Mortality Survey in Bolivia: The Final Report

Investigating and Identifying the Causes of Death for Children Under Five

Ana Maria Aguilar
Ruth Alvarado
Dilberth Cordero
Patrick Kelly
Adalid Zamora
René Salgado

⊗BASICS

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Abstract
BASICS-Bolivia and the MOH-Bolivia conducted a study of mortality in children under 5 years of age in El Alto, Bolivia, from December 1994 through August 1995. The results from the survey are as pertinent today as they were when the survey was completed. This technical report describes how an innovative technology was used to quantify problems in health care delivery. The study, which investigated the deaths of 320 children, under 5, had two main purposes: (1) identify the biological cause of the deaths and (2) determine the problems encountered by caretakers, including care seeking, home care, and medical attention.

Methodology for the study built on previous efforts with verbal autopsy protocols and adapted anthropological procedures to identify problems in care seeking to determine what went wrong when caretakers sought help for their sick children. To weigh problems in care seeking and care giving, the study used the Pathway to Survival. After the study was completed and the information analyzed, the protocols developed for Bolivian study were further refined into a generic manual that will be used in many parts of the world.

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Acronyms

ARI	acute respiratory infection
CDD	control of diarrheal disease
CNPV[1]	National Census of Housing and Population
DD	diarrheal disease
DHS	Demographic Health Survey
ENDSA[1]	National Health Survey
FEJUVE [1]	Federation of Community Juntas (Neighborhood Associations)
HAMEA[1]	Mayor's office of El Alto
JV[1]	Neighborhood Association
NGO	nongovernmental organization
ONAMFA[1]	National Organization of the Child, Women, and Family
ORS	oral rehydration salts
PAHO	Pan American Health Organization
PEA[1]	Economically Active Population
PROSALUD	fee-for-service nongovernmental organization
RPS[1]	Community Health Workers
SCM	standard case management
SNIS[1]	National Health Information Subsystem
SNS[1]	National Health Secretariat
SRSEA[1]	El Alto Regional Secretariat
UDAPSO[1]	National Government's Social Unit
under-5s	children under five years of age
WHO	World Health Organization

[1] The acronyms are abbreviations of Spanish names that have been translated into English.

Foreign Terms

ajayo	evil spirit
ají	chili pepper
anilines or colorants	chemical for tinting
animo	courageous
anticrético	bartered labor for rent
arampu and anachapi	traditional drinks
black table	traditional medicine
eucalyptus/perehil mates	eucalyptus tea
frictions	massages or rubbings
fuira koha	baths
juntas vecinales	neighborhood or community association
kajta	traditional illness similar to severe pneumonia
mates	tea
ñanjha	the devil
pesos bolivianos	currency in Bolivia
suhumó	smoke
sweet table	traditional healing remedy
yatiri	traditional healer
granitos	rash

Acknowledgments

Introduction

BASICS started a small research effort, a mortality survey, in El Alto, Bolivia, in August 1995. Unexpectedly the project became a hallmark achievement, uncovering information that would affect almost every other undertaking during BASICS 5-year project. The Bolivian Mortality Survey was the first survey of this type for BASICS and the largest mortality survey ever completed in Bolivia.

El Alto, a small city near La Paz, is located in the highlands of Bolivia, at the foot of the Andes mountain range. It is home to approximately 500,000 people. The mortality survey in El Alto attempted to identify the cause of death in children under 5 years of age (under-5s), and to understand the household, community, and health services processes that contributed to the child's death. According to the work plan, approximately 320 deaths were to be analyzed, all occurring in El Alto between December 1994 and August 1995.

National data are usually available on child mortality, but local information—critical for local planning—is usually lacking. Unfortunately, there are few viable sources for mortality data. Civil registries in developing countries rarely provide good data; the information is usually incomplete, inaccurate, and late. Problems with death certification are well documented in the literature (Bang, A. and R. Bang 1992; Escudero 1978; Khong 1996; Maudsley and Williams 1996). Recently, attention has focused on obtaining a verbal autopsy, using standardized protocols, when the structure of mortality needs to be identified in a particular setting. Health workers can diagnose up to 80 percent of the causes of death using a low-cost verbal autopsy protocol.

It is not enough just to know the medical cause of a child's death. There should be an investigation to discover what failed the child, either inside the home or in the family's use of health services. This component (the process investigation) is usually not conducted at the same time as a verbal autopsy (an interview to determine the biological and medical cause of death). Researchers in El Alto, however, simultaneously conducted a verbal autopsy and process investigation. For this combined survey, the research team selected the name *mortality survey*.

This technical report, the final report of the mortality survey, includes data up to August 30, 1995, divided into two components:

Logistics of the survey
Identifies and systematizes the experience gained in conducting this type of survey. The logistics section identifies successes and problems encountered by the team when they implemented the survey.

Results of the survey
The survey and results are divided into a verbal autopsy and a process component. If needed, for more in-depth analysis, the results are subdivided into categories of interest, for example, neonatal (first four weeks after birth) versus postneonatal (more than four weeks after birth).

Health Situation in Bolivia

From 1989–1994 infant and child mortality rates gradually improved. According to the Demographic and Health Survey (DHS) of 1994, mortality of children younger than 5 years of age was 116 per 1,000 live births. Infant mortality decreased from 89 (National Health Survey [ENDSA] 1989) to 78 per 1,000 live births (UNICEF 1995). The improvements in mortality rates occurred in urban areas with children more than 1 month old. The mortality rate in rural areas or for the newborn has changed very little. The improvement in health indicators can be partly attributed to the variety of interventions implemented by health authorities. Special attention was paid to promoting oral rehydration salts (ORS), especially targeted since the outbreak of cholera in Bolivia, and appropriately managing diarrhea cases and acute respiratory infections (ARI). Even with these advances, the health of Bolivia's children, particularly the risk of death, is still a primary cause for concern. The social sector, through a coordinated effort, needs to direct resources to identify the social, educational, and economic causes of poor health in children.

The structure of mortality has not changed significantly during the past ten years; the main causes of death in under-5s are diarrhea (36 percent of cases) and ARI, usually pneumonia (28 percent of cases). From the middle to late 1980s, health authorities used special programs to combat these diseases. Neonatal mortality in 1988 was 37 per 1,000 live births (National Health Survey [ENDSA] 1994). By contrast, according to the National Center for Health Statistics' Vital Statistics System, the infant mortality rate in the United States in 1988 was 10.0 per 1,000 live births (*MMWR. Morbidity and Mortality Weekly Report 1991*). However, quality data on the composition of the infant and child mortality or targeted interventions have not been researched or implemented. Table 1 lists the principal indicators for under-5s.

Table 1. Mortality in Children under 5 by Place of Residence: Bolivia 1994

Place of Residence	Neonatal Mortality	Infant Mortality	Child Mortality
Urban area	26	60	88
Rural area	48	92	145
Total	**37**	**75**	**116**

Source: Demographic and Health Survey. La Paz, Bolivia. 1994.

El Alto Health Area

El Alto, constituted as a city in 1988 and the third largest city in Bolivia after La Paz and Santa Cruz, is located in the flat highlands near La Paz. The city, which developed in the area surrounding La Paz's international airport, grew at a rate of 9.3 percent between 1976 and 1992. El Alto's total population, approximately 500,000, are primarily of Aymara Indian descent—they speak Spanish and Aymara. The literacy rate is low, and many of the people, especially the immigrants, maintain their traditional attitudes and beliefs.

Approximately 45 percent of El Alto's population is younger than 15 years of age and 14.5 percent are under 5. Almost 52 percent of the population earns a living in the informal sector—individuals who buy

and sell a variety of materials on the street, including food and services. Even with this activity, easily observable in many parts of El Alto, the National Government's Social Unit (UDAPSO, by its Spanish acronym) estimates that up to 73 percent of El Alto's residents live in "extreme poverty."

As is frequently the case in urban areas with high growth rates, public services have not kept pace. Although 85 percent of homes in El Alto have access to a water source, only 32 percent actually have an in-house connection. Electricity reaches 82 percent of the homes, and drainage and sanitary facilities are available to 35 percent of the homes (only 18 percent report using them).

According to the National Census of Housing and Population (CNPV 1992), only 11 percent of the people in El Alto use public health services. Twenty percent reported that they never used public health facilities, while 5 percent said they preferred traditional medicine. However, in 1994, the National Health Information Subsystem (SNIS) reported that almost half the population used public health services.

The health system network of El Alto, a combination of public, private, and religious health agencies and institutions, includes—
- Five health centers and one referral hospital operated by the National Health Secretariat (SNS) and the municipality
- Thirteen health centers managed by the Dutch Cooperation and PROSALUD, a fee-for-service nongovernmental organization (NGO)
- One hospital managed by the National Organization of Child, Women, and Family (ONAMFA) and the Italian Cooperation that treats referrals from different services
- Seventeen health centers operated by the municipality and the Catholic church
- One 50-bed hospital operated by the Catholic church
- Ten centers operated by various NGOs
- Six private health clinics
- Private medical offices

As in the rest of the country, El Alto has significant underreporting of health data, particularly data on mortality, most often for under-5s. This may result from the costs and onerous process of acquiring a death certificate. Many children never receive a birth or death certificate; they are frequently buried in clandestine cemeteries. For statistical purposes, the children never existed. Nevertheless, the CNPV 1992 reports that in 1991 approximately 3,528 under-5s died in El Alto. The causes of death are unknown and the process that lead to death is even more obscure. The SNIS does not report mortality; most health centers only report events that occur at the Service Center.

Survey Objectives

The objectives of the survey included the following:

- Identify the cause(s) of death for children under 5 in El Alto, Bolivia.

- Identify the process—illness identification, care-seeking behavior, quality of care, and compliance with referral—that influenced the final result (death), and identify points of intervention that could, in the future, prevent other deaths.

- Establish a methodology for mortality surveillance using community participation and data available for analysis by the District Analysis committees.

- Develop a methodology for mortality surveys that can be used in other countries that are similar to Bolivia in size and development.

Methodology (Protocol)

The mortality survey identified under-5s that died in El Alto between 1 December 1994 and 30 August 1995. To determine the medical and sociological aspects of the childrens' death, researchers used structured questionnaires to interview the caretakers: a verbal autopsy to determine the biological or medical cause of death and a process investigation to determine the sociological process that lead to death.

Sampling

As mentioned earlier in the report, the CNPV 1992 reported that in 1991, 3,528 under-5s died. The mortality survey project investigated a sample number of these deaths. Because the CNPV data is sub-divided by census tracts, it was possible to estimate the number of census tracts that could be monitored with the human resources available to the project. Surveyors determined that they could investigate approximately 350 deaths by monitoring 16 census tracts—or approximately 10 percent of the total deaths in one year. This percentage would provide a realistic picture of actual mortality in El Alto. Census tracts were randomly selected. Monitoring would take place during six months (March–August 1995). During the first month, they would identify deaths that occurred during the previous three months (December 1994–February 1995).

Data Collection

To collect data, the researchers established an informant network. The Municipality of El Alto gave the project access to the Department of Municipal Properties, which, in turn, designated the official ceme-teries as a source of information. Unofficial cemeteries also provided data. The civil registry, SNS, and private sources both in El Alto and La Paz were enrolled in the network. To the extent possible, the Federation of Community Juntas (FEJUVE) and the neighbors of the dead child's caretakers were enrolled. Each surveyor was responsible for a set number of census tracts.

If the death certificate said that the child was born dead, surveyors visited the mother to confirm that the child had, in fact, been born dead. The survey did not include these children.

Surveyors

Surveyors were selected from a pool of women known to the SNS. The women spoke Aymara and Spanish, had experience with surveying, and were culturally similar to the caretakers. Seven women were selected and trained to use the survey forms. The women used a survey manual, developed by the project team, with precise instructions about how to conduct an interview and how the respondent should answer each question. The surveyors' training curricula included all aspects of the survey.

The first day of training included the following activities:

- Explained the general program.
- Discussed the signs and symptoms of the most common causes of death.
- Provided clinical hands-on training in a hospital.
- Ethnographer explained the concepts of disease and other cultural issues.

The second and third day of training included the following activities:

- Gave surveyors an interviewer manual.
- Explained the questionnaires.
- Used role plays to familiarize the surveyors with the instruments used in the interviews.
- Conducted practice in four households; two of the households were known and had been previously surveyed by the survey coordinator.
- Administered a pre- and post-test to the surveyors to determine if they understood the methodology.
- Explained the Pathway to Survival (Pathway).
- Surveyors developed a method for graphing data.

Surveyors met with the survey coordinator every morning at 9 A.M., usually for one hour. The coordinator distributed new forms and corrected all surveys that were turned in the previous day. Administrative details were discussed. On Thursdays, the Pathway graphs were delivered, and the following day, the graphs were analyzed.

Instruments

To collect and record information about the deaths of the children, data collection instruments were applied to all deaths of children under 5. The researchers interviewed the caretaker no less than two weeks and no more than two months after the child's death. To ensure quality control, approximately 10 percent of the cases were resurveyed. If the data was doubtful or insufficient, the survey coordinator visited and interviewed the family.

