Update/Le point

The absence of adult mortality data for sub-Saharan Africa: a practical solution

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Information on cause of death among adults in sub-Saharan Africa is essentially nonexistent. Published sources provide statistics on both cause-specific and overall rates of mortality, but closer examination reveals that these data consist mostly of extrapolations and outright guesses. In the absence of accurate and comprehensive registries of vital events for the majority of the region's inhabitants, longitudinal studies of defined population-based cohorts represent the only realistic strategy to fill this void in basic public health information.

The advantage of longitudinal studies is particularly clear for chronic diseases, the category for which the least is known. Noncommunicable diseases account for a significant portion of adult deaths in sub-Saharan Africa, yet the empirical bases for public health policies and interventions are essentially absent. Verbal autopsy has great potential to contribute to understanding about the cause of death among African adults. This method is discussed in the present article, and practical considerations for longitudinal studies using this methodology are reviewed.

Introduction

The dearth of accurate and reliable adult mortality data from developing countries, both all-cause as well as cause-specific mortality rates, has been noted on a number of occasions, and the need for such data underlined (*1*, *2*). There are clear policy applications for demographic and vital statistics in the structuring of public health interventions and health systems, which makes the absence of such data all the more frustrating (*3*). The costs of this ignorance range from economic loss at the level of individual productivity (*4*), to overburdened health-care facilities (*5*), and higher levels of child mortality among the offspring of sick or deceased adults (*6*).

The incompleteness and unreliability, or in many cases the total absence, of national vital registration in some developing countries has made it necessary to seek other sources of information on adult mortality. In Africa, for example, only three countries reported annual cause-specific mortality data to WHO at least once between 1985 and 1989; this represents a population coverage level of 0.25%, compared with 94% in Europe and 80% in the Americas (*7*).

Although estimated statistics are available for causes of death in Africa and the rest of the developing world (*8*), examination of the bases of these data shows that they are model-based extrapolations founded on a number of questionable sources. While it is necessary to make use of models in the absence of direct data, such an approach has the disadvantage of generating false confidence in the numbers produced. If realistic confidence intervals could be attached to vital statistics from sub-Saharan Africa, they would be so wide that the statistic in question would be considered essentially *unknown*.

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Reprint No. **5794**

The above critique should not be misconstrued as an attack on those who have tried to make the best of this limited information base, all the while emphasizing the inadequacy of present sources and arguing that more attention be paid to this issue (*2*). Rather, our purpose is to review the major weaknesses of existing estimates, including the following: statistics that are based on outdated studies; nonrepresentative samples, studies of insufficient size to provide stable estimates; or no data whatsoever.

Murray has critiqued the practice of presenting vital statistics without adequate explanation of their source (*9*). Annual life expectancy and infant mortality data are presented in many reference works; however, particularly for sub-Saharan Africa, the information is obtained by applying demographic models to an extremely small database. Also, the assumptions and empirical foundations of such models are rarely stated, and the choice of parameters can lead to very large differences in the final estimates. Unfortunately, even in the best of cases, these parameters are drawn from data that are outdated or unrepresentative; and all too often they have no empirical basis at all. The World Bank's estimates of adult mortality in Nigeria, for example, are calculated from a hypothetical age pattern of mortality that was derived "qualitatively" from a mix of data from neighbouring countries and a few small studies of childhood mortality in the 1970s (*10*).

Clearly, it is the small number of informative studies that forces researchers to consider sources that are out of date. For example, in a comprehensive discussion of chronic disease epidemiology in sub-Saharan Africa, Hutt cited 122 references, 61 of which were more than 20 years old (*11*). The published literature is therefore increasingly irrelevant to current conditions and trends and should be used with caution.

The limitation inherent in unrepresentative study samples can be levelled against the common source data on cause-specific adult mortality in sub-Saharan Africa: hospital-based studies and clinical series. Timaeus has concluded that in much of sub-Saharan Africa, such statistics are of limited utility (*12*).

