# Mortality Surveillance at Burial Sites in Addis Ababa: Major Methodological Issues and Opportunities for Research

Tekebash Araya, Addis Ababa University
Georges Reniers, University of Colorado (Boulder)
Gail Davey, Addis Ababa University
Yemane Berhane, Addis Ababa University
Eduard Sanders, Kenya Medical Research Institute

## Short abstract

In many developing countries, including Ethiopia, accurate information on vital events is lacking or –at best– incomplete. In this paper, we discuss the utility of a surveillance of burials as a partial substitute for a fully functioning vital registration system, and for monitoring AIDS mortality in particular. In the era of antiretroviral treatment, direct measurement of AIDS mortality rather than the conventional focus on HIV prevalence, will become an essential component of monitoring the success of interventions. We review fieldwork procedures, methodological strengths and weaknesses of the system as well as and some of the opportunities for research. One particular feature of system is that it records lay reports of causes of death. Despite a reluctance to explicitly label AIDS deaths as such, bereaved relatives often use euphemisms that are highly indicative of AIDS mortality and can be used for monitoring purposes.

## Extended abstract

### 1. Introduction

Reliable and comprehensive data on disease levels, patterns, and trends are required to monitor epidemics and to assess the effectiveness of public health approaches for the prevention and control of disease and injury. Mortality statistics are an important part of that, but most countries in sub-Saharan Africa have no vital registration system that captures a sufficient number of deaths to provide meaningful statistics (Murray and Lopez 1996; Cleland 1996; Cooper, Osotimehin, Kaufman, and Forrester 1998; Kahn, Tollman, Garenne, and Gear 1999; Mathers, Ma. Fat, Inoue, Chalapati, and Lopez 2005; Diaz, Loth, Whitworth, and Sutherland 2005). Particularly for monitoring HIV/AIDS epidemics, vital registration type data will become increasingly important. Because of the expansion of antiretroviral treatment programs HIV prevalence data will gradually lose informative value and cause-specific mortality data are an important outcome measure for monitoring the impact of treatment regimes (Diaz et al. 2005; Bennett, Boerma, and Brugha 2006). It is probably no coincidence that those countries that are worst affected by the HIV/AIDS epidemic are precisely those that lack vital registration.

Most available morbidity and mortality records in countries with weak vital registration are based on returns from (government) health institutions. Such records are often scanty and inaccurate (UNICEF 1984; Mtango 1987). The validity of this information is further compromised by the fact that hospital statistics are often not representative of the population because not all communities are equally supplied with health facilities. Even where health services are available, their utilization is often low and selective implying that most deaths still occur at home, away from medical personnel capable of establishing a cause of death (Olubuyide and Solanke 1990; Murray, Yang, and Qiao 1992; Kitange et al. 1996; Cooper et al. 1998) (Nykanen, Tamaona, Cullinan, Van Oosterzee, and Ashorn 1995). Morgue-based statistics suffer from the same shortcomings (Pictet, Le Coeur, M'Pele, Brouard, and Lallemant 1998; London, Mock, Abantanga, Quansah, and Boateng 2002). Nonetheless, health services data may be useful for monitoring trends in the health profile of the population but requires corroboration from other data sources.

Indirect estimation techniques are an exemplary alternative approach that allow for the exploitation of conventional data sources such as censuses and surveys for measuring mortality levels and trends, but the ensuing estimates are often dated far back in time (Feeney 2001; Timaeus and Jasseh 2004). Other productive approaches such as demographic surveillance sites [DSS] or Sample Vital Registration systems do also provide continuous and real time mortality data, but require a separate data collection infrastructure and may be quite labor intensive and expensive to maintain (INDEPTH Network 2002; Setel et al. 2005).

The situation in Ethiopia is very similar to the rest of sub-Sahara African countries as births and deaths go largely unrecorded. The potential mortality impact of AIDS is usually estimated using models based on seroprevalence data (in antenatal clinics), patterns of transmission, and transition rates from HIV infection to AIDS and from AIDS to death (MOH 2004). Alternative (AIDS) mortality estimates have to be derived from scattered resources that include statistics from censuses (CSA 1987); a sample vital registration survey in 1998/99 (CSA 2000); and the 2000 and 2005 Ethiopia Demographic and Health Surveys (CSA and ORC Macro 2001). The Butajira Demographic Surveillance is one of the few data resources that offers long term a morbidity and mortality statistics for a rural area (Berhane et al. 1999).

