Meningitis appeared to be more difficult to assess than other causes, probably because people tend to associate these signs to magic causes. Criteria for the diagnosis were:

- fever until death
- evidence of symptoms of meningitis: head bent backwards, arms and legs bent, swollen fontanelles. Typical convulsions, headaches and photophobia were also used as additional evidence. Declaration of paramedical personnel was also considered as valuable. No case of meningitis has been diagnosed outside of the epidemics of 1983 and 1984.

Epilepsy: like measles, epilepsy is well identified by people. Criteria to attribute the death to this cause were :

- declaration by the family
- symptoms of epilepsy, usually the report of a typical crisis by the family.

Evidence of a treatment against epilepsy was often a help for diagnosis, since most of the people had been treated prior to death.

Malnutrition. This diagnosis was made possible during the project because nutritional status was regularly assessed for all children below the age of 5 years, and they were examined by



a physician at the time of the nutritional assessment. However the questionnaire often gave good indications that the child had lost weight during several weeks prior to death. Death was ascribed to malnutrition if there were no evidence of acute diseases such as measles or whooping cough in the period required for attributing the death to another cause (see below the coding of multiple causes).

#### MATERNAL DEATHS

Maternal deaths were divided into two categories: ante-partum, ie during pregnancy and post-partum ie within 6 weeks after delivery.

Questions concerning maternal deaths were directed towards identifying eclampsy, obstructed labor, severe bleeding, infections and pulmonary embolism.

Eclampsy and pre-eclampsy were identified from signs of hypertension (swollen legs, arms, body, face, trouble hearing) and from a typical crisis. In most cases these women had been seen by a physician during pregnancy and had received treatment for hypertension. Obstructed labor and severe bleeding were reported by the family. Deaths usually occurred during or within 3 days after delivery. Puerperal infections were identified from evidence of fever and usually belly-aches until death. Pulmonary embolism by sudden death from no other cause, with signs of violent chest-aches. In several instances it was possible to get more accurate details from the health center where they had been

brought. All maternal deaths were assessed with the collaboration of a specialist working in a nearby town hospital (Kaolak).

#### OTHER ADULT DEATHS

As shown below, adult deaths aside from maternal deaths were the most difficult to assess from the questionnaires. The only diseases that were possible to assess with a reasonable degree of confidence were cholera, tuberculosis, leprosy epilepsy and accidents.

Cholera is characterized with a dramatic start of diarrhoea or vomiting, usually both occurring at the same time. Symptoms required for diagnosis were: abundant watery diarrhea (like rice water) or vomiting, without fever and obvious signs of dehydration. Death occurs within 3 days and there is good evidence of contamination or of an epidemic (all cholera deaths occurred in 1985 and are not reported in this study).

Tuberculosis, leprosy and epilepsy have typical symptoms; besides they last for a long period and they strike mostly among young adults who go to see the physician and receive adequate treatments. Evidence of these treatments such as prescription or empty boxes of drugs are often the best indicators of the disease for adults.

In some cases it was possible to ascribe death to cardiovascular diseases. But as it will be explained below, the distribution of causes of adult deaths can not be considered as

## IMPORTANCE OF THE ENUMERATOR AND OF THE RESPONDENT

In remote places of developing countries a constant obstacle to surveys and inquiries is how to communicate with people who have a different system of values. The choice and the training of enumerators is determinant for the quality of the answers. Enumerators should be of the same ethnic group as the people who are surveyed, if possible of the same villages 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 in a more widely used language, usually a European language. Enumerators working at the Senegalese Project have at least 4 years of secondary schooling, one of them has 7 years. They have received a special training for this type of survey. Special attention has been devoted at the beginning to the translation of answers given in Sereer. Enumerators are also asked to write down Sereers 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 a 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 child fosterage, ie when the child is not living with his parents, good answers can also been obtained from the person who takes care of the child, usually the grand mother or the mother's sister. Reports from mothers are usually very detailed and accurate, especially when the disease is identified by the people. Mothers notice with precision the symptoms that occur to a child as well as changes in the 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 others as a mother for her child. Among adults, maternal deaths appeared to be the easiest to investigate, since at the time of delivery women are taken care of by other women of 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. Other deaths of young adults often result from long lasting sicknesses; sick people may have visited a physician or a nurse and received treatments. Empty boxes of drugs and prescriptions are probably the best source of information, outside of diseases widely recognized by people, such as epilepsy, leprosy or

cholera. The main problems in investigating deaths are with the elderly. Among the Sereer, old people who feel sick often hide their disease, they do not go to dispensaries, they refuse to take drugs and declare they want to die within the village like their ancestors.

