

Making COD statistics useful for public health at local level in the city of Cape Town

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Objective To review the quality of the coding of the cause of death (COD) statistics and assess the mortality information needs of the City of Cape Town.

Methods Using an action research approach, a study was set up to investigate the quality of COD information, the accuracy of COD coding and consistency of coding practices in the larger health subdistricts. Mortality information needs and the best way of presenting the statistics to assist health managers were explored.

Findings Useful information was contained in 75% of death certificates, but nearly 60% had only a single cause certified; 55% of forms were coded accurately. Disagreement was mainly because routine coders coded the immediate instead of the underlying COD. An abridged classification of COD, based on causes of public health importance, prevalent causes and selected combinations of diseases was implemented with training on underlying cause. Analysis of the 2001 data identified the leading causes of death and premature mortality and illustrated striking differences in the disease burden and profile between health subdistricts.

Conclusion Action research is particularly useful for improving information systems and revealed the need to standardize the coding practice to identify underlying cause. The specificity of the full ICD classification is beyond the level of detail on the death certificates currently available. An abridged classification for coding provides a practical tool appropriate for local level public health surveillance. Attention to the presentation of COD statistics is important to enable the data to inform decision-makers.

Keywords Mortality/statistics; Data collection/methods; Death certificates; Cause of death; South Africa (source: MeSH, NLM).

Mots clés Mortalité/statistique; Collecte données/méthodes; Certificat décès; Cause décès; Afrique du Sud (source: MeSH, INSERM).

Palabras clave Mortalidad/estadística; Recolección de datos/métodos; Certificado de defunción; Causa de muerte; Sudáfrica (fuente: DeCS, BIREME).

الكلمات المفتاحية: الوفيات، إحصائيات الوفيات، تجميع المعطيات، طرق تجميع المعطيات، شهادة الوفاة، أسباب الوفاة، جنوب أفريقيا. (المصدر: رؤوس الموضوعات الطبية، المكتب الإقليمي لشرق المتوسط)

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يمكن الاطلاع على الملخص بالعربية في صفحة 216.

Introduction

Paccaud recently identified the general lack of interest in routine health information systems and highlighted the under-researched and underfunded nature of cause of death (COD) statistics in particular.¹ In a review of the quality of national COD statistics, Mathers et al. identified the need for improvement in a high proportion of countries that submit data to WHO as well as the high number of countries in sub-Saharan Africa that do not submit any data.² There is growing recognition, however, of the importance of health information systems and the integral role of mortality statistics needed for monitoring public health,

allocating resources and developing public health policy.³ Reporting on the outcome of a workshop held in Africa, Rao et al. highlight the need for countries in sub-Saharan Africa to review their vital registration systems and develop a plan to improve COD statistics.⁴

South Africa, a middle-income country, has a well-established national vital registration system administered by the Department of Home Affairs. The national statistical office, Statistics South Africa, is responsible for compiling the death statistics, after coding the COD information certified by medical practitioners on the death notification form. In common with most developing countries, the COD statistics in South

Africa suffer from under-registration of deaths and misclassification of causes.^{5,6} Changes to the death notification form to elicit the underlying COD as proposed in the *International statistical classification of diseases and related health problems*, tenth revision (ICD-10) were introduced in 1998 as part of a broader strategy to improve vital registration.⁷⁻⁹ An element of success resulted, with the coverage of adult death registration improving to over 90%.¹⁰ The adoption of ICD-10 as a coding standard resulted in the 1996 COD statistics being processed with bridge coding of ICD-9 and ICD-10.¹¹ The application of the software Automated Classification of Medical Entities (ACME 2004.2) to identify the

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underlying COD facilitated the production of a report on the causes of death for 1997–2003.^{12,13} Despite these improvements the national statistical system fails to provide timely statistics that can be utilized at district level.

In contrast to the rest of the country, Cape Town has a well-established system of routinely compiling death statistics.¹⁴ Based on the same source documents as are used in the national system, the underlying COD information is coded, captured and processed by the local municipalities. The City of Cape Town is now a single municipality with 11 health subdistricts but previously comprised six municipalities (one of which was also called the City of Cape Town). During the period of transition in local government, the health information was coordinated by a Metropolitan Health Information Group but data collection took place in the six separate municipalities. In 1999, this group identified the need to review the collection of death statistics and establish whether there was a need to change from ICD-9 to ICD-10 coding, which had been adopted as a national standard. They approached the researchers to investigate the quality of their coding and advise them. An action research approach was adopted, as it was considered that the participatory character would facilitate implementation of the findings.¹⁵ Here we describe the investigation, an abridged classification that was developed and the initial statistics compiled after the introduction of the abridged list.