The project team developed four interrelated data collection instruments. An explanation of each instrument and its field use follows. See Annex 1 for copies of the instruments, in Spanish.

Formulary 1: Frontal Page. Collects minimal information to identify the dead child's place of residence. Includes a place to map the address.

Formulary 2: Open History and Verbal Autopsy. Collects information "as told" by the mother, with little prompting except for asking "is that all." The verbal autopsy has a series of closed questions designed to identify the cause(s) of death. The section is subdivided into neonatal and post-neonatal components. Questions for these components are slightly different.

Formulary 3: Socioeconomic Data. Collects data on a variety of social and economic well-being indicators.

Formulary 4: Daily Process Report. Collects information on the daily occurrences, knowledge, perceptions, attitudes, intentions, and practices during the child's illness. Most questions are open-ended.

The forms were used successfully, but both the surveyors and the survey coordinator recommended that the forms be simplified. Each day a separate form was required, as the mother and surveyor reconstructed the day-by-day events that lead to the child's death. Most of the data needed for the indicators were captured appropriately, but the separate forms for each day (two pages per day) produced too much paperwork, which discouraged the surveyors from cross-checking the findings from the different days.

Formulary 5: Consolidation of Process Reports. A consolidation of the findings from Formulary 4. A panel of experts, including physicians and an ethnographer, completed the form. The panel read all the information available on the case, summarized the illness process, and made a medical and social diagnosis.

Formulary 6: Medical Records Review. If the child received medical attention, an attempt was made to find the clinical records and collect the child's clinical, diagnostic, and treatment data.

Data Analysis

Epi Info 6.01 (Center for Disease Control, Atlanta, Ga. 1994) was used to develop databases, including data entry formats for the verbal autopsy questionnaires and a consolidated format for the process questionnaires. A local computer consultant assisted in programming a computerized "expert" algorithm for the verbal autopsy database. Annex 2 shows the expert algorithm. The survey coordinator prepared all surveys and materials for analysis.

In addition to computer analysis, an expert panel (see Formulary 5), composed of three medical doctors and an anthropologist, analyzed the data. The panel met every Friday to review the surveys; occasionally, they met in small groups. Most of the surveys were completed. Each member read all the surveys, made a medical diagnosis, and gave their opinion on whether or not the illness was preventable, the possible breakdowns in the Pathway to Survival (see figure 1), and if the treatment given was appropriate. All final diagnoses were determined by the consensus of the panel. The panel members also analyzed all Pathway charts produced by the surveyors. Missing data were identified and recommendations were made for locating it.

Figure 1.
Pathway to Survival

Source: El Alto Mortality Survey, El Alto, Bolivia. September 1995.
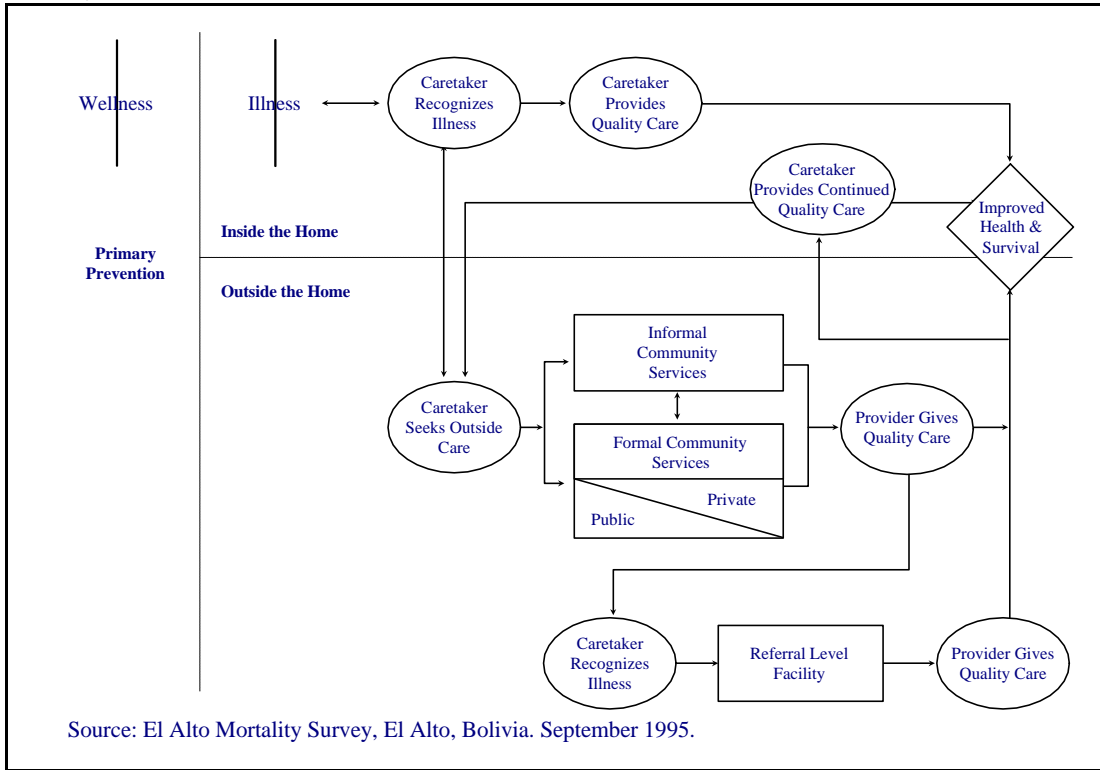
Results

Survey Logistics

A total of 271 deaths were reported and surveyed. Most reports (44 percent) came from community organizations, for example, *juntas vecinales* (neighborhood or community association) and neighbors. Cemeteries were the second most important source of information (43 percent of the total reports). Health services, despite a close collaboration with authorities, reported only 7 percent of the information. The rest of the reports came from a variety of sources, including traditional birth attendants, social workers, the civil registry, and others.

According to the original projections, by the end of the survey, 348 deaths were expected in the 16 census tracts under surveillance. An average of 45 deaths were surveyed every month. The first month of surveillance (March 1995) recorded a number of deaths that occurred during the previous three months (December 1994–February 1995). Table 2 shows the distribution of deaths by census tract.

Table 2. Distribution of Deaths by Census Tracts

District	Census Tract	Expected Avg. Mortality Monthly/Yearly	Expected Mortality at End of Survey (9 months)	Surveys Completed	Percentage of Target Met
1	30	2.3/45	20.7	0	0
	31	4.7/56	42.3	44	104
	60	1.8/22	16.2	4	24.7
	61	4/48	36.0	38	105
	130	2.6/31	23.4	26	111
	131	6.3/75	56.7	7	12.3
	151	2/24	18.0	3	16.7
	152	3.2/38	28.8	30	104.2
	Subtotal		242.1	152	62.8
2	241	4.6/55	29.9	27	90.3
	242	1.4/17	9.1	4	44.0
	350	5.3/64	34.5	18	52.2
	351	4.3/51	28.0	29	103.6
	381	4.2/50	27.3	20	73.3
	382	3.3/40	21.5	16	74.4
	Subtotal		150.3	114	75.8
3	310	.3/04	2.7	5	185.0
	311	1.4/17	12.6	0	0
	Subtotal		11.1	5	45.0
Total			**403.5**	**271**	**67.2**

n = 271

Source: El Alto Mortality Survey. El Alto, Bolivia. August 1995.

Analysis Panel Formed

As previously described in the protocol (see Methodology), an analysis panel was formed, composed of health experts, a social scientist, and health authorities. From the beginning of the survey, the panel met every Friday to analyze all verbal autopsies and process questionnaires. Surveyors plotted the information for each death on the Pathway to Survival (see figure 1) and presented the Pathway to the panel for consideration. The information was analyzed by carefully examining the signs and symptoms of the dead child's illness, as well as actions taken for the child inside the home and at the health service. In addition, computerized algorithms were used to analyze the verbal autopsy questionnaires. The algorithms produced as many as three confirmed or possible diagnoses for each case. The computerized diagnoses were compared to the panel's diagnosis and each case was assigned a definitive cause of death.

During the process investigation, 29 in-depth interviews were conducted, including cases selected at random or considered "of particular interest" by the survey coordinator or panel. Most caretakers could remember with reasonable certainty the events that lead to the death of their child. The in-depth interviews were shared with the panel. The interviews and the process questionnaires were used to identify the breakpoints in the Pathway. The shortest time between the death of the child and the interview was 6 days and the longest time was 3 months.

The following interview describes the events before the death of three-year-old, Miguel Angel:

> *My son was fine. On January 21, he had a small eruption in his stomach and became ill with diarrhea. I took him to the health center. I was given a syrup for him, but he continued with diarrhea. For three days, I just gave him salva tea for the diarrhea. On Wednesday, I took him to the clinic and was given a syrup, some ORS (oral rehydration salts) and drops for the vomiting and diarrhea. I was told to come back the next day. I didn't take him back because I took him to a healer. He told me not to take him outside. That is why I did not take him back (to the clinic)—to take care of him.*

> *On Friday, I took him again to the healer because my son was still sick. The healer called his soul. He smoked my son with a sweet table and with sweets. He became slightly better. I called the healer again on Tuesday. The healer told me that my son was going to die. "You have to resign yourself," he said. I gave my son the ORS and he got better. On February 4, I went to my hometown, and he again got sick. I called the healer and he told me to buy a "black table" (a form of traditional medicine). During the trip he got better. Everything was good. He ate well and was playing. All of a sudden he got sick again— fast breathing and vomiting; he turned purple and he was also very thin. My son died of diarrhea, vomiting, and fever.*

Census Tracts

It was difficult to define the exact areas to be included in the census tract, particularly in rapidly growing areas, because the official maps could not be kept up-to-date. As new settlements were developed, the maps did not clearly show if the new settlements should be included in the census tract being monitored; the official government decisions on the inclusion of settlements had not been made.

Surveyors

In a number of situations, the surveyors were not well accepted despite efforts made by the survey planners to carefully identify surveyors whose culture and language were close to those of the residents of El Alto. In fact, the survey coordinator later stated that the cultural (horizontal) proximity was actually part of the problem. Caretakers did not want to relate their experiences to someone they considered an equal. After the survey coordinator intervened, the caretakers easily told their stories.

Daily meetings with the surveyors were needed to maintain their motivation and to solve logistical, administrative, and personal problems. As with many long-term activities, the initial enthusiasm slowly gave way to complacency. The survey coordinator found that the regular daily meetings were a good place to voice concerns. Working with the caretakers whose children had recently died was emotionally difficult for the surveyors. The survey coordinator often had to act as counselor and support for the surveyors and, in many cases, for the caretakers. Surveyors felt an obligation to return something to the caretakers after listening to, in most cases, the sad story of their child's death. The surveyors suggested that they would like to help the family by offering them a gift of food.

Verbal Autopsy

Researchers developed a verbal autopsy questionnaire to help surveyors solicit information about the death of the child being surveyed, the child's health history, and the caretaker's and family's history.

Structure of Mortality

The final picture of mortality began to emerge around the time of the 100th interview. After that milestone, only small variations in the structure of mortality were observed. As shown in figure 2, 72 percent of the deaths of children under 5 occurred during the first year of life. Of the total infant mortality (n=194), a significant number of deaths, almost 44 percent (85), were classified as neonatal mortality. Of the total neonatal mortality, 72 percent occurred during the first seven days of life. Of the early neonatal mortality (first seven days of life), 31.4 percent of the deaths occurred during the first day of life.

Figure 2.
Mortality in Children under 5 by Age Group

1–12 months
40.2%

< 1 month
31.4%

13–59 months
28.4%

8–29 days 28.2%

2–7 days 28.2%

< 1 day 43.5%

n = 271

Source: El Alto Mortality Survey, El Alto, Bolivia. September 1995.
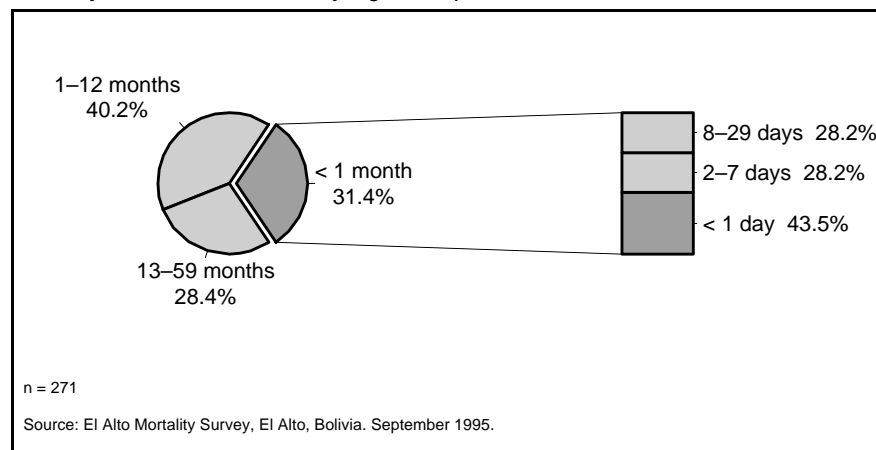
Another significant finding was that male children died at a higher rate than female children (53.9 percent males to 46.1 percent females). This finding is consistent with the literature of gender-specific mortality (Kurz and Johnson-Welch 1997). (See figure 3.) Around 3 years of age, female mortality gradually increases and eventually becomes comparable to that of males.