Table 1 indicates how important is the age effect on the quality of the reporting on causes of deaths. Among neonates information is obtained in 97.0 % of the cases and a diagnosis is made in 73.2 % of the reports. Among children 1 month to 5 years, 96.8 % of questionnaires are properly filled and diagnosis is possible from the questionnaire in 78.5 % of the cases. Among children 5 to 14 years there were 97.6 % of proper report and a diagnosis was possible in 47.5 % of cases only. For maternal mortality questionnaires were always filled up and a diagnosis was possible in 64.3 % of the cases. Among young adults, 15 to 49 years, questionnaires were answered in 74.5 % of the cases, but diagnosis was made in 28.9 % of the cases. Among the elderly, ie above 50 years of age, for both men and women 40.0 % of the questionnaires came back with no answer, and among those that were filled up a probable cause of death was ascribed in only 21.6 % of the cases.

The choice of the respondent also has an impact on the quality of the answers. Respondents have been divided into two groups: close relatives and others, since there were no evidence of any difference among close relatives. Close relatives are defined as mother or father for children or grand mother for

foster children and as spouse, parents or children for adults, depending on their age. The quality of answers is always better when close relatives have answered the questionnaire, whatever the age at death (table 2). Results are statistically significant when all age groups are considered together. Close relatives rarely refuse to give details on the death (6.7 %, against 25.4 % for other relatives) and on the average the questions are better answered, since a diagnosis has been made in 69.8 % of cases against 50.3 % only when other relatives have answered.

#### DELAY IN ANSWERING

The delay in answering the questionnaires also has an impact on the quality of the answers. People interviewed too early after 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 in the sequence of events that are necessary for assessing the cause of death. The routine demographic survey in Niakhar is done once a year only, and on the average deaths have been investigated 5.2 months after the event. Table 3 indicates that quality of the answers does vary significantly with the delay after death. The best period to ask the questions seems to be between 3 and 9 months after death. Deaths investigated too early have a twofold higher percentage of no answer (17.9) and a lower percentage of cause assessed (57.9 %) than those investigated between 3 and 9 months (9.2 % and 70.1 %). Deaths of children investigated more than 9

months after were also more poorly reported: the questionnaire was not properly filled in 17.0 % of cases, and a cause could be attributed in only 62.8 % of the cases. Differences between those interviewed 3 to 9 months after the death and the others are statistically significant ( $P < 0.05$ ).

#### CODING

The questionnaires used in this study are considered by the authors as being a minimum questionnaire 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 one 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 of 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 had preferred to follow exactly the sequence of morbid episodes that resulted into death. For instance, a sequence of measles followed by diarrhoea could be coded as measles as the first disease and diarrhoea as the second disease, without giving to any disease a priority other than the sequence order. However, as shown below, the information on the exact sequence of diseases obtained from this type of questionnaire is rather poor and furthermore, outside of common

sequences such as measles and diarrhoea, there were very scarce information on conditions other than the main cause. We then adopted later a hierarchical classification of "probable main cause", "probable immediate cause" and "probable associated cause". The definition of the "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 also for comparisons with other data, 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 had to be adopted. This problem arises only with a small number of diseases, in particular measles, whooping cough, diarrhoea and pneumonia. The main cause was coded measles when the death occurred during the 6 weeks after the onset of measles. The main cause was coded whooping cough when the death occurred during the 100 days of cough after the onset of the disease. In case of double infection of measles and whooping cough, the first disease was coded as the main cause and the other as the immediate cause. In cases of diarrhoea or pneumonia as a complication of a disease, the complication was coded as an immediate cause if it lasted until death or an associated cause if not. In cases of double infection with diarrhoea and pneumonia, the first disease to occur was coded the main cause and the other as the immediate cause.