In an attempt to resolve some of the limitations in the availability of data for studying mortality, we discuss the utility of a surveillance of burials that resorts under the Addis Ababa Mortality Surveillance Project. Registration of burials is a fairly simple alternative methodology to provide information on the number of deaths as well as their background characteristics. A convenient feature of the burial surveillance is that it taps into an existing infrastructure of burial sites. In some cemeteries rudimentary registration system had been ongoing for years prior to the initiation of our study.

The burial surveillance was initiated in February 2001 at all cemeteries in Addis Ababa. Socio-demographic background characteristics of the deceased as well as the lay report of the cause of death are collected by cemetery clerks from close relatives or friends while they make the arrangements for burial. So far, we have used these data –sometimes in combination with other datasets– to document the impact of HIV/AIDS on mortality; to examine the representativeness of hospital statistics; to assess the diagnostic accuracy of lay reporting of causes of death and to monitor the demographic impact of AIDS (Sanders et al. 2003; Araya et al. 2004; Reniers et al. 2005; Reniers, Araya, and Sanders 2006). The burial records have also been used as a sampling frame for verbal autopsies that were conducted in 2001 and 2004. With the expansion of

antiretroviral therapy (ART) programs, the burial surveillance will be instrumental in documenting its population-level effects.

In this paper, we describe the methodology, the challenges encountered in setting up and maintaining the burial surveillance and the methods used to ensure data quality. We conclude with an exploration of the research opportunities that a quasi-vital registrations system of this kind allows.

## 2. Description of the study area

The burial surveillance is being administered in Addis Ababa, the capital of Ethiopia. The projected population for 2005 is 2,864,00. The majority of the population belongs to the Orthodox Christian faith (82%). Just under 15% is Muslim. Protestants, Catholics and Jews are the remaining religious minorities (CSA 1999). Cremation is not practiced in Addis Ababa, and burials are conducted at religious- or municipality-based cemeteries.

At the start of the study, the Addis Ababa City Government was administratively classified into 28 *Woredas*, and 328 *Qebeles*[1] (CSA 1995). In January 2003, the city was administratively restructured into 10 Kifle-ketemas (Sub-cities) and 196 Qebeles (Addis Ababa City Government 2003). In August 2004, the administrative Qebeles were again reorganized into 99 bigger Qebeles (Addis Ababa City Government 2004).

The first sera with HIV antibodies in Ethiopia were identified in 1984 (Tsega, Mengesha, Nordenfelt, Hansson, and Lindberg 1988) and the first AIDS cases were diagnosed in 1986 (Lester, Ayehunie, and Zewdie 1988). In 1994, HIV prevalence in Addis Ababa was 6.0% and 6.9% in adult males and females, respectively, with a male-to-female ratio of 0.97:1 (Fontanet et al. 1998). For 2003, HIV prevalence was estimated to be over 14% (MOH 2004). Recent data from a DHS survey that involved HIV serostatus testing have not yet been released.

## 3. Field Work Procedures

Prior to the start of the surveillance, we did a citywide assessment of burial sites (cemeteries) by visiting churches, mosques and the municipal offices. Out of the 70 cemeteries, five cemeteries were found to have kept registries with information of principal study interest. (i.e., age, sex and date of burial). These data were used in a retrospective analysis of trends in all-cause mortality (Sanders et al. 2003).

We subsequently obtained permission from all religious authorities and the Labour and Social Affairs Bureau for permission to conduct a surveillance of burials. A prospective burial surveillance was initiated at 70 cemeteries in February 2001. New cemeteries are included in the study as they are established. Of the 85 cemeteries currently under surveillance, 64 are Ethiopian Orthodox Churchyards[2], nine are municipality-based (that accept corpses from various religions denominations), eight are Muslim cemeteries, and four for other religions.

[1] *A Qebele is the smallest administrative unit of the city.*
[2] Two of them are Yesenbete Mahber's. These are Ethiopian Orthodox community organizations and they do not depend from the Ethiopian Orthodox Church.