Figure 3.
Mortality in Children under 5 by Gender

Source: El Alto Mortality Survey, El Alto, Bolivia, September 1995.
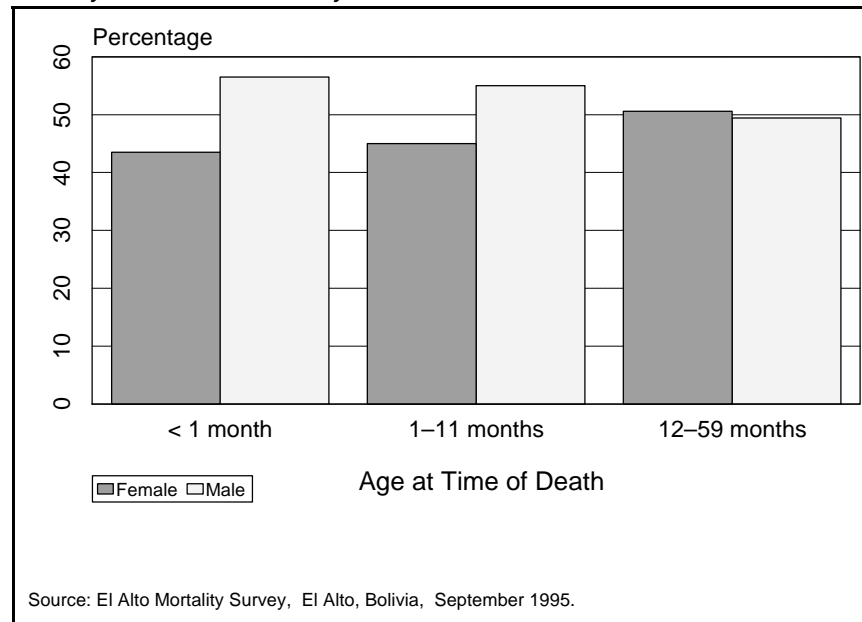
Cause of Death

To arrive at the probable cause of death, two procedures were followed. First, a computerized algorithm was run on the database (Epi Info 6.01), and three possible diagnoses were presented. Second, an expert committee reviewed all verbal autopsy questionnaires and in-depth interviews, and proposed a maximum of three cause-of-death diagnoses. Figure 4 shows a comparison between the two methods. The expert committee, in most cases, arrived at a more precise diagnosis than the computerized algorithm. This is not surprising, because the algorithm was not sophisticated enough to detect and use all possible data. In addition, the expert committee used open-ended questions to refine the diagnosis. The computerized algorithm could not do this. To compare the diagnosis (see figure 4), some of the diagnoses made by both methods had to be reclassified into broader groups. The significant differences between the two categories of diagnoses (algorithm and expert committee) resulted from the algorithm; the algorithm produced two "possible" categories, for example, possible ARI or possible diarrheal disease (DD), that were not proposed by the expert committee.

To simplify the comparisons between the algorithm and the expert committee, the "confirmed" and "possible" diagnoses were grouped. Most of the discrepancies between the two diagnosis were with ARI-related mortality and neonatal mortality. In the case of ARI deaths, if the expert committee's category of "ARI and DD" was added, then the results of the expert committee and algorithm would be similar. In the

neonatal category, the computerized algorithm often incorrectly diagnosed neonatal mortality and placed it in an "other" or "unknown" category. In general, the expert committee arrived at a better diagnosis by using the mother's open-ended stories and the child's clinical records. The committee's diagnosis was more specific (not reflected in the groupings made for reasons of comparison). Nevertheless, the main causes of death were ARI (for example, severe pneumonia) and dehydrating diarrhea. Either singly or in combination, the two illnesses caused approximately 55 percent of all deaths.

Figure 4.
Comparison of Diagnosis by Algorithm and Expert Committee

n = 271

Source El Alto Mortality Survey. El Alto, Bolivia. September 1995.
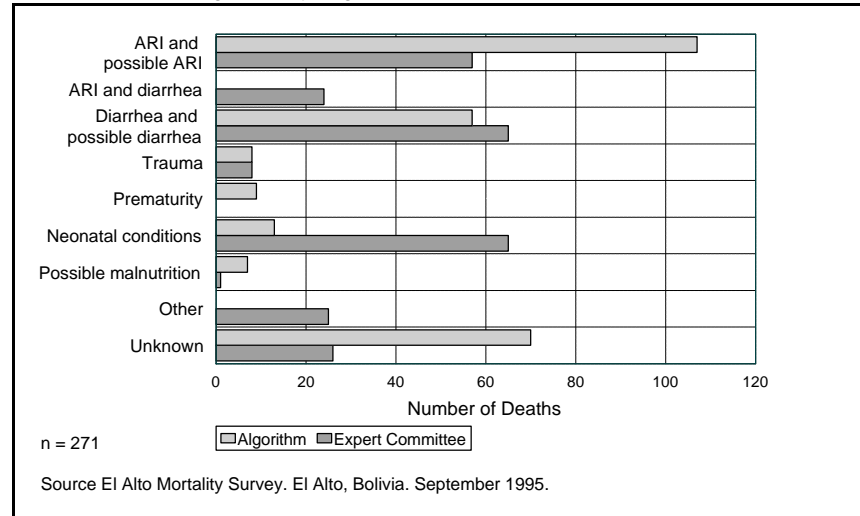
Description of Families and Households

The mother was usually the principal respondent (defined as the individual who, according to the interviewer, answered most of the questions and appeared to have the most knowledge about the death of the child). In 84 percent of the cases the mother was the principal person interviewed, followed by the father in 9.2 percent of cases and others (siblings of parents and grandparents) for the remainder. In most cases (55.7 percent), the mother was the only respondent, and in 34 percent of the interviews more than one individual answered questions (usually the mother and father).

The surveys were conducted primarily in Spanish (69.4 percent); in 21 percent of the cases the respondent conversed in both Aymara and Spanish. Only 9.6 percent of interviews were conducted exclusively in Aymara. No significant communication problems were reported, because all interviewers and respondents spoke both Aymara and Spanish fluently.

The recollection that follows was related by a mother of three children whose second child, Blademir (at 29 months), died from dehydration caused by diarrhea.

My son began to get sick with diarrhea around the end of last November. I gave him home remedies, bought some herbs from the women, and he got better. Later I had him "shaken" just a little. My friends told me that because he had fallen, the earth had "gotten" him. He recuperated, but he wasn't growing. My son had cold hands and feet, and, at the end, he also forgot how to walk.

When I became "unpregnant" of this child, the midwife told me he was going to die. He was born feet first and faced the ground. The midwife told me that we had to change his "luck." Later he was sick and I cured him with some pills I bought at the drug store. I neglected this child. I had three children. The child that died was the second child.

I don't live well with my husband. I had to go out and sell to get food for my children. That is why I had to leave my son with my little brother. When I was selling, I wondered about my sick child. He didn't grow. He didn't talk. I took him to the cemetery. I "washed" him with graveyard dirt. He must have gotten sick when I was pregnant and I saw some dead animals or people.

Time went by. For me, my son was normal. I also had to take care of my youngest daughter. Before carnival, my mother died. I was with great sorrow, but my husband was happy with his drinking. We fought. We didn't have money. Because of our sorrow we forgot about our son. Two days before he died he got worse. On May 25, in the afternoon, I "wrapped" him with some herbs. I don't recall the name of the herbs. We wrapped him in a black cloth with some leaves covering his whole body. My son talked to me. It seemed that he was getting better. I didn't understand what my son was telling me. We gave him tea in spoonfuls. I went out of the room to tell my sister he was better. She told me to have faith in the Lord. I went to see him and he was already dead.

Households

Approximately 39 percent of the mothers interviewed said that their family owned the house where they lived. The other families were renting or had an *anticrético* arrangement with the owner (bartered labor for rent). Most households had water available through two main sources: in-house piped water (58 percent) and extra domiciliary sources, usually a public water fountain (41.7 percent). Most households had electricity (86 percent). Approximately 35.1 percent had dirt floors; the remainder had cement floors or other flooring. In most households (67.5 percent), the entire family lived and slept in one room (excluding the kitchen and bathroom). The median number of individuals per household was four. These data are not significantly different from those of the average family living in Bolivia, where, according to the 1994 Demographic and Health Survey, there are 4.5 persons per household.

Mothers

The mean age of a mother who experienced the death of a child was 26.2, with a range from 16 to 50 years of age. As shown in figure 5, the distribution pattern of deaths followed the same pattern as the fertility rate for their respective age groups (DHS 1994, p. 26). Overall, mortality was not disproportionately attributed to one specific caretaker age group.

Figure 5.
Distribution of Child Deaths by Mother's Age

n = 271

Source: El Alto Mortality Survey, El Alto, Bolivia, August 1995.
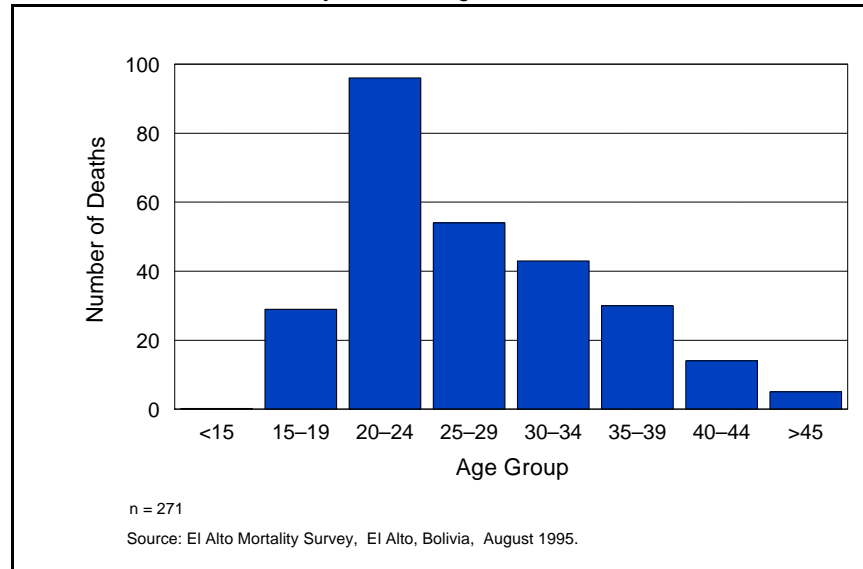
The mother's level of schooling has often been cited as a significant risk factor for offspring mortality. In this survey, the mean years of schooling for the mother was 5.2, with a range from 0 to 13 years. A literacy question was not included in the survey, but it is accepted by most people that mothers with three or fewer years of schooling are functionally illiterate. Based on this assumption, approximately 33.9 percent of infant and child deaths occurred to mothers who were illiterate. Almost 58 percent of deaths occurred to mothers with fewer than five years of schooling.

Mothers in the sample had a mean of 3.7 pregnancies, with a range from 1 to 13. A significant finding was that 21.8 percent of the deaths occurred in first-born children. When the second child was considered, almost half (47 percent) of all deaths occurred in the first- or second-born child. After the initial peak in mortality in first- and second-born children, the distribution of mortality gradually diminishes—although it does not disappear—with subsequent pregnancies.

For most mothers, the death of her child was the only child death she had experienced. According to the survey, for 72.7 percent of mothers, this was the only child death in her family. A smaller percentage, 16.6 and 5.5 percent of mothers, had previously experienced two and three deaths, respectively. Only 5.2 percent had experienced more than three deaths.

Slightly more than 50 percent of the mothers said their main occupation was the household. Approximately 45 percent said they engaged in remunerated work outside the home (including working for food). For children more than 1 month old at the time of death, most mothers (89.2 percent), regardless of occupation, said that the child had been under their care 24 hours a day. Only a very small percentage (5.9 percent) cared for their child fewer than 12 hours a day. In cases where the mother engaged in remunerated work, excluding food for work, the mean monthly income was around B 165 (*pesos bolivianos*), equivalent to U.S.$33. With few exceptions (less than 20 percent), mothers did not belong to any organized community group.

Most families participating in the survey consisted of a mother and a father living together. Approximately 91 percent of the caretakers described their union as stable. About 8.6 percent were single mothers and only one child had been cared for by a single father.

Language barriers frequently caused poor communication and a lack of understanding between Spanish-speaking providers and Aymara-speaking caretakers. However, in this study most of the mothers were bilingual and they understood Spanish (81 percent). Only 5.5 percent of the mothers said that they only spoke Aymara. A small percentage (13 percent) spoke only Spanish.

Fathers
The mean age of the father was 30.5 years, with a range of 17 to 52 years. Fathers had more years of schooling than mothers, with a mean of 7.4 years. A significant proportion (approximately 24.8 percent) had 12 or more years. The occupation most often cited by the father was construction work (approximately 18 percent of the total fathers surveyed). Fathers also worked as policemen, drivers, and self-employed businessmen. Although data about income, especially when the mother was asked, may not be accurate, it was clear that most men are vastly underpaid—even if the wife's estimate of her husband's income is tripled. The median monthly income was estimated to be B 316 (U.S.$63).