Malnutrition was coded as the main cause of death if no main disease such as measles, whooping cough or other diseases of children was considered as the cause of death. Malnutrition could be considered as the main cause if diarrhoea or pneumonia was the immediate cause. If another disease was considered as the main cause, such as measles, malnutrition was considered as an associated cause. Measles was considered an associated cause if the death occurred between 6 weeks and 6 months after the onset of the rash; Whooping cough, if the death occurred between 100 days and 6 months after the onset of the cough. Tetanus is coded as such for umbilical tetanus, tetanus after vaccination, circumcision or after a minor cut. In case of a more serious injury the accident is coded as the main cause and tetanus as an immediate cause. Epilepsy is coded as the main cause even if death is caused by an accident resulting from epilepsy; in this case the accident is an immediate cause. Mental disorders are always considered as associated cause, never as a main cause.

## RESULTS

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

Among neonates, 26 deaths were attributed to neonatal tetanus, 32 to prematurity or hypotrophia, 10 to pneumonia of the new born and 2 to congenital defects. No analysis of immediate cause was made. Associated causes were mostly due to the death of the mother, which often means the death of the child. In rural

places orphans have little chances of survival. They can receive assistance from charitable organisations, which exist and are efficient in the country but in many cases the child has to survive on cow milk for the first 4 weeks of life until he might be breastfed by his grand mother or his mother's sister.

Among deaths of children less than 5 years of age, 132 were attributed to diarrhoea and 68 to pneumonia-bronchopneumonia-bronchitis, from far the two leading causes of deaths. 39 were attributed to measles, 19 to whooping cough, 38 to malaria and 13 to malnutrition. Among rarer causes of deaths there were 1 case of food poisoning, 1 case of meningitis, 1 case of tetanus, 2 cases of septicemia, 3 cases of chicken pox, 2 cases of hepatitis, 1 case of anemia, 2 cases of epilepsy, 1 case of late effect of meningitis, 1 case of hydrocephalia and 1 case of intestinal obstruction. In addition there were 2 accidents.

Among deaths of children 5-14 years there were 4 cases of diarrhoea, 3 cases of meningitis, 1 case of measles, 6 cases of malaria, 3 cases of pneumonia and 2 accidents.

6 out of the 14 maternal deaths recorded were possible to ascribe a cause directly from the report in the questionnaire. Furthermore, 7 also had been seen by a physician, since maternal deaths often occur in a hospital.

Among ante-partum deaths 1 was an extra-uterine pregnancies hemorrhage, 1 was due to pre-eclampsia and 1 had no report from the family since it occurred outside of the village

and the case was not found at the hospital. Among the 11 post-partum deaths 2 were due to pulmonary embolism, 2 to post-partum hemorrhagia, 1 to placenta-praevia, 1 to eclampsy, 1 to post-partum infection and 1 to uterine failure.

Among deaths of young adults, 2 were attributed to tuberculosis, 1 to septicemia, 2 to epilepsy, 2 to pneumonia, 1 to nephrotic syndrome and 3 to accidents.

Among the elderly only few probable causes of death were specified: 1 case of diarrhoea, 1 food poisoning, 4 tuberculosis, 1 leprosy, 1 septicemia, 1 hemiplegia, 3 hypertensive heart diseases, 1 myocardial infarction, 1 intracerebral haemorrhage, 4 pneumonia, 1 asthma. In addition there were 3 accidents.

The analysis of immediate causes of death add only little to knowledge of the main causes (table 4). Diarrhoea was found to be followed by pneumonia in 7 instances among 137 cases. Whooping cough was followed in 5 instances by diarrhoea, in 2 by pneumonia and in 1 case by measles. Among 40 cases of measles, 6 were followed by diarrhoea, 3 by pneumonia and 1 by whooping cough. Malnutrition as a main cause was followed by diarrhoea in 3 cases and pneumonia in 2 cases, among 13 deaths. Last, pneumonia-bronchitis was followed by diarrhoea in 3 cases. All in all, among 494 probable causes of death assessed from the questionnaire, only 50 (10 %) have been added a probable immediate cause of death.

Associated causes also added little to the main probable cause. Diarrhoea was associated in 22 instances (1 with whooping cough, 9 with measles, 1 with malaria and 9 with pneumonia). Malnutrition was also found often associated to other causes of death: in 11 cases with diarrhoea, in 1 case with whooping cough and in 1 case with pneumonia. In this project, the main interest of using associated causes remains for measles, whooping cough and malnutrition, since it allows one to evaluate the late effects of those diseases on mortality which are routinely recorded. The fact that the child has had an 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.