The *'Baytewar'* cemetery constitutes a special case. It is one of the eight municipal-based cemeteries that accepts and buries corpses of individuals without relatives or friends to facilitate a funeral service[3]. The Baytewar cemetery also accommodates bodies collected from hospitals that are not claimed by relatives. Many of these are perinatal cases delivered by the obstetric wards of hospitals in Addis Ababa[4]. The Baytewar cemetery accommodates about 15% of all the burials in the capital (10% if neonates are excluded) and that is a relatively high figure for an African country where social networks of support are conventionally thought of as being very tight.

At each burial site one or two cemetery-based clergymen or municipal officers are assigned to register burials using a surveillance form designed for the purposes of the surveillance (Annex I). The surveillance form initially included spaces to collect information on the date of burial, age, name, sex, address, and presumed cause of death (i.e. the lay report of the cause of death). In the course of the second year of study (starting from 9 May 2002) additional data on marital status, region of birth, ethnicity and religion of the deceased is being collected. The cemetery clerks record this information from relatives or friends of the deceased while they are making the arrangements for burial. Twelve supervisors are assigned to monitor the registration of burials in five to seven cemeteries each. All supervisors report to the project office on a weekly basis. A field coordinator monitors the activities of the supervisors, reviews burial surveillance forms for completeness and where possible for consistency (e.g., accuracy in recording of children's age, matching of sex against the recorded title of the deceased, etc.*)*. Occasionally he conducts site visits to monitor data collection.

## 3. Coverage and data quality

One of the weaknesses of the surveillance is the underreporting of infant deaths. Presumably because children that die before the naming ceremony (40 days for boys and 80 days for girls) are sometimes not given a formal funeral service, they are underrepresented in the surveillance. Our estimated probability of dying before the age of 5 is only just above half of that obtained via the DHS survey (CSA and ORC Macro 2001) and adjusting for the under-reporting for infant deaths alone would raise the overall CDR by more than 1 per 1000.

After correcting for the underreporting of early childhood deaths, the crude death rate (CDR) estimated from the burial surveillance and projected census data oscillates between 9 and 10 per 1000. This figure is higher than an official estimate of 7.6 per 1000, but is still on the low side for a population that is severely affected by the HIV/AIDS epidemic and suggests that there may be sources of under-reporting of adult deaths as well. These may include: the repatriation of bodies for burial; the return of sick migrants to their families for care, the burial of Addis Ababa residents beyond the city administration limits; and possibly also illegal burials. In the paper we discuss each of those sources of underreporting in greater detail as well as efforts that are underway to quantify them.

About 10% of the records have missing values for either age or sex but that fraction is reduced to less than 1% if the records from the Baytewar cemetery are excluded (table 1).

[3] Baytewar is an Ethiopian Amharic word that is used to refer to a stranger or someone who is socially isolated.
[4] When deaths occur at an early age usually within 6 days of life while the baby is in a hospital, the majority of parents give a written consent to leave the bodies at the hospitals.