Analysis of the health care system in Nigeria has shown that the vast majority of the population has virtually no access to hospitals, clinics or health professionals. Stock found that the population per physician in Kano, Nigeria's second largest city, was over 4500 and nearly 300000 in the rest of the state (*13*). Alubo has shown that financial and geographical barriers to health care system utilization in Nigeria are so severe that estimates based on hospitalized cases can only be considered relevant to a small, elite fraction of the population (*14*). Furthermore, there is a growing perception among the population of the country that the health infrastructure has become so dilapidated that seeking care at hospitals actually places individuals at *greater* risk of death or injury (*15*). The vast majority of Nigeria's population therefore receives care from providers outside the formal health system, who, though they may supply useful services, do not report statistics to national or international authorities.

Longitudinal studies

In the absence of national vital statistics based on registration of births and deaths in sub-Saharan Africa, and with only a small proportion of individuals able to visit hospitals or clinics, community-based surveys remain the only means of gathering data suitable for determining the rate and causes of adult mortality. Orphanage studies have been a popular approach to this problem (*16*), but entail sources of bias such as adoption (*12*) and misreporting of age at death (*17*). Furthermore, this technique permits the estimation of only the lower limit of all-cause adult mortality, with little potential for cause-specific estimates. Orphanhood and widowhood studies may therefore provide a general index of health and social conditions, but cannot contribute significantly to policies and interventions associated with specific conditions.

Population-based surveys are, therefore, the best alternative for determining cause-specific estimates. Longitudinal designs not only greatly reduce the required sample size, but permit collection of incident events. Studies based on this design therefore represent the best option for providing vital statistics for Africa.

Six, longitudinal, community-based studies to determine vital statistics have been described by Tarimo (*18*), and each of them has been analysed in detail (*19–24*). These six studies, however, were primarily directed towards childhood mortality and infectious diseases, whose diagnosis is generally more straightforward than the larger number of potential causes of adult mortality. Furthermore, several are now quite old, with one (Pare–Taveta, in Kenya–United Republic of Tanzania) dating from the 1950s. Finally, despite the overall success of these large and carefully conducted studies, experience with adult mortality ascertainment has generally been disappointing. Some comments on these studies are presented below.

Apparently no attempt to assess adult mortality was made in the Pare–Taveta (Kenya–United Republic of Tanzania) project, with the focus instead being on malaria-associated mortality among chil-

dren (*19*). Although the Kilombero (Kenya) project did report an all-cause mortality rate among adults (15 years of age and older), the relatively small number surveyed (811 over 2 years) led to a rather wide 95% confidence interval around the estimated rate (0.7–2.3% per year), and the study design did not provide cause-specific data for adults and did not have sufficient power to do so (*20*). The Kenaba (Gambia) study followed only 700–900 individuals, recording 168 deaths among adults (15 years of age and older) between 1951 and 1975; cause-specific data and reliable all-cause rates were, therefore, only available for childhood deaths. (*21*).

The Malumfashi (Nigeria) study was similarly directed towards childhood infectious disease, and only 52 adult deaths (among those aged 15 years and older) were recorded in 2 years, despite a total enrolment of 43000 individuals. The investigators reported a general reluctance on the part of the participants to discuss death or moribund symptoms and considerable resentment towards completing lengthy questionnaires on deaths, particularly in view of the lack of medical services available (*22*). The investigators were therefore forced to estimate adult mortality from orphanhood and widowhood data (*25*).

The longitudinal study of childhood deaths in Machakos, Kenya, enrolled only participants under 5 years of age. Age-specific adult mortality rates were estimated based on household surveys during the 7 years of follow-up, but the investigators did not consider them to be valid (*23*). Of the 291 adult deaths recorded (involving those aged ≥15 years), however, 73 (25%) resulted from neoplasia or cardiovascular disorders (*26*). Finally, the Danfa Comprehensive Rural Health Project (Ghana), conducted from 1969 to 1979, focused on family planning and health behaviours. Examinations were completed on about 4000 individuals throughout the study period, along with annual census visits to each participating household, but death rates were apparently only determined for children (*24*).