#### DISCUSSION

This type of standardized questionnaire has an advantage on unstructured interviews. It does not require a well qualified physician for conducting the interviews as it is done in some research projects. The expertise of a physician is required only for the reading of the filled questionnaire and for checking in the field when needed.

Another interest of this type of questionnaire is to produce some kind of evidence for assessing causes of death. In

showing causes of deaths there are in fact several levels of evidence. A first step is the declaration of the family. A second step is the use of a systematic questionnaire aiming at assessing a probable cause. A third step is a clinical examination by a physician prior to death. A fourth step is an in depth study of the case prior to death, with biochemical examinations. A fifth and ultimate step is the necropsy, which is probably the sole rigorous way of assessing causes of death.

In developing countries mortality surveys often record causes that people are able to identify, such as diarrhoea or measles and causes that they may learn at a health center when the person has been brought there, tetanus or meningitis for instance. Although this record may be sometimes of interest, it is often of a poor reliability since categories used by people do not necessarily coincide with modern categories. Furthermore, since there is no systematic attempt to analyse deaths, many causes end-up not declared and results may be strongly biased at a statistical level, even though the causes of deaths that are recorded are properly assessed.

However, since most of probable causes of death rely on the recognition of the disease by the family it is important to show that the questionnaire has improved the quality of the answers. Table 6 indicates the correspondences between most common causes of neonatal deaths as they are declared by the family and probable causes assessed from the questionnaire. Some diseases appear as relatively well reported and others far from

being useful. Neonatal tetanus appears as very poorly reported by families, mostly because people ascribe it to a magical cause. Prematurity, low birth weight-hypotrophia coincide more closely: 27 cases out of 32 accepted as such; but 9 cases have been attributed to other causes. Chestache also appears as linked with pneumonia, but only 5 out of 10 cases do coincide.

For children less than 5 years of age (table 7), diarrhoea appears as relatively well reported by people (117 out of 132 cases). 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 a poor reporting (cough or crises for pertussis, fever for measles whereas the same people are able to report exactly the disease when more questions are asked). Cough, chest-aches and cold along with malaria-fever-hot body are the most confuse categories where the benefits of the questionnaire are the greatest. Malaria would have been mis-diagnosed in 70 % of cases and pneumonia-bronchitis in 30 % of cases, if only spontaneous reports of the family had been taken as such. Of course accidents are consistently reported in both cases. The case of meningitis among children less than 5 years would have been missed, but this is not true for older children where all cases of death from meningitis had been properly reported for by the family.

If correspondences can be established for children diseases, little can be done for adults, due to the poor performance of the questionnaire. With respect to maternal death no comparison were done since relatives do not analyse these deaths.

It should also be noted that a problem of translation can often complicate a comparison between what people say and what is later analysed. Causes recorded by the enumerator were translated into French and not always with accuracy. For instance cases of epilepsy were properly reported by the family but enumerators had written "crises" on the questionnaire, as they would have done for another word used by people to designate other types of convulsions, due to hyperthermia, malaria or to other causes.

Epidemiological evidence added a lot to the accuracy of determining probable causes of death. This was particularly true for measles and whooping cough. Results from Machakos indicate that tuberculosis can be identified as a cause of death for children less than 5 years old when longitudinal data on morbidity are recorded. This also seemed to be the case in an on-going survey of morbidity in Senegal (unpublished).

It can be argued that little reliability can be obtained from people with no modern education. This does not proved to be the case from this investigation or at least this difficulty should not be overestimated. Most of the reports

obtained in this survey are consistent and results are similar to those found by other more in depth surveys. When a cause could not be assessed from a properly filled questionnaire it was usually because a series of complex symptoms were indicating either a disease not identifiable (several diagnoses possible) or a series of diseases that were too complex to be properly assessed.

The reading and the interpretation of the questionnaire involves subjectivity and judgement. Although there were strict guidelines, questionnaires analysed by two different persons end-up sometimes with different diagnosis which lead to an "undetermined cause".

It would be extremely valuable to compare results of such a study with necropsies. There would obviously be certain discrepancies, at least because clinical signs do not always guarantee 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 causes will still have a value. In a study of deaths over time, or before and after intervention or between control and intervention areas, if the same questionnaire is used, differences in the distribution of probable causes of deaths will give clues for evaluating the causes associated with differences.



## 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 for the reading of the questionnaires and the assessment of "probable causes of death".