Children
In most cases (88.6 percent), the child that died was the mother's last pregnancy. Most children were born at home (75.3 percent); 23.6 percent were born in a hospital or clinic. According to the respondents, approximately 22 percent were born before term and 24.7 percent were considered by the parents to be smaller than normal. The caretaker showed a child health card for 19.6 percent of the children. Of the children that had a verifiable health card, only 28.3 percent had a complete vaccination schedule for their age. Of the children that survived to at least to six months of age, 27.3 percent had been breastfed exclusively for at least six months; 56 percent of children were being breastfed at the time of the illness that caused death. For children older than three months of age at the time of death, most (approximately 70 percent) had experienced an illness during the three months prior to the event that caused their death. DD (42.8 percent) and ARI (36.6 percent) caused the largest number of illnesses. Only 4.1 percent of children were hospitalized prior to the illness that caused death. According to the respondents, 30.3 percent of the children that died were malnourished at the time of death.

Pathway to Survival Analysis

The Pathway to Survival shows the conceptual framework for the next step in the analysis of the El Alto childhood mortality survey (see figure 6), and it separates the actions that occur both inside and outside the home into distinct moments or processes. This approach focused our attention and analysis on the parts of the whole. Although no human endeavor is as simple as the Pathway suggests, it was useful for concentrating ideas. One might say that the children in this study took a "detour to death" from the Pathway. The interventions should correct that detour.

Figure 6.
Pathway to Survival

Source: El Alto Mortality Survey, El Alto, Bolivia. September 1995.
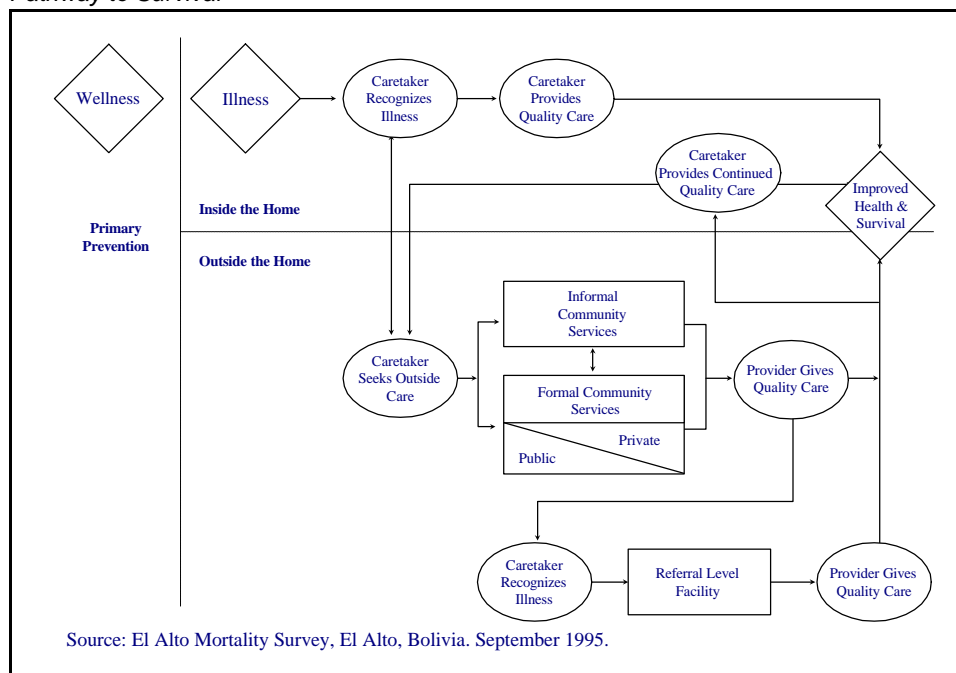
Defining Terms

The researchers needed to define some of the previously undefined terms in the Pathway (for example, appropriate care and wellness). Appropriate care was usually defined by the panel experts as *that which meets the national standards of care for the particular disease*. Standards are identified for both the mother and health workers. However, traditional healers are not formal health workers and they usually do not meet such rigid standards. The researchers needed to consider traditional healers differently and define different standards for them.

Wellness is a difficult term to define. Frequently, a state of wellness is the condition of the patient before the illness that caused death. However, it became evident quite early in the analysis that many children were not "well" before their final illness. Some children were malnourished, while some children were

suffering from other diseases that did not cause death but contributed to it. Still other children had been considered "unwell" even before they were born (for example, an accident during the seventh month of pregnancy caused one mother to believe that her child "was with the devil"). It may be possible to define wellness by the presence of certain external factors that indicate appropriate health care, including the presence of a growth monitoring chart, a complete vaccination schedule, ascription to a particular health service (including NGOs or feeding programs), and a sanitary birthing place. If we consider these factors, only 9 of the 271 children surveyed met this "wellness" criteria. From the day of their birth, the children were at risk.

Identifying Breakdowns in the Pathway

Breakdowns in the Pathway were analyzed in two ways. First, quantitative and qualitative data from surveys were consolidated into a database which, in turn, was analyzed with (Epi Info 6.01). A significant number of indicators were identified in the original protocol. Consolidated results for each case were shared with the panel, and the panel was asked to suggest reasons for the breakdown. The panel also analyzed the in-depth interviews.

To simplify the process, the researchers decided to use the diagnosis made by the expert panel instead of the diagnosis made by the algorithm, because the expert panel's diagnosis tended to be more specific, as mentioned earlier in this report. To maintain clarity and consistency, most of the analysis considered three intervals of time considered crucial by the researchers: the first day of the child's illness, the day before death, and the day of death.

Length of Illness
Sick children in El Alto tend to die quickly, regardless of their illness or disease. The *length of illness* was the time between the mother first noticing that her child was sick and the day of the child's death. Most of the deaths (53 percent) occurred during the first day of illness. The median length of illness was three days. Sixty percent of the children and most neonates (80 percent) died by the third day of the illness that killed them. By the fifth day of illness, 80 percent of the deaths had occurred.

Caretakers Recognize Illness
Although many caretakers (39 percent) recognized that their child was seriously ill, in most cases the caretakers did not seek help from formal providers (SNS, private practitioner, and NGOs). Only 58.7 percent of all caretakers sought help on the first day of illness, including children already being treated by a provider. Surprisingly, caretakers who said they knew the illness was severe acted on this knowledge in only 58.8 percent of the cases. Caretakers were asked, in open-ended questions, what signs they considered to be the most serious. They identified respiratory problems (fast or difficult breathing), not eating well, vomiting, continued diarrhea, loss of consciousness, and fever. When asked what signs they considered signs of improvement, their responses correlated almost exactly with the abatement of the danger signs.

Caretakers Provide Care Inside the Home
The majority of caretakers (71 percent) provided home care to the sick child. Unfortunately, most of the home care (97.9 percent), as identified by the panel experts, was not appropriate and did not meet the home care criteria for that particular disease. Caretakers tended to give *mates* (tea) or *frictions* (massages or rubbings), and traditional remedies (smoke inhalation and others). Although the majority of home

remedies were harmless, a small percentage (6.1 percent) were dangerous. Some caretakers gave inhalations with *ají* (chili pepper) or chemical irritants to children with pneumonia. In other cases, children were given *anilines* or *colorants* (chemical for tinting) to ingest. Other less dangerous, yet potentially problematic remedies, included bathing the child with urine and massaging the child with alcohol.

Caretakers Seek Care Outside the Home

Surprisingly, 61.6 percent of the children whose illness resulted in death were not seen at any time during their illness by an SNS public health center, hospital, or private practitioner. Only 17 percent of the sick children were seen in a public facility run by the SNS. However, caretakers stated that the average time to reach a formal health service in El Alto is only 20 minutes, either by walking or by taking public transportation. Ninety percent of the population can reach a health provider within 35 minutes.

According to the respondents, 15.9 percent of the children that died received only home care, and caretakers for the children did not consult with anyone except relatives or neighbors. In spite of the perception that traditional health care is frequently used, a small number of deaths (5.9 percent) were seen exclusively by a *yatiri* (traditional healer).

Some caretakers used more than one resource when, in their mind, the child was not improving or they felt uncomfortable with the care the child received. If home care is considered a provider, children were given care an average of 1.6 times during the course of their illness. Diarrhea was treated more often than any other illness. Overall, the children were treated an average of 1.9 times.

Figure 7 shows the composition of care sought during the first days of illness. Of the 31.4 percent of caretakers that sought help outside the home on the first day of the illness that caused death, most sought help from relatives (27.8 percent) and from a medical provider (43 percent). It is interesting to note that traditional healers were not consulted as often as the researchers expected. When caretakers were asked about their satisfaction with the help they received, most expressed satisfaction (72.9 percent) regardless of where the care was obtained. Respondents were satisfied with the advice received from their relatives and neighbors 72 percent to 75 percent of the time. Pharmacies were described as satisfactory places to obtain care, but they were not used as often; health centers and public hospitals had similar results (72 percent). Only private clinics were less satisfactory (62 percent were not satisfied).

Figure 8 shows how the different providers were consulted at different times during the illness. Medical practitioners were consulted increasingly as the illness worsened. By the day of death, 72.2 percent of the families who sought help found it with a medical practitioner. Conversely, as the illness progressed, relatives and neighbors were consulted less and less. Traditional healers were used primarily during the illness, and apparently were not consulted as often at the beginning of the illness or on the day of death. In spite of a clear progression of choices for care, families did consult more than one source at the same time. On the last days of illness, care was sought from more than one provider on the same day.

Figure 7.
First Option for Care at Beginning of Illness

Private Care
15.2%

Public Services
27.8%

Traditional Healer
11.4%

CHW
1.3%

Pharmacies
11.4%

Relatives
27.8%

Neighbors
5.1%

n = 271

CHW is Community Health Worker

Source: El Alto Mortality Survey, El Alto, Bolivia, September 1995.
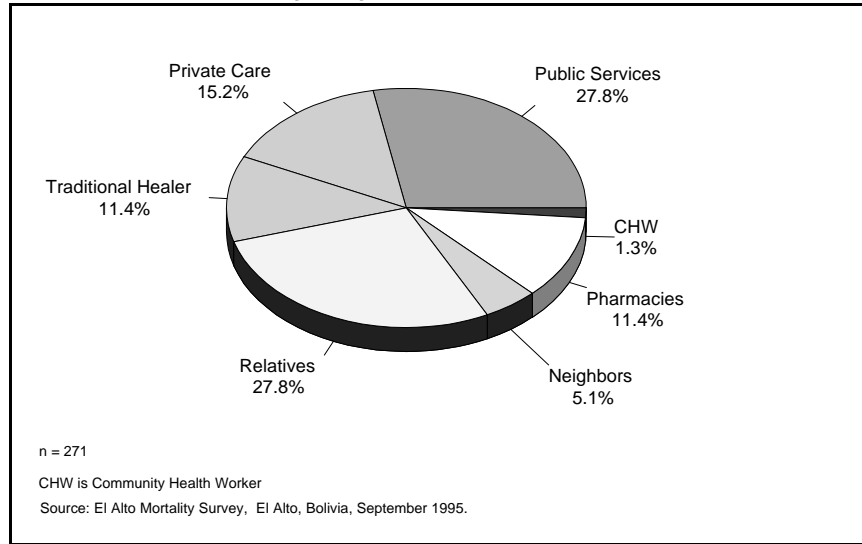
Figure 8.
Help Sought at Different Times during Illness

Number of Cases

Stages of Illness

Beginning · During · Day of Death

■Medical Practitioner □Traditional Healer ■Relatives/Neighbors □Pharmacists ■Other

Source: El Alto Mortality Survey, El Alto, Bolivia, September 1995.
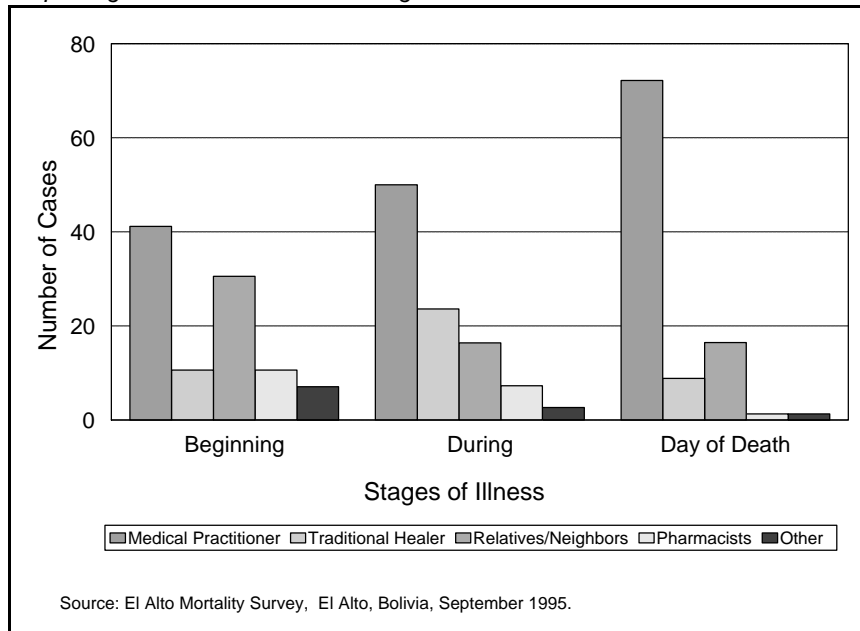
The death of an 8-month-old baby, Aymara, was preceded by a cycle of advice and treatment from doctors, healers, and, finally, a clinic.