Although there are other examples of longitudinal studies and surveillance systems at the community level in sub-Saharan Africa, the general situation is much the same as with the six studies highlighted in Feachem & Jamison's monograph. In virtually all cases, the emphasis is on infectious diseases and morbidity and mortality among children. This may originate from the belief that once African children reach adulthood they have overcome the period of greatest risk relative to industrialized nations. However, Phillips et al. have projected that the risk of dying between the ages of 15 years and 60 years is roughly two–four times greater in developing than in developed countries, and that adults account for ca. 21% of avoidable years of life lost in unindustrialized countries (*2*). These values are only rough estimates, since the research needed to form the foundation for such health planning has, on the whole, not been carried out. Also, it cannot be argued that interventions are only plausible and cost-effective in the case of childhood communicable diseases, since various studies have reported the tremendous economic and social impact of chronic conditions worldwide, as well as the potential for realistic interventions (*27*, *28*).

The special problem of noninfectious diseases

Because in sub-Saharan Africa there has been emphasis on communicable diseases in previous studies and interventions, information about chronic diseases is exceptionally limited (*11*). Nevertheless, it is likely that neoplastic and cardiovascular diseases account for a sizable portion of adult deaths in the region, particularly among those aged 45 years and older. The chronic condition for which the most information is available is hypertension, and there is general consensus that its prevalence is on the increase in Africa (*29*).

Although hypertension is probably the commonest cardiovascular condition in Africa (*30*), it continues to be referred to as an "emerging" problem that is "becoming" important, just as it has been for the last 30 years (*31*). Such cautious language is apparently used because of the lack of basic data on its prevalence, as well as the incompatibility of such findings with the accepted paradigm of Africa being challenged primarily by infectious diseases (*32*).

Basic information on other chronic diseases is even more limited. Review of the data on non-insulin-dependent diabetes mellitus (NIDDM) in sub-Saharan Africa suggests that its prevalence is less than 1% (*33*). While several reports cite NIDDM prevalences in Africa for purposes of making international comparisons, examination of the sources reveals that the levels for the continent as a whole are based on hospital surveys or on single population surveys in specific countries (*34*).

The situation for cancer is quite similar, with virtually all the extant data originating from hospital series. Most of the studies on cancer in sub-Saharan Africa over the last 15 years centre on Kaposi's sarcoma, cervical cancer, and other neoplasms associated with sexually transmitted viral infections, often involving high-risk groups, such as prostitutes (*35*). The use of clinical series and special high-risk groups to obtain statistics on cancer prevalence means that no reliable population-level estimates can be made.

Estimates of the level of trauma as a cause of death are also restricted to hospital-based reports (*36*). Although these studies show trauma, especially related to motor vehicle accidents, to be a leading cause of adult death in several countries, the incidences reported apply only to individuals who sought treatment at health facilities.

Obtaining cause of death data

Because a large proportion of the population of sub-Saharan Africa has no access to clinics or hospitals, longitudinal surveys must necessarily be relied upon as sources of data on adult mortality. This requires a method for determining cause of death in the absence of medical examination or hospital autopsy. One solution to this, first proposed by WHO in 1956, is the use of lay reporting (*37*). When lay reporting involves retrospective ascertainment of the symptoms preceding a death, it is termed verbal autopsy. The method has been used extensively for childhood deaths (*38*), but its use for adult deaths has mostly involved maternal mortality (*39*).

The use of verbal autopsies to collect reliable adult mortality data at the community level assumes that it is possible to classify deaths into useful categories based on the results of retrospective interviews. Although analysis of the sensitivity and specificity of verbal autopsy diagnoses has been carried out for childhood deaths (*40*) and for the evaluation of drug interventions among adults (*41*), it remains to be shown that the above assumption is true for longitudinal, population-based studies of adult cohorts. Studies are under way to investigate this, including a large community-based surveillance programme in Karachi, Pakistan (Marsh D, personal communication, 1994), together with a similar study by Asuzu et al. in urban Nigeria (*42*).