**Table 1: Distribution of the number of burials by age, sex and cemetery (2001-2006, Addis Ababa, Ethiopia**

| | All cemeteries | | Non-Baytewar | | Baytewar | |
|---|---|---|---|---|---|---|
| Age group | Both sexes | Percent (%) | Female N (%) | Male N (%) | Female N (%) | Male N (%) |
| 0-4 | 16008 | 16.0 | 4010 (4.5) | 5117 (11.3) | 861 (14.0) | 1045 (17.0) |
| 5-9 | 1051 | 1.1 | 446 (0.5) | 549 (1.2) | 21 (0.3) | 35 (0.6) |
| 10-14 | 992 | 1.0 | 404 (0.9) | 532 (1.2) | 22 (0.4) | 34 (0.6) |
| 15-19 | 2194 | 2.2 | 1064 (1.2) | 899 (2.0) | 110 (1.8) | 121 (2.0) |
| 20-24 | 4620 | 4.6 | 2317 (2.6) | 1653 (3.6) | 308 (5.0) | 341 (5.6) |
| 25-29 | 8920 | 8.9 | 4814 (5.4) | 3312 (7.3) | 299 (4.9) | 494 (8.0) |
| 30-34 | 9063 | 9.1 | 4372 (4.9) | 4048 (8.9) | 196 (3.2) | 446 (7.3) |
| 35-39 | 10106 | 10.1 | 4724 (5.3) | 4864 (10.7) | 139 (2.3) | 377 (6.1) |
| 40-44 | 7425 | 7.4 | 3068 (3.5) | 4002 (8.8) | 69 (1.1) | 285 (4.6) |
| 45-49 | 6453 | 6.5 | 2657 (3.0) | 3537 (7.8) | 60 (1.0) | 198 (3.2) |
| 50-54 | 5562 | 5.6 | 2434 (2.7) | 2947 (6.5) | 38 (0.6) | 143 (2.3) |
| 55-59 | 3880 | 3.9 | 1594 (1.8) | 2187 (4.8) | 13 (0.2) | 86 (1.4) |
| 60-64 | 5327 | 5.3 | 2265 (2.6) | 2926 (6.5) | 22 (0.4) | 114 (1.9) |
| 65-69 | 3677 | 3.7 | 1522 (1.7) | 2062 (4.5) | 18 (0.3) | 74 (1.2) |
| 70-74 | 4414 | 4.4 | 2080 (2.3) | 2259 (5.0) | 17 (0.3) | 58 (0.9)) |
| 75+ | 10149 | 10.2 | 5619 (6.3) | 4434 (9.8) | 26 (0.4) | 70 (1.2) |
| Total | 99841 | 100.0 | 43390 (48.9) | 45328 (51.1) | 2219 (36.1) | 3921 (63.9) |
| Missing age | 5557 | 5.3 | 483 (0.54) | | 5074 (31.38) | |
| Missing sex | 5328 | 5.1 | 33 (0.04) | | 5295 (32.75) | |
| Total | 105398 | | | | | |

Because the socio-demographic background characteristics about the deceased are reported by friends or relatives that go to the burial site to make the arrangements for burial, these data are not always of the quality that demographers or epidemiologists are used to. Age heaping, for example, is serious (Whipple index of 283), and that implies that age smoothing is necessary for most life table applications (e.g. Reniers et al. 2006). In the future we aim to implement a protocol where the relative has to bring an ID card of the deceased in order to arrange for the burial service. This, however, is a legal matter that requires governmental support and may take time to accomplish.

For similar reasons that ages are misreported, we find that addresses are often misreported. Addresses are important for tracing caregivers for conducting follow up verbal autopsy interviews. Until recently, an address in Ethiopia consisted of a *Woreda* number, a *Quebele* number and a house number. Street names are not commonly used and even house numbers are not usually used to give directions to someone's house and therefore not always known by relatives or friends that report at deceased at the cemetery. During previous VA fieldwork we had to exclude close to 20% of the cases from the sampling frame because no complete and consistent address was available. In addition 14% of the households could not be retrieved by the VA interviewers. The administrative restructuring of the city into Subcities in stead of Woreda's and larger Quebeles is not helping our case either. In the paper we will provide

greater detail about the accuracy in the reporting of addresses and the changes that we are to implement to improve the traceability of households.

**Table 2: distribution of lay diagnoses of causes of death by sex (Addis Ababa, 2001-2005), age 20-64 (in %)***

| | Women | Men | Total (N) |
|---|---|---|---|
| **Communicable diseases** | **59.6** | **57.5** | **30,105** |
| Tuberculosis/Lung disease | 27.2 | 28.2 | 14,228 |
| Cold | 22.9 | 20.0 | 11,036 |
| Acute febrile illness | 3.1 | 4.2 | 1,874 |
| AIDS | 2.6 | 1.8 | 1,122 |
| Diarrhoeal diseases | 1.6 | 1.5 | 808 |
| Herpes Zoster | 1.1 | 0.8 | 471 |
| Other communicable diseases | 1.2 | 1.0 | 566 |
| **Maternal causes** | **2.1** | | **532** |
| **Non-communicable diseases** | **29.7** | **30.3** | **15,455** |
| Cardiovascular disorders | 7.2 | 6.7 | 3,597 |
| Liver cirrhosis** | 4.6 | 7.6 | 3,144 |
| Neoplasms | 4.7 | 2.2 | 1,784 |
| Renal disorders | 3.2 | 3.2 | 1,657 |
| Diabetes | 1.7 | 2.5 | 1,081 |
| Other non-communicable diseases | 8.2 | 8.1 | 4,192 |
| **Symptoms, signs and syndromes** | **5.6** | **5.6** | **2,888** |
| Mental problem | 2.1 | 2.7 | 1,250 |
| Emaciation | 0.0 | 0.0 | 13 |
| Cough/Coughing disease | 0.2 | 0.2 | 99 |
| Other symptoms signs and syndromes | 3.2 | 2.7 | 1,526 |
| **External causes** | **3.0** | **9.9** | **3,313** |
| **Subtotal of specific diagnoses (N)** | **25,720** | **26,573** | **52,293** |
| **Subtotal of specific diagnoses (%)** | **87.5** | **83.2** | |
| **Unknown - weakly specified** | **12.5** | **16.8** | **9,029** |
| No COD assigned, unknown, found dead | 5.5 | 9.3 | 4,561 |
| Sickness / accidental sickness | 5.4 | 6.5 | 3,674 |
| Medically not recognized community beliefs | 1.3 | 0.9 | 676 |
| Aged | 0.3 | 0.1 | 117 |
| **Total** | **29,381** | **31,941** | **61,322** |