Results of surveys over 2 years on a population of 23000 people indicate that deaths of neonates, deaths of children below the age of 5 years as well as maternal deaths can be assessed with a reasonable degree of confidence. Deaths of older children and young adults are more difficult to assess; reports on deaths of the elderly were too poor to be of statistical significance.

For all ages combined, 87.7 % of questionnaires were properly filled up and a cause could be identified in 64.9 % of those cases. The report and the 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 early and not too late after death; the optimal delay seemed to be between 3 and 9 months after the death.

Among the causes of deaths that were identified from the questionnaires, the most common were: diarrhoea and dysentery, pneumonia-broncho-pneumonia-bronchitis, malaria,

measles, whooping cough, malnutrition, tetanus and a composite category of prematurity-low birth weight-hypotrophia for neonates. Among other infectious diseases, were identified meningitis, septicemia, chickenpox, hepatitis, tuberculosis and leprosy. Among other diseases, outside of maternal deaths, epilepsy, hemiplegia, hypertension, myocardial infarction, intracerebral hemorrhage, asthma and anemia. It should be noted that some of these causes have been assessed from physicians and found either in health center registers or from prescriptions records.

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

Although the reliability of this approach can always be questioned in a context of low modern education countries, results seem to be consistent with other investigations. The use of a standardized questionnaire allows one to give at least arguments for the assessment of probable causes of deaths. At the same time it indicates the limits of the approach which are within the limits of the list of causes under investigation.

# REFERENCES

- Biraud, Y. 1956. Méthode pour l' Enregistrement par des Non-Medecins des Causes Elémentaires de Décès dans des Zones Sous-Développées. WHO unpublished document /HS/60.
- D'Souza, S. 1981. A Population Laboratory for Studying Disease Processes and Mortality. ICDDR,B. Special Publication N 13.
- Garenne, M. 1984. The Concept of Follow-up Survey and its Implications for Data Collection: Example of Using a Computerized Questionnaire for Improving the Recording of Early Deaths in Rural Senegal. Paper presented at the IUSSP seminar on micro-approaches, Canberra, 3-7 september 1984. To be published in the proceedings.
- Mata, L. 1978. The Children of Santa Maria. Harvard U. Press.
- McGregor, I.A. 1976. Health and Communicable Diseases in a Rural African Environment. Oikos. 27 : 180-192.
- Van Ginneken, J.K. and A.S. Muller. 1984. Maternal and Child Health in Rural Kenya. Croom Helm. London.
- WHO, 1978. Lay Reporting of Health Information. WHO. Geneva, 27p.

Table 1 : Quality of answers according to age at death and type of questionnaire. Niakhar, 1983-1984.

	Probable Cause Specified	Cause Undeterm. from quest.	No Answer	All	% No answer	% quest spec.
Neonates	71	26	3	100	3.0	73.2
Children <5	328	90	14	432	3.2	78.5
Children 5-14	19	21	1	41	2.4	47.5
Maternal deaths	9	5	0	14	0.0	64.3
Adults 15-49	11	27	13	51	25.5	28.9
Adults 50 +	22	80	68	170	40.0	21.6
Total	460	249	99	808	12.3	64.9

Table 2 : Quality of answers according to the respondent, the age at death and the type of questionnaire, Niakhar, 83-84

	Probable Cause Specified	Probable Cause Undetermined	No Answer	All	% No Answer	% Causes Specified
NEONATE						
Mother, Father Grand-mother	55	25	0	80	0.0	68.8
Other relatives	16	1	3	20	15.0	94.1
CHILDREN 0-5						
Mother-Father Grand-mother	280	74	8	362	2.2	90.2
Other relatives	48	16	6	70	8.6	72.7
CHILDREN 5-14						
Mother-Father Grand-mother	15	14	0	29	0.0	51.7
Other relatives	4	7	1	12	8.3	36.4
MATERNAL DEATHS						
Mother, spouse	5	2	0	7	0.0	71.4
Other relative	4	3	0	7	0.0	57.1
ADULTS 15-49						
Spouse, parents	7	10	5	22	22.7	41.1
Other relatives	4	17	8	29	27.6	19.0
ADULTS 50 +						
Spouse, children	8	35	25	68	36.8	18.6
Other relatives	14	45	43	102	42.2	23.7
ALL						
Closest relative	370	160	38	568	6.7	69.8
Other relatives	90	89	61	240	25.4	50.3

Table 3 : Quality of answers according to the delay between death and interview, Niakhar, 1983-1984.