Chandramohan et al. have reviewed the use of verbal autopsies in 35 studies and discussed their potential for use in classification of causes of adult death (*43*). Eight of the studies reviewed attempted to apply verbal autopsies to adult deaths, while another six were devoted strictly to maternal mortality. Among the studies of adult mortality, 8–29 disease categories were used. While a small number of categories produces data of more limited usefulness, use of a large number has an obvious effect on reliability. The studies reviewed also differed with respect to questionnaire design, the respondent who provided information, the recall period, and the algorithms for designating medical diagnoses based on verbal autopsy results.

The verbal autopsy method, despite its potential promise, is associated with considerable difficulties, and assessment of its usefulness must await much further application in the field. Although validation of verbal autopsy findings against hospital diagnoses is essential, access to health care in the communities of interest may be so limited that this approach fails. An even more fundamental threat to the validity of the assessment of all-cause mortality lies in the potential under-ascertainment of events. Furthermore, mortality is a highly age-dependent process; since many older individuals may not know their date of birth, external comparisons that require age-adjustment may not be feasible.

Practical considerations

Once a potential methodology for ascertaining cause-specific adult mortality data from sub-Saharan Africa has been identified, the remaining task is to assess its feasibility. Three primary considerations apply. First, the derived estimates must have some degree of generalizability. Second, the technical requirements cannot be so demanding that large resources are needed. Third, since the essential data are responses to questions by members of a cohort, the community must cooperate with the survey procedures and be sufficiently stable to provide long-term follow-up.

With the need for generalizability, it is tempting to assume that populations with similar living conditions have similar mortality structures. If true, this would greatly reduce the number of studies needed to obtain mortality estimates, but ultimately continues the practice of "inventing" public health data. Alternatively, an attempt could be made to test the reproducibility of estimates in independent samples. Clearly, this is the only sensible solution. The larger the number of studies, and the more diverse the settings, the more accurate and reliable will be the emergent composite picture of underlying mortality patterns. It is not possible to state an ideal number of longitudinal studies in a given setting, although the basis for a consensus can only begin with more than two studies.

The technical requirements for mortality surveillance are limited in the field; however, to obtain meaningful results there needs to be an interface between epidemiological expertise, local health workers, and authority figures in the society concerned. While there are many examples of successful collaborations of this type, they may be hard to sustain in the long term. In addition to this fundamental need for multi-layered collaboration, use of sample size calculations can help to identify the minimum requirements for the resources necessary to conduct such studies.

Although it is an important element of a feasibility assessment, the specification of the sample size to obtain reliable and interpretable results is relatively straightforward. For the most basic estimation of overall mortality in a cohort of adults, the size needed (n) is a function of the estimated proportion of deaths, the alpha level (α) and the tolerated error (δ) as shown below:

$$n = \left(\left(z_{1-\alpha}\right)^2 (pq)\right) \Big/ \delta^2$$

where p = the proportion of deaths and $q = 1-p$.

For example, if it is assumed that adult mortality is roughly 2% per year in the community to be followed, α is set to the conventional value of 0.05 ($z = 1.96$), and δ is taken to be 0.01, the size of the cohort must be at least 753 for 1 year of follow-up. Because the proportion of deaths increases with time in a fixed cohort, the sample size increases with the number of years of follow-up, e.g. 1476 for 2 years, 2167 for 3 years, 2828 for 4 years, etc. However, this only addresses the overall mortality. Determination of cause-specific mortality requires use of the proportions for each of the specific mortality end-points attained through the verbal autopsy, which suggests a limit for the number of categories of cause of death that might be sought.