> *The baby got sick Monday evening. I took her to the doctor on Tuesday and he told me that she had an infection. The doctor told me to prepare rehydrations (ORS). He also gave her an injection. She got a little better but was still sick. I also took her to the "yatiri" (healer) to cure her. On Wednesday, I took her again to the doctor. He gave her some syrup and suppositories for the fever. On Thursday, I took her to the yatiri again. We read coca leaves. I made her drink "arampu" and "anachapi" (traditional drinks). That night I took her to the clinic. They massaged her and put in a tube and she died.*

Only a few reasons were given for selecting one type of provider over another. Traditional healers were consulted primarily because of the caretaker's supernatural perceptions of disease. During particular times, for example, at the onset of the illness, during the sickness, and on the day of death, most providers were sought because of the "trust" the caretaker had in their ability to heal. A smaller percentage of caretakers said that their main reasons for using a particular provider were proximity to the caretaker's home and the presence of particular signs and symptoms that, in the mind of the caretaker, only a particular provider could resolve.

Table 3 shows the approximate relationship between the perception of danger on the first day of the child's illness and how the caretaker responded. On the first day of their child's illness, 51 mothers recognized that their child was severely ill but only 58.8 percent sought help. Mothers who did not recognize the seriousness of the illness sought help in only 39.6 percent of cases. Unexpectedly, after the first day of illness and before the day of death most of the mothers who sought care had not initially recognized the danger signs in their sick child. Apparently, mothers who did not initially recognize the severity of the illness now recognized a problem or the problem became worse and they sought help.

Table 3. Mother's Action Based on Her Perception of Danger on First Day of Illness

	Sought Help at Start of Illness	Sought Help or Continued Care During Illness	Sought Help on Day of Death
Recognized danger	30/51	31/51	21/51
Did not recognize danger	36/91	72/91	43/91

Source: El Alto Mortality Survey. El Alto, Bolivia. September 1995.

Danger signs and the decision to seek help can be explained further (see Caretaker Recognizes Illness Inside the Home). The age of the child played an important role in recognizing danger signs. Neonates were perceived by the caretaker as being more vulnerable to disease and supernatural forces, so they received better care. The literature reports a similar correlation between a child's age and the attention the child receives. However, this finding contradicts a commonly held ethnographic belief that the Aymara culture considers children under 2 years old less important than older children. If this belief was true at some point, in the urban milieu of El Alto, it is now changing. When we looked at diseases that

cause the majority of deaths, only a few were considered dangerous by caretakers. Of the total number of diarrhea cases (65) that eventually caused death, only 21 cases were recognized by the caretaker as being dangerous. The statistics for pneumonia were similar—only 17 out of 57 cases of pneumonia were initially considered dangerous by the caretaker.

Providers Give Care

Of the cases seen by health services, the expert panel judged that the majority received inappropriate care. Only 18 cases (22.2 percent of those who sought care) received care that met minimum quality standards set by the SNS. Eleven treatments (14 percent) given by the health services were considered dangerous or the treatments delayed appropriate life-saving care (for example, the child was not hospitalized or referred). The panel judged as inappropriate all treatments given by traditional healers. However, only 7 of 64 (11.3 percent) of the treatments given by healers were considered dangerous.

In spite of the civil registry report, and the opinion of most experts, a death certificate was issued for most deaths of children older than 1 month. Eighty percent of children older than 1 year received a death certificate (86.3 percent), usually issued by a physician. The physician's role as a primary source of death certificates might be partially explained by the fact that a fee involved. The average cost for a death certificate is B 35–80 (U.S.$7–16), enough incentive for the physician. The cost, however, may prevent the family from seeking a death certificate for a young child. Most children older than 1 month were buried in officially sanctioned cemeteries. Only a few neonates (16 out of 85) received a death certificate. Of the 85 neonates that died during the study, only 53 were buried in official cemeteries.

It is sad to reflect that in life few of the children that died were seen by a physician but, in death, most were seen—only to be officially pronounced dead.

Pathway to Survival by Disease and Other Variables

In the previous analysis, all deaths were analyzed as a group. The researchers determined that a breakdown by specific variables might uncover more information. Deaths caused by ARI and DD were of particular interest. Table 4 (also see Comparison of Pathway by Variable) compares the principal steps in the Pathway for all deaths: deaths from ARI/DD, deaths for neonates younger than 1 day and older than 1 day, and deaths by gender. This stratification by variables reduces the number of cases and, therefore, affects the validity of the results. Despite the appearance of certain trends, the analysis presents a good picture of the processes taking place at the family, community, and health facility level.

ARI and DD Deaths

All deaths identified by the expert committee as being caused by ARI or DD were selected for specific analysis. Accidents and trauma were excluded from the analysis. Children younger than 1 day old were excluded. As with the computer analysis, each quantifiable step of the Pathway was weighed. Human behavior, of course, is not as simple as the Pathway suggests. As stated earlier, we found that mothers used providers in different ways. In some cases, mothers sought help because their children exhibited specific signs and symptoms that worried them. In other cases, the mothers did not identify any particular sign or symptom, but they still sought care. This and other findings indicate that the Pathway is more complex and has more crossing arrows than indicated in the original graphic.

Caretakers Recognize Illness

Figure 9 shows the analysis of 146 deaths from ARI and/or DD. The results are similar to the general findings for all 271 deaths. In only 63 of 146 cases (43 percent) did the caretaker recognize that the child was seriously ill, a slightly higher percentage than the recognition of all illnesses (39 percent). Vomiting, fever, and not eating well were cited most often as signs and symptoms that caused concern.

Figure 9.
Pathway to Survival for Acute Respiratory Infection/Diarrheal Disease Deaths

n = 146

Source: El Alto Mortality Survey. El Alto, Bolivia. September 1995.
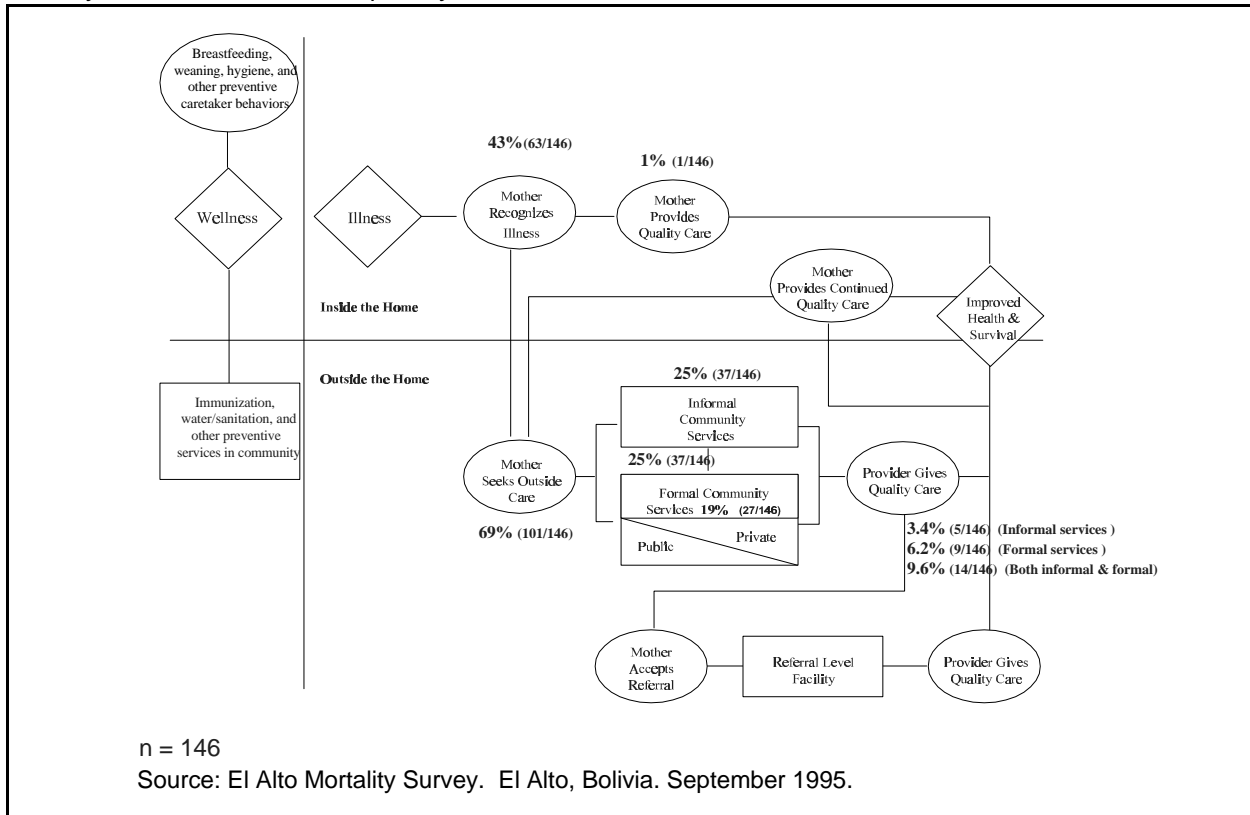
Caretakers Provide Care Inside the Home

Regardless of whether the mother recognized the severity of the illness, quality care in the home was given in only 1 of 146 of the cases.

Caretakers Seek Care Outside the Home

Although the majority of caretakers did not recognize that their child was seriously ill, a significant number, 101 of 146 (69 percent), did seek some outside care. Of the total number of children that died from ARI or DD, 37 of 146 (25 percent) were seen by informal providers; 37 of 146 (25 percent) were seen by a combination of informal and formal health services, and 27 of 146 (19 percent) were seen only by formal health services. Only 44 percent of the sick children came in contact with a formal health facility or private provider during their illness, while 21 percent were seen in MOH health facilities.

Providers Give Care

As poor as the provider quality of care was for all diseases, the care provided for ARI and DD was worse. Of the 146 deaths surveyed, only 9 cases (6 percent) received appropriate care in formal health services. (If only cases that were seen in formal service are considered, then 33 percent of cases received appropriate care.) Informal providers offered quality care in 5 of 146 cases (3.4 percent or 14 percent if only cases seen by informal providers are considered). Sick children seen by both formal and informal providers received quality care in 9 of 146 cases (6.3 percent).

The following recollection is a familiar one. Zapata Quenta Miriam died after first being treated at a hospital, then by traditional medicine, and, finally, with syrup from a pharmacy.

> *My daughter got sick with a cold. I took her to the Heart of Jesus Health Center. She had diarrhea, temperature, and vomiting. She was in the hospital for three days. She got better so we took her home.*
>
> *We thought she was well, but we were surprised when she got sick again. She was with diarrhea, temperature, and cough. We gave her eucalyptus tea and bathed her once a day with black table (traditional medicine) to get rid of "ñanjha" (the devil). We bought some syrup in the pharmacy and we gave it to her three times a day.*
>
> *All the healings did not do anything. That is why on 4-14-95 my daughter died at 7 A.M. She is gone. What else can I do? It is God's will. She was my first daughter, the most loved.*

As reported in the literature, the health planners in El Alto found it significant that the deaths of under-5s followed a clear age-related trend. As shown in figure 10, ARI deaths occurred in the first six months of life with a peak during the first three months. By the sixth month of life, 66 percent of ARI deaths had occurred. Conversely, diarrhea deaths occurred after the first three months of life and peaked at seven months. By the age of 18 months, 83 percent of diarrhea deaths had occurred. More than 90 percent of the deaths occurred by the childrens' second birthday.

Comparison of Pathway by Variable

Table 4 compares the Pathway using different variables. As with the other indicators, the total number of deaths related to that particular variable were used. The quality of care given by the provider was subdivided by the quality of care given in three categories: (1) informal services, (2) formal services, and (3) mixed use of informal and formal services. The three numbers in the cells refer to each of the parts, in the order mentioned (see table 4, number 7). Neonatal quality of care was difficult to categorize.

There were no significant differences between diseases. However, it is clear that younger children were cared for more appropriately than older children, and that male children were taken to an outside provider more often than female children.