Methods

A rapid appraisal of the quality of coding was undertaken. The key role players in running the system from the then two major municipalities, the City of Tygerberg (JD) and the City of Cape Town (HM), were joined by researchers to set up the study team. The team reported regularly to the Metropolitan Health Information Group and on occasion to the health management team.

In the first phase of the rapid appraisal, a sample of death forms was selected systematically from the forms processed at the end of 1999 in each office. The sample size of 50 forms from each health subdistrict was pragmatic and was expected to yield 550 forms out of the approximately 20 000 deaths per year. The quality of the COD information was subjectively assessed by one of the research team (JN) who has clinical

Table 1. Level of agreement according to cause of death (ICD-9 Basic Tabulation List)

Cause of death (ICD-9 Basic Tabulation List)	Agreement (%)	Total number of cases
Intestinal infectious diseases	17	6
Tuberculosis	73	26
Other bacterial diseases	50	4
Other infectious and parasitic diseases	59	32
Malignant neoplasm of lip, oral and pharynx	100	1
Malignant neoplasm of digestive organs	90	20
Malignant neoplasm of respiratory organs	87	23
Malignant neoplasm of bone, skin, and breast	60	5
Malignant neoplasm of genitourinary organs	58	12
Malignant neoplasm of other, unspecified site	16	12
Malignant neoplasm of lymphatic and haemopoetic systems	100	2
Carcinoma in situ	100	1
Other and unspecified neoplasm	100	2
Endocrine and metabolic diseases	18	17
Nutritional deficiencies	100	1
Diseases of blood and blood forming organs	0	1
Diseases of nervous system	63	8
Hypertensive diseases	13	24
Ischaemic heart disease	76	33
Diseases of pulmonary circulation	85	13
Cerebrovascular disease	84	25
Other diseases of circulatory system	42	7
Other diseases of respiratory system	76	42
Diseases of other parts of the digestive system	46	11
Diseases of urinary system	81	25
Direct obstetric causes	100	1
Diseases of musculoskeletal system	0	1
Congenital anomalies	40	5
Certain conditions in perinatal period	67	15
Signs and symptoms and ill-defined conditions	68	38
Transport accidents	92	26
Misadventure during medical care	20	5
Accidental fall	16	6
Accidents caused by fire and flames	100	7
Other accidents, including late effects	25	12
Suicide and self-inflicted injury	100	5
Homicide and injury inflicted by other	98	53
Other violence	50	8
Overall	67	523

training and nosological experience. The quality of the information was scored on a scale as follows:

- **adequate:** where there is at least one clearly stated diagnosis, or more than one diagnosis with an immediate and underlying COD;
- **incomplete:** where a vague diagnosis with no underlying cause is listed;
- **poor:** with no proper diagnosis, e.g. “natural cause” or “unnatural cause”.

In addition, the frequency and pattern of multiple causes of death were described to identify the extent to which the cod-

ers would need to apply rules to identify underlying causes and also identify common comorbidity.

The agreement between the experienced coder (JN) and the routine coder on these forms was assessed at single cause level, as well as the ICD-9 Basic Tabulation List (BTL) level of 56 aggregate causes that is used by the municipalities to report statistics. Because the forms had personal identifiers they were treated as strictly confidential and kept in envelopes, which were locked away when not in use.

In a parallel process to the rapid ap-

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praisal, retrospective data collected over the two-year period (July 1997–June 1999) in the two major municipalities, Tygerberg and Cape Town, were analysed to investigate the coding practices used and the trend in the ill-defined category. The remaining municipalities were omitted for expediency as they worked very closely with the Tygerberg team and were considered to have a very similar coding practice.

In the final process of the rapid appraisal, routine mortality reports produced for health managers were examined and discussions were held with the health managers to determine what information was required by health managers to assist with health services planning and management and how it could best be presented.

Findings

Quality of COD information

In total, 536 death forms were sampled for assessment. There were between 38 and 51 forms from each of the 11 health subdistricts. It was found that 75% (95% confidence interval (CI) = 71–79) of the forms had adequate information while 13% (95% CI = 10–16) had incomplete information and 11% (95% CI = 8–14) had poor information.