Notes:

* Percentages have been calculated using the subtotal of sufficiently 'specific' diagnoses as the denominator

** It was not always clear whether lay diagnoses referred to communicable or non-communicable diseases. In these cases arbitrary decisions had to be made. For example, all liver problems not explicitly referred to as *hepatitis* (in the community known as '*ye wof beshita'* and here classified under 'other communicable diseases') were interpreted as *liver cirrhosis*. The lay diagnosis in Amharic these cases usually mentioned *'gubet beshita*', which literally means *liver disease*.

Shortly after the initiation of the burial surveillance, we started collecting lay reports of causes of death. These lay reports are routinely translated into English and categorized using a cause of death classification scheme that is adapted from the Global Burden of Disease Study. An example of that is presented in table 2.

Over 80% of the reported diagnoses are specific enough to be classifiable under one of the listed causes of death and that is perhaps a surprise in and by itself. This result encouraged us to start comparing lay reports with more established methods for assigning causes of death (table 3 and table 4).

In table 3 the lay report is considered a diagnostic test for the 'true' cause of death whereby we use discharge diagnosis of the cause of death for patients that died in a hospital as the reference standard. To that end we conducted a surveillance of hospital deaths and matched the records with those from the cemeteries (Reniers et al. 2005). In table 4, we focus on TB/AIDS deaths and use the physician review of a set of verbal autopsies as the reference standard. Though far from perfect, these tables illustrate that the lay reports are a reasonable approximation for monitoring broad groups of causes of death and for AIDS mortality in particular; despite a reluctance to label AIDS deaths explicitly as such. In the paper, we discuss these results in greater detail.

**Table 3: The diagnostic value of lay diagnoses of causes of death using the hospital discharge diagnoses as reference standard in a set of matched hospital and burial records, 2001, Addis Ababa, Ethiopia.**

| | Lay report | | | | | | |
|---|---|---|---|---|---|---|---|
| **Hospital diagnosis** | Communicable diseases | Maternal causes | Non-communi-Cable | Symptoms, signs and syndromes | External injuries | Undetermined | Total |
| Communicable diseases | 305 | 2 | 54 | 4 | 10 | 51 | 426 |
| Maternal causes | 4 | 4 | 2 | 2 | 1 | 1 | 14 |
| Non- communicable | 37 | 1 | 195 | 8 | 11 | 51 | 303 |
| Symptoms, signs and syndromes | 5 | 0 | 4 | 17 | 0 | 5 | 31 |
| External injuries | 12 | 0 | 9 | 2 | 192 | 9 | 224 |
| Total | 363 | 7 | 264 | 33 | 214 | 115 | 996 |
| Undetermined | 27 | 1 | 11 | 1 | 10 | 14 | 64 |
| **Diagnostic indicators** | | | | | | | |
| Sensitivity | 0.72 | 0.29 | 0.64 | 0.55 | 0.86 | - | |
| Specificity | 0.90 | 1.00 | 0.90 | 0.98 | 0.97 | - | |
| PPV | 0.84 | 0.57 | 0.74 | 0.52 | 0.90 | - | |

Notes: Lay diagnosis and the hospital diagnosis are sometimes categorized under different headings even though they most likely referred to the same medical problem (e.g., the lay diagnosis 'mental problem' is classified under 'symptoms, signs and syndromes' whereas intra cranial space occupied lesion (ICSOL) as a medical diagnosis resorts under non-communicable diseases). This is particularly so for AIDS related conditions where lay and medical diagnoses sometimes refer to different manifestations of AIDS (e.g., 'lung disease' as a lay diagnosis and 'cervical cancer' for medical diagnosis, or, 'nerve problem' and 'TB'). In all these cases, lay diagnoses were reclassified to make them consistent with the medical diagnosis. In total, 55 cases were reclassified from inconsistent to consistent categories.

