ELSEVIER

Journal of Clinical Epidemiology 65 (2012) 309–316

Journal of Clinical Epidemiology

Validation study of cause of death statistics in Cape Town, South Africa, found poor agreement

Elsie H. Burger[a,*], Pam Groenewald[b], D. Bradshaw[b], Alison M. Ward[c], Patricia L. Yudkin[c], Jimmy Volmink[d,e]

[a]*Division of Forensic Medicine, Department of Pathology, Faculty of Health Sciences, Stellenbosch University, Cape Town, South Africa*
[b]*Burden of Disease Unit, Medical Research Council of South Africa, South Africa*
[c]*Department of Primary Health Care, University of Oxford, United Kingdom*
[d]*Faculty of Health Sciences, Stellenbosch University, Cape Town, South Africa*
[e]*South African Cochrane Centre, Medical Research Council, Tygerberg, South Africa*

Accepted 8 August 2011; Published online 9 December 2011

Abstract

Objective: The validity of the underlying cause of death on death notification forms was assessed by comparing it to the underlying cause determined independently from medical records.

Study Design and Setting: Retrospective study of 703 deaths in two suburbs of Cape Town, South Africa. Two medical doctors completed a medical review death certificate to validate the registration death certificate for each decedent. Agreement, sensitivity, and positive predictive value were measured for underlying causes of death using the World Health Organization (WHO) mortality tabulation list 1.

Results: Agreement was poor, with only 55.3% (95% confidence interval [CI]: 51.7, 59.0) of diagnoses matching at WHO mortality tabulation list 1 level. Validity of reported causes of death was poor for HIV, cardiovascular diseases, and diabetes. With correct reporting, the cause-specific mortality fraction for HIV increased from 11.9% to 18.3% (53.6%; 95% CI: 36.9, 77.6), for ischemic heart disease from 3.3% to 7.3% (121.7%; 95% CI: 53.5, 228.7), and for hypertensive diseases from 3.3% to 5.7% (73.9%; 95% CI: 14.4, 167.8). For diabetes, the mortality fraction decreased from 6.0% to 2.3% (−64.3%; 95% CI: −77.1, −37.8) and for ill-defined deaths from 7.4% to 2.3% (−69.2%; 95% CI: −81.0, −51.6).

Conclusion: Current cause-specific mortality levels should be cautiously interpreted. Death certification training is required to improve the validity of mortality data.

Keywords: Death certificates; Epidemiology; South Africa; Vital statistics; Validation study; Cause of death; Death notification

1. Introduction

Medical certification of the cause of death (COD) is a critical link in the chain of vital statistics, connecting the clinical situation to public health information. The South African death notification form (DNF) follows the World Health Organization (WHO) criteria for medical certification: the causes of death are listed sequentially from immediate COD through intermediate causes, with the underlying COD being recorded in the lowest line of Part I of the medical certificate of COD [1,2].

According to the Births and Deaths Registration Act 51 of 1992, all deaths in South Africa have to be registered [3]. Usually the DNF is completed by the attending medical professional in hospital or by the family physician of the deceased. If a person dies at home without any medical attendance, but is known to a medical professional, the doctor may complete the form, or the case may be referred to the Forensic Pathology Service, where a forensic practitioner will complete the DNF after a postmortem examination. In either case, a history of previous and current diseases needs to be collected from the relatives of the deceased.

A recent study in Cape Town showed that doctors do not follow the rules for completing this form, and critical demographic information is often omitted [4,5]. Furthermore, a comparative analysis by the WHO has rated South Africa in the group of countries with poor quality death registration data because a high proportion of deaths are reported with ill-defined conditions as the COD [6]. Another problem that has emerged is the concern of doctors about the lack of confidentiality in the way the form is handled [7,8]. Doctors are often loath to enter ‘‘sensitive conditions’’ such as

* Corresponding author. Tel.: +27-21-931-8043; fax: +27-21-933-3367.
E-mail address: ehb@sun.ac.za (E.H. Burger).

0895-4356/$ - see front matter
doi: 10.1016/j.jclinepi.2011.08.007

What is new?