Figure 10.
Acute Respiratory Infection/Diarrhea Disease by Age Group

ARI is acute respiratory infection and DD is diarrheal disease.
Source: El Alto Mortality Survey, El Alto, Bolivia, September 1995.
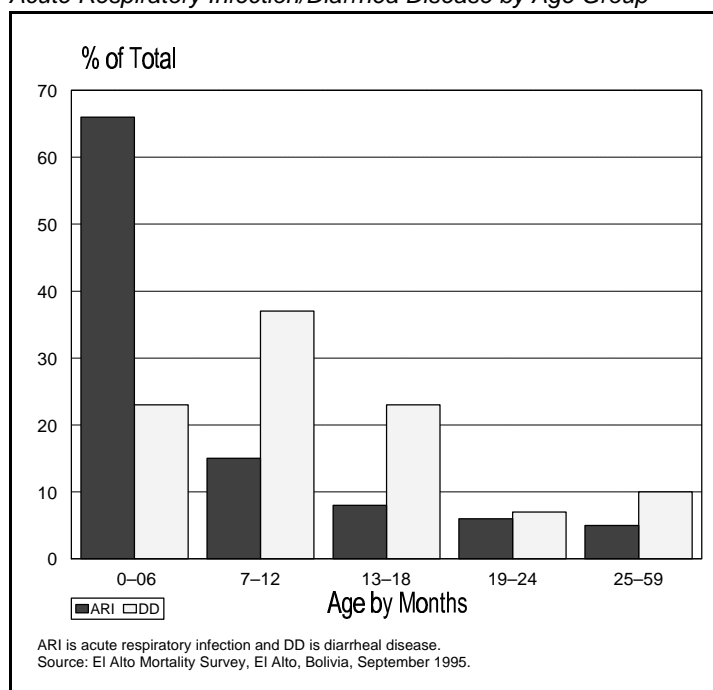
Table 4. Comparison of Pathway to Survival by Variable (%)

Indicator	% All Deaths (n=271)	% ARI/DD Deaths (n=146)	% Neonates (< 1 month) (n=85)	% Boys (all causes) (n=146)	% Girls (all causes) (n=125)
1. Mother recognizes illness	40.2	43.2	52	45.9	33.6
2. Mother provides quality care	1.1	.8	23	1.4	.8
3. Mother seeks outside care	57.6	69.2	42	63.0	51.2
4. Informal community services	22.1	25.3	13	23.3	20.8
5. Formal community services	18.1	18.5	15	22.6	12.8
6. Mixed use of formal and informal services	17.3	25.3	5	17.1	17.6
7. Provider gives quality care • Informal services • Formal services • Mixed use of informal and formal services	 .7 6.6 7.4	 3.4 6.2 9.6		 2.7 8.2 11.0	 1.6 4.8 6.4

Source: El Alto Mortality Survey. El Alto, Bolivia. September 1995.

ARI = acute respiratory illness
DD = diarrheal disease

Conclusions and Recommendations

The verbal autopsy and the social diagnosis worked well together. The verbal autopsy identified the cause of death and the social diagnosis helped quantify the various steps that lead to the death. Although knowing the cause of death is critical to planners, results from this survey show that interventions can be targeted effectively if the breakdowns in the Pathway are identified and quantified.

Data from the verbal autopsy must be interpreted with care. The published literature describe significant problems with the sensitivity and specificity of certain diagnoses (Kalter et al. 1990; Snow et al. 1992). Depending on their prevalence in the area, malaria and ARI are frequently misdiagnosed. However, measles, neonatal tetanus, and trauma can be effectively diagnosed with a verbal autopsy. We did not include a comparison group or a control group with known causes of death, so it is impossible to quantify sensitivity and specificity for our sets of questions and algorithms. Nevertheless, the pattern of illness was very similar to what was expected for El Alto. SNS officials felt confident that the mortality structure was very close to reality.

Two fundamental conclusions can be deduced from this study:

1. Care seeking in El Alto is inadequate.
2. Medical care in El Alto's facilities is clearly inappropriate.

Following are comments on the two issues, suggestions for improvement, and other relevant information.

The mortality survey is an important tool for involving the community.
It is obvious from the results of the survey that the community played an important part in obtaining data. Because health workers in most countries—including developed countries—are not trained to involve the community, health workers must be given practical tools to interest and engage the community in health care. A mortality survey helps the community diagnose its own problems. At the same time, the interview process can deliver one-on-one counseling to high-risk population groups. In the long term, this may be crucial. The results of the survey show that there were a number of deaths in families where a death had already occurred.

In addition to collecting data, the community can also help plan and monitor the health care delivery. It is clear that mothers have specific ideas about what constitutes good health care. It was noted during the survey that, as their child's disease worsened, so did the mother's dissatisfaction with the care the child was given. Mothers can and should be encouraged to participate in the assessment of the quality of care in the community. If any child in the community dies, they have the right to ask why. Only when the community is empowered to solve its own problems can the quality of care be improved.

In El Alto, health-related problems were found inside and outside the home. Most problems were found in the home.
Obvious problems include the mothers' ignorance of appropriate care for the diseases that cause death, insufficient recognition of the danger signs of an illness, and inappropriate care-seeking behavior, in spite of active long-term control of DD and ARI programs in the region. Most children died of preventable and easily treatable diseases (pneumonia and diarrhea). If we extrapolate the survey findings to the total population of El Alto, we can expect to have, in one year, 735 deaths from pneumonia, 840 deaths from

diarrhea, and 312 deaths from a combination of pneumonia and diarrhea. Appropriate health education could prevent many of these deaths.

Neonatal deaths are unacceptably high.
The survey revealed that 44 percent of infant deaths occurred during the neonatal period. Even this high figure was considered low by some of the researchers; they felt that the reporting network missed many neonatal deaths. Because pregnancy outcomes were not followed, it is very probable that reporters could miss deaths that occurred within the first hours of life, or deaths that were classified as "born dead" but the baby had actually died minutes after a live birth. Whatever the case, this finding has important consequences for the types of interventions needed to further reduce infant mortality. El Alto health authorities need to investigate and identify the causes and conditions of neonatal deaths and, based on those findings, develop targeted interventions. The data from the El Alto survey are similar to data published in the literature (Burkhalter 1995).

Speed with which illness progressed is a significant consideration in developing interventions.
The mean duration of illness before death was three days. Analyses were not done by disease that caused death or by age at time of death. However, it was noted that neonates tended to die within the first few days of life. The message here is that the mother must have appropriate prenatal and birthing service. In the case of the neonate, it is even more critical that appropriate care be provided within hours. To prevent deaths, care must be provided for the neonate during and immediately after birth.

Both home care and facility care were usually of a poor quality.
In studying cases that resulted in death, most children were seriously ill from the beginning of the illness or soon after the mother recognized the danger signs. The mother should not attempt to give home care but should take the child immediately to a provider—the indicator for home care should be low. There are two exceptions:

- If the child clearly does not have danger signs related to the disease, but the child does have other signs or symptoms, the caretaker should give home care.

- If the child is taken to a provider and the provider gives home care, the home care recommendations should be followed by the caretaker.

These are two different situations and, to evaluate them, two different indicators should be developed.

Regardless of the cause of death, care provided by Western-style medical practitioners was poor. The survey was not designed to identify why standard case management (SCM) protocols were not followed by the provider. The results, however, demonstrated a need to do the following:

- Study the medical practice related to the most important causes of death and identify the reasons for noncompliance with standardized protocols of treatment.

- Based on those results, develop better training methodologies and/or curricula, increase the supply of drugs and materials, and develop sustainable supervisory methods.

Open histories can be used to develop interventions.
Initially, open histories were used to establish rapport between the caretaker and surveyor. Health histories, however, offer a wealth of information to the individuals designing interventions. In the caretaker's own words, the histories describe the events that led to the death of the child. The descriptions reveal the folklore, angst, and problems the caretakers faced when they made decisions. The principal care-seeking problems found by caretakers in the community are exemplified in the descriptions. Narrative descriptions with relevant health messages can be retold through mass media, group sessions, or on an interpersonal one-on-one level. Providers can also use the narratives to teach appropriate SCM and counseling skills.

Care-seeking patterns were not what researchers expected.
Overall, only 18 percent of the caretakers sought care from a Western-style medical provider. The researchers expected this result. They were surprised, however, that traditional providers were not used more often. It is possible that the caretakers did not disclose that part of their care seeking. However, the changes in care seeking—increased use of medical providers and decreased use of traditional healers as the illness progressed—illustrate the fact that caretakers believe that a medical provider can be trusted more than a traditional healer. This finding supports the opinion of caretakers that the two main reasons for seeking care where they did were trust and proximity. Interventions should seek to increase the demand for Western-style health services.

In most cases, a child's death occurred because the caretakers failed to recognize that the child was seriously ill. Interventions need to be developed to teach caretakers about danger signs during an illness and the need to seek medical help as soon as danger signs appear.

Gender issues should be considered when interventions are developed. The survey showed that illness recognition and care seeking were more frequent for male children than for female children. Further analysis of data could determine if the gender preference continues across ages, diseases, or settings.

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Annexes

Annex 1: Verbal Autopsy Questionnaire (Spanish)

Annex 2: Verbal Autopsy Questionnaire (English)

Verbal Autopsy Questionnaire

Instructions to the surveyor: Section 1 below will be complete when your supervisor gives you the questionnaire. The Verbal Autopsy Surveyor's Procedures Manual explains how to use this information to help you conduct the interview. Complete section 2 according to the instructions in the procedures manual. The actual interview starts with section 3.

Section 1: Background information from census taker or death reporter

1.1   Census taker's or death reporter's code number . . . . ____/____/____

1.2   Address of household: Street and number_____

1.3   Neighborhood/area   _____

1.4   Census tract or village   _____

1.5   Name of child . . . . _____

1.6   Sex of child . . . . 1. Male ___
                                                                                                  2. Female ___

1.7   Date of report . . . . ____/____/____
                                                                                                  (dd   mm   yy)

1.8   Child's age at time of death:

1.8.1 Age in completed days (if less than 28 days of age) . . . . days ___ ___

1.8.2 Age in completed months (if 28 or more days of age) . . . . months ___ ___

Section 2: Information about the interview

2.1   Language of the interview . . . . _____

2.2 Surveyor's code number	____/____	Date of first interview attempt	____/____/____

2.3 Date of interview	____/____/____	Date and time arranged for second interview attempt	____/____/____
Date form checked by supervisor	____/____/____	Date and time arranged for third interview attempt	____/____/____
Date entered in computer	____/____/____	Date interview abandoned	____/____/____

Instructions to the surveyor: Introduce yourself and explain the purpose of your visit. Say that you are interested in the illness that led to death. Ask to speak to the person who was the child's main caretaker during the illness. If this is not possible, arrange a time to revisit the household when this person will be home.

Section 3: Background information from caretaker

3.1   "What is your name?" . . . . _____

3.2   "What is your relationship to _____?" . . . . 1. Mother ___
2. Father ___
3. Grandmother ___
4. Grandfather ___
5. Aunt ___
6. Uncle ___
7. Other male (specify _____) ___
8. Other female (specify _____) ___

3.3   "Who was _____'s usual caretaker?" . . . . ._____. . . 1. Mother ___
2. Father ___
3. Grandmother ___
4. Grandfather ___
5. Aunt ___
6. Uncle ___
7. Other male (specify _____) ___
8. Other female (specify _____) ___

3.4   *Record whether other persons are present at the interview or not*
1. Yes, other persons present ___
2. No, only the respondent is present ___
(If "No", go to 3.5)

3.4.1 "Of the persons in the room with us now, who helped care for the child during the child's illness?"

	Present at interview	Helped care for child
1. Mother	___	___
2. Father	___	___
3. Grandmother	___	___
4. Grandfather	___	___
5. Aunt	___	___
6. Uncle	___	___
7. Other male (specify _____)	___	___
8. Other female (specify _____)	___	___

3.5 *If mother is not present at the interview, ask:* "Is the mother still alive?" . . . . 1. Yes ___
2. No ___
8. Don't know ___

3.6 "What is your/_____'s mother's age (in years)?" . . . . years ___ ___
(Don't know = 88)

3.7 "How many years of school did you/_____'s mother complete?" . . . . years ___ ___
(Don't know = 88)

3.8 "What is your/_____'s mother's occupation?" . . . . . . _____

3.9 "How many times have you/_____'s mother been pregnant?" . . . . number of times ___ ___
(Don't know = 88)

3.10 "How many times have you/___'s mother given birth (including ___)?".... number of times ___ ___
(Don't know = 88)

3.11 "How many living children do you/____'s mother have now?" . . number of living children ___ ___
(Don't know = 88)

3.12 "How many of your/_____'s mother's children have died (including _____)?"
. . . . number of deceased children ___ ___
(Don't know = 88)

3.13 "Do you/_____'s mother belong to any community organizations?" . . . . 1. Yes ___
2. No ___
8. Don't know ___
(If "No" or "Don't know," go to 3.14)

3.13.1 *If "yes," ask:* "What is it's name?" . . . . . . _____

3.14 "How old is/was _____'s father (in years)?" . . . . years ___ ___
(Don't know = 88)

3.15 "How many years of school did _____'s father complete?" . . . . years ___ ___
(Don't know = 88)

3.16 "What is/was the father's occupation?" . . . _____

3.17 "Did _____ live with both his/her parents, with just his mother, just his father, or with other
people?" . . . . 1. Both parents ___
2. Mother only ___
3. Father only ___
4. Other (specify _____) ___
8. Don't know ___

3.18 "What language is spoken most often in the household where _____ lived?" . . . . . _____

3.19 "At the time that _____ died, for how many months had the family lived in their current
house?" . . . . months ___ ___

3.20 "Does the house where _____ lived have its own water supply?" . . . . 1. Yes ___
2. No ___
8. Don't know ___

3.21 "What is the floor made of in the house where _____ lived?" . . . . 1. Wood/cement ___
2. Earth ___
8. Don't know ___

3.22 "Other than the kitchen and bathroom, how many rooms are there in the house
where _____ lived?" . . . . number of rooms ___ ___
(Don't know = 88)

3.23 "Including _____, how many people lived in the household?" . . . . number of people ___ ___
(Don't know = 88)

3.24 "What is the name of the health facility where you usually took _____?"