**Table 4: Diagnostic values for lay reports of causes of death for identifying TB/AIDS mortality using the physician review of verbal autopsy interviews as a gold standard (Addis Ababa, both sexes, age 20-64)**

| | Lay report | | | | | |
|---|---|---|---|---|---|---|
| **Reference Standard (physician review of VA)** | TB/AIDS | Herpez zoster / Diarrhea / Uterine cancer / Mental problem / Emaciation | Lung disease/ Cough disease | Cold | Other | Total |
| AIDS | 16 | 17 | 88 | 52 | 48 | 221 |
| NoAIDS | 2 | 7 | 14 | 20 | 143 | 186 |
| Undetermined | 0 | 0 | 0 | 1 | 5 | 6 |
| **Diagnostic indicators** | | | | | | |
| PPV | 0.89 | 0.71 | 0.86 | 0.72 | 0.25 | |
| Sensitivity | 0.07 | 0.08 | 0.40 | 0.24 | 0.22 | |
| Specificity | 0.99 | 0.96 | 0.92 | 0.89 | 0.23 | |
| **Cumulative values for the diagnostic indicators** | | | | | | |
| PPV | 0.89 | 0.79 | 0.84 | 0.80 | | |
| Sensitivity | 0.07 | 0.15 | 0.55 | 0.78 | | |
| Specificity | 0.99 | 0.95 | 0.88 | 0.77 | | |

## 4. Research opportunities

Past, current and planned research using these data will be discussed in the full paper.

## 5. Results and preliminary conclusions (section to be completed)

Burial surveillance data of the type that are collected in Addis Ababa are perhaps not as refined as one would wish them to be, but they fill a gap in a setting where the alternative is no or at best scattered data sources. The availability of new census data in combination with efforts to assess the nature and scale of under-reporting in the burial surveillance will strengthen the quality of our mortality estimates in the future and will add to the value of burial surveillance data as a partial substitute for a vital registration system. The burial surveillance also provides a sampling frame for the selection of cases for verbal autopsy interviews. An attractive feature of the burial surveillance is that it relies heavily on an existing infrastructure and that significantly reduces the running costs of the project.

Since the initiation of the Addis Ababa Mortality Surveillance Project, the main objective has been to track AIDS mortality. In that respect the burial surveillance and its satellite data collection systems have proven a useful approach for documenting the HIV/AIDS impact on adult mortality either through life table techniques or via extrapolations from lay reports of causes of death. Out of a total of over 20,000 deaths annually, estimates from the burial surveillance attribute over one out of two adult deaths (age range 20-64) to AIDS. Even though these figures highlight the severity of the epidemic, our estimates are roughly half of those

reported by the Ministry of Health (MOH 2004). The MOH estimates are based on antenatal clinic (ANC) sentinel surveillance data. Admittedly, our estimates of AIDS deaths are dependent on the completeness of the burial surveillance and are rather conservative. Yet, if the burial surveillance were only 80% complete (for adult mortality), then this would translate into an estimate ranging from 9,000 to 10,500 annual adult AIDS deaths; still barely half the number published in the MOH-report. These results thus suggest that extrapolations from ANC sentinel surveillance data may severely overstate the magnitude of the AIDS epidemic and that they require corroboration by community-based serological surveys, or, by studies that use observed mortality data as an input.

Observed mortality data now also serve as a monitoring system for evaluating the population level impact of antiretroviral treatment (ART). Reduction in AIDS mortality is the ultimate outcome measure of the success of treatment and that can only be established via trends in cause-specific mortality indices. Via our surveillance system we were not only capable of recording a reduction in AIDS morality since the expansion of treatment programs, but we also identified patterns that are suggestive of bias in the access to treatment. These inequities we observed in terms of gender and indices of socio-economic status.

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