- Comparison of underlying cause of death (COD) entered in death notification forms and mock certificates based on medical notes, showed poor agreement.
- Especially HIV, ischemic heart disease, and hypertension were underreported, whereas diabetes was overreported as underlying COD.
- With proper completion of death notification forms, ill-defined causes of death can be decreased.
- Caution is required when current cause-specific mortality rates and trends are interpreted.
- Training of doctors in proper completion of death notification forms is essential.

HIV/AIDS on the form, for fear of recrimination or through reluctance to distress the relatives of the deceased. This has resulted in considerable underreporting of HIV as a COD [9–11].

Relative to other areas in the country the proportion of ill-defined causes of death is low in the Cape Town mortality data (6%) [12]. However, there have been no studies in Cape Town examining the validity of the COD reported on death certificates. The Provincial Government of the Western Cape has made a commitment to actively seek information needed to address and reduce the burden of disease in the province [13]. Because the official COD data processed by Department of Home affairs and Statistics South Africa is only available at national and provincial level, the City of Cape Town health department developed a local mortality surveillance system to provide COD statistics at district level, which has subsequently been rolled out to the rest of the Western Cape province [14]. We set out to assess the validity of the underlying COD determined from the diseases stated on the DNF, by comparing it to the underlying cause determined independently through medical records. This article focuses largely on the natural causes of death because many forensic pathologists in South Africa prefer not to indicate the manner of death for injuries on the DNF, resulting in relatively high proportions of undetermined external causes.

2. Methods

We obtained copies of the DNFs of all residents of the Cape Town suburbs of Bonteheuwel and Langa, who died during the period June 1, 2003 to May 31, 2004. These communities are situated adjacent to each other, around 15 km from the city center, and were chosen for their convenient location and good links with our research team [4,5]. The populations of the suburbs still reflect their old *apartheid* classifications: Bonteheuwel a ''colored'' area, and Langa an ''African'' area. Based on information gathered during the 2001 census [15], the population sizes of Bonteheuwel and Langa are approximately 55,707 and 49,667, respectively. These copies of the DNFs were held by the City Health Department, and permission for their use was obtained from provincial and city health officials. For each case, we captured the causes of death from the medical certificate on the registration DNF and tried to locate the patient's medical folder to obtain clinical and/or autopsy information. We visited the larger hospitals serving Bonteheuwel and Langa first, with subsequent visits to smaller hospitals, clinics, and Forensic Pathology Services divisions. The medical folders were reviewed by trained research nurses, and a standardized data capture form was completed for each case. Information gathered included demographic details and the medical history and information on the COD from the medical records.

Using the completed data capture form (but blinded to the registration DNF information), two medical doctors working in pediatric practice and two doctors working in general medicine completed medical review DNFs for each case. These doctors were trained in correct death certification before starting the task. The training included the need to focus on pathophysiological mechanisms and temporal profiles, thus assuring that the COD sequence is correct and logical. Arbitrarily, all cases of children younger than 14 years were assigned to the pediatric doctors, whereas the rest were assigned to the doctors in general practice. In each case, the two doctors completed the medical review DNFs separately, and afterward compared their findings. If they disagreed about the underlying COD, the case was referred to one of the authors (E.H.B.) for arbitration. Serological confirmation of HIV or a stage IV diagnosis was required to diagnose HIV infection [16]. Because the certification of deaths because of diabetes mellitus (DM) is a contentious issue, the pathogenesis of cardiovascular disease and DM was discussed with the doctors, and the following broad guidelines were given. In cases where a person died because of a cardiovascular disease, but DM was also present, DM should be assigned to Part 2, as a contributing cause/risk factor. DM would be considered to be the underlying COD, where the terminal cause was sepsis, hyper-, or hypoglycemia. These guidelines were given in accordance with general medical opinion that coronary atherosclerosis is not *caused* by diabetes, but may be accelerated by that disease [17–19].

The causes of death as completed in the registration DNF and in the medical review DNF were coded to International Classification of Diseases 10th revision (ICD-10) [2] using the Mortality Medical Data System (MMDS) software [20], although manual coding was necessary in some cases where the terms describing the COD were not recognized by the software, and for injuries and perinatal conditions. Euphemisms for HIV/AIDS such as ''retroviral