_____

3.24.1 "How long does it usually take to reach there?" . . . . minutes ____ ____ ____
(Don't know = 888)

Section 4: Information about the child

4.1 "Can you tell me _____'s date of birth?" . . . . ____/____/____
(dd   mm   yy)

4.2 "Where was _____ born?" . . . . 1. Home ___
2. Hospital ___
3. Other (specify _____) ___
8. Don't know ___

4.3 "How many children did you/_____'s mother have before _____ was born?" . . . . number ___ ___
(Don't know = 88)

4.4 "Can I please see _____'s health card?" . . . . 1. Yes ___
2. No, *or* don't have a health card ___
8. Don't know if have a health card ___
(If "No" or "Don't know," go to 4.5)

Mark whether each antigen was given:

4.4.1 BCG . . . . 1. Yes ___ 2. No ___	4.4.5 Measles 1. Yes ___ 2. No ___
4.4.2 DPT1 . . . 1. Yes ___ 2. No ___	4.4.6 OPV1 . . 1. Yes ___ 2. No ___
4.4.3 DPT2 . . . 1. Yes ___ 2. No ___	4.4.7 OPV2 . . 1. Yes ___ 2. No ___
4.4.4 DPT3 . . . 1. Yes ___ 2. No ___	4.4.8 OPV3 . . 1. Yes ___ 2. No ___

4.4.9 Record the last weight from the health card. . . . . kilograms ____ ____.____
(No weight recorded = 88.8)

4.4.10 Record the date of the last weight. . . . . ____/____/____
(dd   mm   yy)

4.5   "Was _____ ever breastfed?" . . . . 1. Yes ___
2. No ___
8. Don't know ___
(If "No" or "Don't know," go to 4.6)

4.5.1 *If "Yes," ask:* "For how many months did _____ drink only breastmilk?" . . . . months _____
(Don't know = 88.88)

4.5.2 *If "Yes," ask:* "How old (in months) was ___ when (s)he stopped breastfeeding?" . . months_____
(Don't know = 88.88)

4.6   "What was the date of _____'s death?" . . . . ____/____/____
(dd   mm   yy)

4.7   "How many days long was the illness that led to _____'s death?" . . . . days ___ ___

4.8   "During the illness that led to death, did you seek care for _____ outside the home?"   1. Yes ___
2. No ___
(If "No," go to 4.11)

If "Yes," ask: "Where or from whom did you seek care? Did you seek care from……

4.8.1 a traditional healer?" . . . . 1. Yes ___
2. No ___

4.8.2 a religious leader?" . . . . 1. Yes ___
2. No ___

4.8.3 a hospital?" . . . . 1. Yes ___
2. No ___
(If "No," go to 4.9.4)

4.8.3.1 *If "Yes" for hospital, ask:* "What is the name and address of the hospital?"

4.8.4   a health center or clinic?" . . . . 1. Yes ___
2. No ___
(If "No," go to 4.8.5)

4.8.4.1 *If "Yes" for health center or clinic, ask:* "What is the name and address of the facility?"

                          _____

                          _____

                          _____

4.8.5   a community-based practitioner associated with the health system, including a TBA?" 1. Yes ___
                                                            2. No ___

4.8.6   a private physician?" . . . . 1. Yes ___
                                                            2. No ___
                                                   (If "No," go to 4.8.7)

4.8.6.1 *If "Yes" for private physician, ask:* "What is the physician's name and address?"

                          _____

                          _____

                          _____

4.8.7   a pharmacy, drug seller, store, market?" . . . . 1. Yes ___
                                                             2. No ___

4.8.8   another provider?" . . . . 1. Yes (specify _____) ___
                                                             2. No ___

4.8.9   a relative or friend outside the household?" . . . . 1. Yes ___
                                                             2. No ___

(If no care was sought outside the home, go to 4.11.)

4.9   "How many days was _____ ill before you first sought care for the illness outside the home?"
. . . . days ___ ___

(If no care was sought at a health facility, go to 4.11.)

4.10   "How many days was (s)he ill before you first sought care at a hospital or other health facility?"
. . . . days ___ ___

4.11   "Where did _____ die?" . . . . 1. Hospital ___
                                                  2. Other health facility ___
                                      3. On route to hospital or health facility ___
                                                  4. Home ___
                                      5. Other (specify _____) ___

                            (If "On route to hospital/health facility," "Home," or "Other," go to section 5)

Child's Identification Number _____ _____ _____ ____

For deaths at hospital or health facility, ask:

4.11.1 "What is the facility name and, address?" . . . .

_____

_____

_____

Section 5: Open history question

"Could you tell me briefly about your child's illness that led to death?"

Prompt: "Was there anything else?"

Instructions to Surveyor: Allow the respondent to tell you about the illness in his or her own words. Do not prompt them except to ask whether there was anything else.

_____

_____

_____

_____

_____

_____

_____

_____

_____

_____

_____

_____

_____

_____

5.1   *Check all items mentioned spontaneously:*

5.1.1 . . . . Diarrhea (local terms: _____, _____) ___

5.1.2 . . . . Cough (local terms: _____, _____) ___

5.1.3 . . . . Fever (local terms: _____, _____) ___

5.1.4 . . . . Rash (local terms: _____, _____) ___

5.1.5 . . . . Injury (local terms: _____, _____) ___

5.1.6 . . . . Coma (local terms: _____, _____) ___

5.1.7 . . . . Convulsion (local terms: _____, _____) ___

5.1.8 . . . . Stiff neck (local terms: _____, _____) ___

5.1.9 . . . . Tetanus (local terms: _____, _____) ___

5.1.10 . . . . Measles (local terms: _____, _____) ___

5.1.11 . . . . Kwashkiorkor (local terms: _____, _____) ___

5.1.12 . . . . Marasmus (local terms: _____, _____) ___

5.1.13 . . . . Difficult breathing (local terms: _____, _____) ___

5.1.14 . . . . Fast breathing (local terms: _____, _____) ___

5.1.15 . . . . Wheezing (local terms: _____, _____) ___

5.1.16 . . . . Complicated delivery (local terms: _____, _____) ___

5.1.17 . . . . Malformation (local terms: _____, _____) ___

5.1.18 . . . . Multiple birth (local terms: _____, _____) ___

5.1.19 . . . . Very small at birth (local terms: _____, _____) ___

5.1.20 . . . . Very thin (local terms: _____, _____) ___

5.1.21 . . . . Born early (local terms: _____, _____) ___

5.1.22 . . . . Pneumonia (local terms: _____, _____) ___

5.1.23 . . . . Malaria (local terms: _____, _____) ___

5.1.24 . . . . Jaundice (local terms: _____, _____) ___

5.1.25 Other terms (specify: _____, _____, _____, _____, _____)

Section 6: Injury

6.1   "Did _____ die from an injury, bite, burn, poisoning, or drowning?" . . . . 1. Yes ___
2. No ___
8. Don't know ___
(If "No" or "Don't know," go to section 7)

6.1.1   *If "Yes," ask:* "What kind of injury?" . . . . 1. Motor vehicle accident ___
2. Fall ___
3. Drowning ___
4. Poisoning ___
5. Bite or sting by venomous animals ___
6. Burn ___
7. Violence ___
8. Birth injury ___
9.Other injury (specify _____) ___

6.1.2   "Did _____ die within 24 hours of this injury?" . . . . 1. Yes ___
2. No ___

IF "YES, DIED WITHIN 24 HOURS," GO TO SOCIAL AUTOPSY

IF "NO," CONTINUE WITH SECTION 7

Section 7: Age determination

7.1   *Record the child's date of birth from question 4.1.* . . . . ____/____/____
(dd   mm   yy)

7.2   *Record the child's date of death from question 4.10.* . . . . ____/____/____
(dd   mm   yy)

7.3   *Determine the age:*

Mark the child's age in months at the time of death: (Subtract the birth date [question 7.1] from the date of death [question 7.2].)
. . . . 1. Less than one month ___
2. One month or more ___

7.3.1   "I calculate that _____ was __ days/months old when (s)he died. Is this correct?" . . . 1. Yes ___
2. No ___

**IF "ONE MONTH OR MORE," SKIP TO
POSTNEONATAL SECTION**

**IF "LESS THAN ONE MONTH," CONTINUE
WITH NEONATAL SECTION**

Section 8: Neonatal deaths

8.1   *Record the child's age in days at the time of death (from question 7.3)* . . . . days ____ ____

8.2   "Did this child's pregnancy end early, on time, or late?" . . . . 1. Early ___
     2.On time ___
     3. Late ___
     8. Don't know ___

8.3   "Did the waters break before labor or during labor?" . . . . 1. Before ___
     2. During ___
     8. Don't Know ___
     (If "During" or "Don't know," go to 8.4)

8.3.1   *If the waters broke before labor ask:* "How much time before labor began did the
     waters break?" . . . . 1. Less than one day ___
     2. More than one day ___

8.4   "How much time did the labor and delivery take?" . . . . 1. Less than 12 hours ___
     2. More than 12 hours ___
     8. Don't know ___

8.5   "Did (s)he have any malformations at birth?" . . . . 1. Yes ___
     2. No ___
     8. Don't know ___
     (If "No" or "Don't know," go to 8.6)

If "Yes," ask: "Where were the malformations? Were they on the:

8.5.1   head?" . . . . 1. Yes ___
     2. No ___

8.5.2   body?" . . . . 1. Yes ___
     2. No ___

8.5.3   arms or hands?" . . . . 1. Yes ___
     2. No ___

8.5.4   legs or feet?" . . . . 1. Yes ___
     2. No ___

8.6   "At the time of birth was _____ . . . . 1. Very small ___
     (Read all the possible answers to the respondent.)   2. Smaller than usual ___
     3. About average ___
     4. Larger than usual? ___

8.7 "Was _____ able to breathe after the birth?" . . . . 1. Yes ___
2. No ___
8. Don't know ___

8.8 "Was _____able to suckle in a normal way after birth?" . . . . 1. Yes ___
2. No ___
8. Don't know ___
(If "No" or "Don't know," go to 8.9)

8.8.1 *If "Yes," ask:* "Did _____ stop suckling?" . . . . 1. Yes ___
2. No ___
(If "No" or "Don't know," go to 8.9)

8.8.1.1 *If "Yes," ask:* "How many days after birth did _____ stop suckling?" . . . . days ___ ___

8.9 "Was _____able to cry after birth?" . . . . 1. Yes ___
2. No ___
8. Don't know ___
(If "No" or "Don't know," go to 8.10)

8.9.1 *If "Yes," ask:* "Did _____ stop crying?" . . . . 1. Yes ___
2. No ___
(If "No" or "Don't know," go to 8.10)

8.9.1.1 *If "Yes," ask:* "How many days after birth did _____ stop crying?" . . . . days ___ ___

8.10 "During the illness that led to death, did _____ have spasms or convulsions?" . . . . . . 1. Yes ___
2. No ___

8.11 "During the illness that led to death did (s)he become unresponsive/unconscious?" 1. Yes ___
2. No ___
8. Don't know ___

8.12 "During the illness that led to death did (s)he have a bulging fontanelle?" . . . . 1. Yes ___
2. No ___
8. Don't know ___

8.13 "During the illness that led to death did _____ have redness or drainage from the
umbilical cord stump?" . . . . 1. Yes ___
2. No ___
8. Don't know ___

8.14 "During the illness that led to death did (s)he have a skin rash with bumps containing pus?"
. . . . 1. Yes ___
2. No ___
8. Don't know ___

8.15 "During the illness that led to death, did _____ have a fever?" . . . . 1. Yes ___
2. No ___
8. Don't know ___
(If "No" or "Don't know," go to 8.16)

8.15.1 *If "Yes," ask:* "How many days did the fever last?" . . . . days ___ ___

8.16 "During the illness that led to death, did _____ have frequent liquid, watery, or loose stools?"
. . . . 1. Yes ___
2. No ___
8. Don't know ___

8.17 "During the illness that led to death, did _____ have
(local terms for diarrhea: _____, _____)?" . . . . 1. Yes ___
2. No ___
8. Don't know ___
*(If "No" or "Don't know" for 8.16 **and** 8.17, go to 8.18)*

If "frequent liquid, watery or loose stools or local term for diarrhea," ask:

8.17.1 "For how many days did (s)he have liquid/watery/loose stools?" . . . . days ____ ____

8.17.2 "Was there visible blood in the liquid/watery/loose stools?" . . . . 1. Yes ___
2. No ___
8. Don't know ___