	Probable Cause Specified	Probable Cause Undetermined	No Answer	All	% No Answer	% Causes Specified
< 3 months	110	80	40	230	17.9	57.9
3-5 months	185	79	27	292	9.2	70.1
6-8 months	115	61	16	193	8.3	65.5
> 9 months	49	29	16	94	17.0	62.8
all	460	249	99	808	12.3	64.9

Table 4 : Deaths according to main probable cause and probable immediate cause, Niakhar, 1983-1984

Main Probable Cause	Probable immediate cause				all
	Diarrhoea	Pneumonia	Other-specified	None	
Diarrhoea	0	7	1	129	137
Whoop.cough	5	2	1	11	19
Meningitis	0	0	0	4	4
Measles	6	3	1	30	40
Malaria	0	0	0	44	44
Other infect.	2	0	0	17	19
Malnutrition	3	2	2	6	13
Pneumonia-Br	3	0	0	74	77
Maternal	0	0	1	13	14
Neonatal	0	0	0	100	100
Other spec.	0	0	1	16	17
Accident	0	0	3	7	10
Undetermined	6	0	1	211	218
No answer	0	0	0	96	96
All	25	14	11	758	808

Table 5 : Deaths according to main probable cause and probable associated cause, Niakhar, 1983-1984

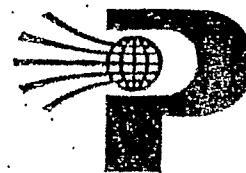
Probable Cause	Probable associated causes					None	all
	Diarrhoea	whoop cough	measles	malnutrition	other spec.		
Diarrhoea	0	2	7	11	5	112	137
Whoop.cough	1	0	0	1	0	17	19
Meningitis	0	0	0	0	0	4	4
Measles	9	0	0	0	0	31	40
Malaria	1	0	1	0	0	42	44
Other infect.	0	0	1	1	1	16	19
Malnutrition	1	0	0	0	3	9	13
Pneumonia-Br	9	0	1	1	1	65	77
Maternal	0	0	0	0	1	13	14
Neonatal	0	0	0	0	2	98	100
Other spec.	0	0	1	1	1	14	17
Accident	0	0	0	0	1	9	10
Undetermined	1	1	0	0	5	211	218
No answer	0	0	0	0	4	92	96
All	22	3	11	15	24	733	808

Table 6 : Neonatal deaths according to main probable cause and the cause declared by the family.

Main Probable Cause	Cause declared by the family							
	Chest -ache	whoop cough	fevers	tetanus	Premature Low weight	Other	Unknown	All
Congenital defects	0	0	0	0	0	1	1	2
Premature Low weight	0	0	0	0	27	0	5	32
Pneumonia	5	2	0	0	1	0	2	10
Tetanus	0	0	1	6	3	5	11	26
Other spec.	0	0	0	0	0	1	0	1
Undetermined	2	0	1	1	5	4	13	26
No answer	0	0	0	0	0	0	3	3
All	7	2	2	7	36	11	35	100

Table 7 : Deaths of children 1 month to 5 years according to the main probable cause and the cause declared by the family, Niakhar, 1983-84.

Main Probable Cause	Cause declared by the family											All
	diar rhoea	cough chest ache	whoop cough	fever mala ria	menin gitis	cri sis	weight loss	accident other	unkn own			
Diarrhoea	117	1	0	2	0	0	0	2	5	0	5	132
Whooping cough	2	1	13	1	1	0	1	0	0	0	0	19
Meningitis	0	0	0	0	0	0	1	0	0	0	0	1
Measles	8	0	0	1	30	0	0	0	0	0	0	39
Malaria	1	1	0	21	0	0	12	0	2	0	1	38
Other Infectious	3	0	0	0	0	0	3	0	2	0	1	9
Malnutrition	2	0	0	2	0	0	0	3	5	0	1	13
Pneumonia-br	5	29	0	21	0	1	4	0	6	0	2	68
Other specified	0	0	0	0	0	0	2	1	3	0	1	7
Accidents	0	0	0	0	0	0	0	0	0	2	0	2
Undetermined	9	9	0	23	0	2	10	2	26	0	9	91
No answer	5	0	0	1	0	0	0	0	0	0	8	14
All	152	41	13	72	31	3	33	8	49	2	28	432



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