Finally, the verbal autopsy approach is essentially an attempt to enhance the self-awareness of a social group and must satisfy an immediate and identifiable need for members of that group. The organization and receptivity of the target community thus becomes a crucial, perhaps determining, factor. In areas where indigenous authority figures still maintain influence, their cooperation is clearly necessary, though not sufficient, for ensuring the success of verbal autopsies. Unless the participants are approached openly and honestly, however, any surveillance project runs the risk of being perceived as a foreign, perhaps even colonial, venture — a perception, needless to say, that is grounded on experience.

Just as "natural history" experiments are never ethical on patient cohorts, collecting person-years of follow-up in a cohort with the sole purpose of counting fatal events is neither morally justifiable nor practically achievable. In fact, communities are not likely to tolerate the imposition of passive surveillance. While the outcome is intended to provide valuable information for the society as a whole, a single isolated community will almost never see itself primarily as a natural experiment. Investigators who are blind to this reality will destroy the study's most valuable resource — the goodwill and support of the community. A balance must be struck therefore; some infusion of immediate assistance to the community must be forthcoming, despite the impact this may have on health conditions.

Conclusions

There can be little in the way of intelligent and productive health interventions in sub-Saharan Africa without an adequate basis in health statistics. For over 250 million adults in the region, the base of available knowledge is exceedingly thin, and for noncommunicable diseases is essentially nonexistent. Estimates for vital statistics, including causes of adult mortality, are published with the best of intentions, but do a disservice by creating the false impression that they have an empirical basis. It is time to recognize that official estimates are at best only approximate within a factor of ten.

With appropriate effort, it is clearly possible to collect reasonable estimates for the cause-specific rates of adult mortality in sub-Saharan Africa. Longitudinal studies of community cohorts are the most promising method for obtaining the desired data. Furthermore, verbal autopsies completed by local lay interviewers appear to be the most plausible way to obtain causes of death in areas characterized by limited access to medical personnel and facilities. Representative communities of at least 5000–10000 adults followed for 3–5 years are entirely appropriate for collecting data that could have broad public health value. Such studies must be considered a high priority, since they precede any consideration of how best to allocate health service resources within the region.

Acknowledgements

Supported in part by a grant from the National Institutes of Health (USA) (HL 45508). We thank Ms M.K.C. Jones and Ms N. Barkey for helpful comments on the manuscript.

Résumé

L'absence de données sur la mortalité adulte relatives à l'Afrique subsaharienne: solution pratique

Il n' existe pratiquement aucune information sur les causes de décès chez les adultes en Afrique subsaharienne. De nombreuses sources citent des statistiques portant sur les taux de mortalité à la fois généraux et par cause mais un examen plus attentif révèle que ces données sont en fait, pour la plupart, des extrapolations et de pures hypothèses. En l'ab-

sence de registres de l'état civil exacts et complets concernant la majorité des habitants de la région, les études longitudinales de cohortes définies basées sur la population représentent la seule stratégie réaliste capable de combler ce vide pour ce qui est de l'information fondamentale en matière de santé publique.

L'avantage des études longitudinales est particulièrement évident dans le cas des maladies chroniques, catégorie pour laquelle on en sait le moins. Les maladies infectieuses ont fait l'objet de plusieurs études précédentes et la plupart des mesures prises par les organismes internationaux visent à déterminer les niveaux de maladies transmissibles (notamment chez les enfants) et à mener des interventions propres à en réduire le fardeau. Par contre, bien que les maladies non transmissibles soient responsables d'une part importante des décès d'adultes en Afrique subsaharienne, les politiques et interventions en matière de santé publique manquent, pour l'essentiel, de fondements empiriques.

Le présent article étudie les points forts et les insuffisances des études précédentes sur la mortalité adulte en Afrique subsaharienne. Nombre de ces études étant axées sur les maladies transmissibles de l'enfance, l'application des techniques de surveillance permettant de déterminer la mortalité adulte en fonction des causes est limitée. On se penche actuellement sur l'utilité potentielle de la méthode de l'autopsie verbale comme moyen de s'assurer de la cause du décès chez les Africains adultes. La taille de l'échantillon et les autres conditions requises pour mener des études longitudinales à l'aide de cette méthodologie sont passées en revue.

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