8.18 "During the illness that led to death, did _____ have a cough?" . . . . 1. Yes ___
2. No ___
8. Don't know ___
(If "No" or "Don't know," go to 8.19)

8.18.1 *If "Yes," ask:* "For how many days did the cough last?" . . . . days ____ ____

8.19 "During the illness that led to death, did _____ have difficult breathing?" . . . . 1. Yes ___
2. No ___
8. Don't know ___

8.20 "During the illness that led to death, did _____ have fast breathing?" . . . . 1. Yes ___
2. No ___
8. Don't know ___

8.21   "During the illness that led to death, did _____ have indrawing of the chest?" . . . . 1. Yes ___
2. No ___
8. Don't know ___

GO TO SOCIAL AUTOPSY QUESTIONNAIRE

Section 9: Postneonatal deaths

9.1   *Record the child's age in completed months at the time of death (from question 7.3).*
. . . . Number of completed months ____ ____

9.2   "During the illness that led to death did _____ have a fever?" . . . . 1. Yes ___
2. No ___
8. Don't know ___
(If "No" or "Don't know," go to 9.3)

9.2.1   *If fever, ask:* "How many days did the fever last?" . . . . days ____ ____

9.3   "During the illness that led to death did _____ have frequent liquid, watery or loose stools?"
. . . . 1. Yes ___
2. No ___
8. Don't know ___

9.4   "During the illness that led to death did (s)he have (local terms for diarrhea:
_____, _____)?" . . . . 1. Yes ___
2. No ___
8. Don't know ___

---

*(If "No" or "Don't know" for 9.3 **and** 9.4, go to 9.5)*

If frequent liquid/watery/loose stools or local term for diarrhea, ask:

9.4.1   "For how many days did (s)he have liquid/watery/loose stools?" . . . . days ____ ____

9.4.2   "Was there visible blood in the liquid/watery stools?" . . . . 1.Yes ___
2. No ___
8. Don't know ___

9.5   "During the illness that led to death did _____ have a cough?" . . . . 1. Yes ___
2. No ___
8. Don't know ___
(If "No" or "Don't know," go to 9.6)

9.5.1   *If "Yes", ask:* "For how many days did the cough last?" . . . . days ____ ____

9.6 "During the illness that led to death did _____ have difficult breathing?" . . . . 1. Yes ___
2. No ___
8. Don't know ___

9.7 "During the illness that led to death did _____ have fast breathing?" . . . . 1. Yes ___
2. No ___
8. Don't know ___

9.8 "During the illness that led to death did _____ have indrawing of the chest?" . . . . . 1. Yes ___
2. No ___
8. Don't know ___

9.9 "Did _____ experience any generalized convulsions during the illness that led to death?"
. . . . 1. Yes ___
(Demonstrate a generalized convulsion) 2. No ___
8. Don't know ___

9.10 "Was _____ unconscious during the illness that led to death?" . . . . 1. Yes ___
2. No ___
8. Don't know ___

9.11 "At any time during the illness that led to death, did _____ stop being able to grasp?" 1. Yes ___
2. No ___
8. Don't know ___
(If "No" or "Don't know," go to 9.12)

9.11.1 *If "Yes," ask:* "How long before (s)he died did _____ stop being able to grasp?"

. . . . 1. Less than 12 hours ___
2. 12 hours or more ___

9.12 "At any time during the illness that led to death, did _____ stop being able to respond to a
voice?" . . . . 1. Yes ___
2. No ___
8. Don't know ___
(If "No" or "Don't know," go to 9.13)

9.12.1 *If "Yes," ask:* "How long before (s)he died did _____ stop being able to respond to a voice?"
. . . . 1. Less than 12 hours ___
2. 12 hours or more ___

9.13　"At any time during the illness that led to death, did _____ stop being able to follow movements with his/her eyes?" . . . . 1. Yes ___
2. No ___
8. Don't know ___
(If "No" or "Don't know," go to 9.14)

9.13.1　*If "Yes," ask:* "How long before (s)he died did _____ stop being able to follow movements with his/her eyes?" . . . . 1. Less than 12 hours ___
2. 12 hours or more ___

9.14　"Did _____ have a stiff neck during the illness that led to death?" . . . . 1. Yes ___
(Demonstrate a stiff neck.)　　　　　　　　　　　　　　　　　　　　　　　　2. No ___
8. Don't know ___

9.15　"Did _____ have a bulging fontanelle during the illness that led to death?" . . . . 1. Yes ___
2. No ___
8. Don't know ___

9.16　"During the illness that led to death, did _____ have a skin rash?" . . . . 1. Yes ___
2. No ___
8. Don't know ___
(If "No" or "Don't know," go to 9.17)

9.16.1　*If "Yes", ask:* "Where was the rash?" . . . . 1. Face ___
2. Body ___
3. Arms/legs ___
8. Don't know ___

9.16.2　"How many days did the rash last?" . . . . days ____ ____

9.17　"During the illness that led to death, did _____ bleed into his/her skin or from any body opening?"
. . . . 1. Yes ___
2. No ___
8. Don't know ___

9.18　"Was _____ very thin during the month before (s)he died?" . . . . 1. Yes ___
2. No ___
8. Don't know ___

9.19　"During the illness that led to death, did _____ have swollen legs or feet?" . . . . 1. Yes ___
2. No ___
8. Don't know ___

9.20   "Did _____ have 'kwashiorkor' (local term: _____) during the month before (s)he died?"
. . . . 1. Yes ___
2. No ___
8. Don't know ___

9.21   "During the illness that led to death did _____ have pale palms?"
(Show photo and/or explore local terms: _____, _____) . . . . 1. Yes ___
2. No ___
8. Don't know ___

9.22   "During the illness that led to death did _____ have white nails?"
(Show photo and/or explore local terms: _____, _____) . . . . 1. Yes ___
2. No ___
8. Don't know ___
(Go to Social Autopsy Questionnaire)

End of Verbal Autopsy

GO TO SOCIAL AUTOPSY QUESTIONNAIRE

Annex 3: Criteria for Diagnosis

Annex 3

Criteria for Diagnoses by Verbal Autopsy Investigation of the Death of a Newborn (less than 28 days) or Postneonate (29 days to 2 years)

Probable Diagnosis	Diagnostic Criteria
Pneumonia	Either cough or difficult breathing, **and either** fast breathing or chest indrawing (*Neonate:* "Yes" to **either** Q 8.20 or Q 8.21, **and** "Yes" to **either** Q 8.22 or Q 8.23; *Postneonate:* "Yes" to **either** Q 9.5 or Q 9.6, **and** "Yes" to **either** Q 9.7 or Q 9.8).
Acute diarrhea	Frequent liquid, watery or loose stools or local term for diarrhea for less than 14 days, **and** no blood in the stools (*Neonate:* "Yes" to **either** Q 8.16 or Q8.17, **and** "1 to 13 days" for Q 8.17.1, **and** "No" to Q 8.17.2; *Postneonate:* "Yes" to **either** Q 9.3 or Q 9.4, **and** "1 to 13 days" for Q 9.4.1, and "No" to Q 9.4.2).
Acute dysentery	Frequent liquid, watery or loose stools or local term for diarrhea for less than 14 days, **and** blood in the stools (*Neonate:* "Yes" to **either** Q 8.16 or Q8.17, **and** "1 to 13 days" for Q 8.17.1, **and** "Yes" to Q 8.17.2; *Postneonate:* "Yes" to **either** Q 9.3 or Q 9.4, **and** "1 to 13 days" for Q 9.4.1, **and** "Yes" to Q 9.4.2).
Persistent diarrhea	Frequent liquid, watery or loose stools or local term for diarrhea for 14 or more days, **and** no blood in the stools (*Neonate:* "Yes" to **either** Q 8.16 or Q8.17, **and** "14 or more days" for Q 8.17.1, **and** "No" to Q 8.17.2; *Postneonate:* "Yes" to **either** Q 9.3 or Q 9.4, **and** "14 or more days" to Q 9.4.1, **and** "No" to Q 9.4.2).
Persistent dysentery	Frequent liquid, watery or loose stools or local term for diarrhea for 14 or more days, **and** blood in the stools (*Neonate:* "Yes" to **either** Q 8.16 or Q 8.17, **and** "14 or more days" for Q 8.17.1, **and** "Yes" to Q 8.17.2; *Postneonate:* "Yes" to **either** Q 9.3 or Q 9.4, **and** "14 or more days" for Q 9.4.1, **and** "Yes" to Q 9.4.2).
Measles	At least four months old, **and** fever and rash for 3 or more days, **and** rash on the face (*Postneonate:* 120 days or older by Q 4.10 minus Q 4.1, **and** "Yes" to Q 9.2, **and** "3 or more days" to Q 9.2.1, **and** "Yes" to Q 9.16, **and** "Face" to Q9.16.1, **and** "3 or more days" to Q 9.16.2).
Severe malnutrition	Postneonate who was very thin **or** had swollen legs or feet **or** had local term for kwashiorkor (*Postneonate:* "Yes" to Q 9.18 **or** Q 9.19 **or** Q 9.20).
Meningitis	• Neonate with fever, **and** bulging fontanelle, **and either** convulsions or unresponsive/unconscious (*Neonate:* "Yes" to Q 8.15, **and** "Yes" to Q 8.12, **and** "Yes" to **either** Q 8.10 or 8.11). • Postneonate with fever, **and either** stiff neck or bulging fontanelle, **and either** convulsions, unconscious, stopped being able to grasp, stopped being able to follow movements with eyes, or stopped being able to respond to a voice (all for more than 12 hours) (*Postneonate:* "Yes" to Q 9.2, **and** "Yes" to **either** Q 9.14 or 9.15, **and** "Yes" to **either** Q 9.9, 9.10, 9.11, 9.12, or 9.13, **and** matching "12 hours or more" to Q 9.11.1, 9.12.1, or 9.13.1).

Bacteremia/ septicemia	• Neonate in whom the waters broke more than one day before labor **or** had redness or drainage of the umbilical cord stump **or** had a skin rash with bumps containing pus, **and** fever, **and** no other cause of death (*Neonate:* "Before" to Q 8.3, **and** "More than one day" to Q 8.3.1 **or** "Yes" to Q 8.13 **or** "Yes" to Q 8.14, **and** "Yes" to Q 8.15, **and** no verbal autopsy pneumonia or meningitis diagnosis). • Postneonate with fever, **and** one or more of the following signs: unconscious, stopped being able to grasp, stopped being able to respond to a voice, or stopped being able to follow movements with eyes, **and** no other cause of death (*Postneonate:* "Yes" to Q 9.2, **and** "Yes" to **either** Q 9.10, 9.11, 9.12, or 9.13, **and** no verbal autopsy pneumonia or meningitis diagnosis).
Dengue fever	Postneonate with fever, **and** hemorrhage from an orifice or into the skin (*Postneonate:* "Yes" to Q 9.2 **and** "Yes" to Q 9.17).
Malaria	Postneonate with fever, **and** no stiff neck, **and** no bulging fontanelle, **and** no measles, **and either** convulsions, unconscious, stopped being able to grasp, stopped being able to respond to a voice, stopped being able to follow movements with eyes (all of the last three for more than 12 hours) or difficult breathing (*Postneonate:* "Yes" to Q 9.2, **and** "No" to Q 9.14 **and** "No" to Q 9.15, **and** no verbal autopsy measles diagnosis, **and** "Yes" to **either** Q 9.9, 9.10, 9.11, 9.12 or 9.13, **and** matching "12 hours or more" to Q 9.11.1, 9.12.1 or 9.13.1).
Injury	Death due to an injury sustained **after** birth (*Neonate or Postneonate:* "Yes" to Q 6.1, **and not** "Birth injury" to Q 6.1.1, **and** "Yes" to Q 6.1.2).
Birth trauma	Neonate who died of a birth injury (*Neonate:* "Yes" to Q 6.1 **and** "Birth injury" to Q 6.1.1 **and** "Yes" to Q 6.1.2).
Birth asphyxia	Neonate who was not able to breathe after birth, **and** had no fever **and** had one or more of the following signs: convulsions/spasms or not able to suckle in a normal way after birth or not able to cry after birth (*Neonate:* "No" to Q 8.7, **and** "No" to Q 8.15, **and** "No" to **either** Q 8.8 or 8.9 or "Yes" to Q 8.10).
Low birth weight	Neonate whose pregnancy ended early **or** who was very small at premature birth (*Neonate:* "Early" to Q 8.2 **or** "Very small" to Q 8.6).
Congenital malformation	Neonate who was malformed at birth (*Neonate:* "Yes" to Q 8.5).
Neonatal tetanus	Neonate who was able to suckle and cry normally at birth, **and** stopped suckling or crying at more than 2 days of age, **and** had either spasms or convulsions (*Neonate:* 3 to 27 days old by Q 4.10 minus Q 4.1, **and** "Yes" to **both** Q 8.8 and 8.9, **and** "Yes" to **either** Q 8.8.1 or 8.9.1, **and** "more than 2 days" to Q 8.8.1.1 or Q 8.9.1.1, **and** "Yes" to Q 8.10). The diagnosis of neonatal tetanus should not be made in the presence of birth asphyxia or birth trauma.