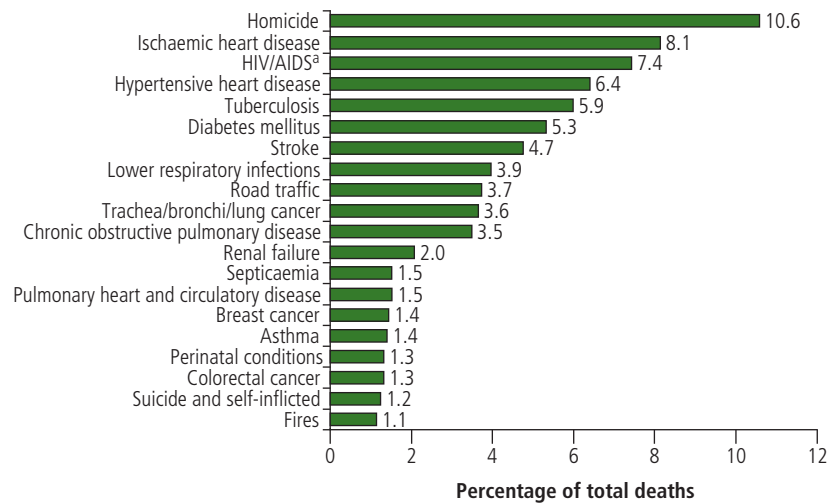
Multiple causes

Fifty-nine percent of the cases had only a single COD written on the form, while 26% had two causes including common combinations such as stroke with hypertension and tuberculosis (TB) with human immunodeficiency virus (HIV). Only 2% had four causes on the certificate. This finding suggests that there is much scope for improving the quality of medical certification so as to provide sufficient details to allow for accurate identification of the underlying cause.

Agreement of coding

The agreement between the underlying COD identified by the researcher and that coded by the municipality could not be assessed for 13 cases where the sample forms could not be matched with the routine data from the same period. Out of the remaining 523 cases, 55% (95% CI = 51–59) of the codes agreed exactly at the three-digit level of ICD-9. When assessed at the level of BTL group, 67% (95% CI = 63–71) of the cases agreed. The extent of agreement differed accord-

Fig. 1. Leading causes of death, Cape Town, 2001 (*n* = 23 185)



^aHIV/AIDS = human immunodeficiency virus/acquired immune deficiency syndrome.

WHO 06.19

ing to the COD: Table 1 shows the level of agreement in each BTL group.

The reason for disagreement tended not to be a result of coding errors but rather that the municipality coders had coded the immediate cause instead of the underlying cause. When discussed with the coders it was found that, with the exception of identifying lung cancer or HIV/acquired immune deficiency syndrome (AIDS) as underlying causes in the municipality of Cape Town, the standard practice was to code the immediate cause.

Analysis of retrospective data revealed similar proportions for the two major municipalities at the single ICD-9 cause level. However, there were noticeably different coding practices for the less well-defined conditions such as “injuries with unknown intent”.

Reporting and utilization of the statistics

The data collected by each municipality are presented in several formats and are made available to several key meetings and processes for planning. Key indicators, such as the infant, under-5-year-old and crude mortality rates as well as the top 10 causes of death for children and adults, are collated on a routine basis and reported from time to time to the health management committee. The information was used by management in situation analysis assessments but has not been used in a specific quantitative way to monitor the impact of programmes.

Historically, the health sections of

municipalities produced annual reports that were distributed widely and made available to the general public, and these included a description of mortality patterns. South African municipalities have gone through a period of intense restructuring over the last 10 years and these reports were produced in a limited way, thus reducing public access to mortality information. It was also observed that there is much scope to enhance the presentation of the statistics to highlight the conditions that result in premature mortality or to highlight inequalities in health.

Development and implementation of an abridged classification for coding

Examination of the applications of the death data revealed that the list of COD allowed by ICD-9 or ICD-10 is beyond the specificity of information recorded on many of the forms processed and more than what is required for general public health surveillance. In light of this, and using ICD-10 as a basis, the team developed an abridged classification or shortlist for coding COD statistics at local level (Table 2, web version only, <http://www.who.int/bulletin>). The most prevalent causes of death in Cape Town, e.g. ischaemic heart disease and TB, as well as causes of concern to the health authority, e.g. malaria, were used as criteria for inclusion. Other causes were grouped into appropriate categories to ensure that a sufficiently detailed profile of the causes of death would

still be possible and compatible with the burden of disease categories used in the South African national burden of disease study.¹⁶ The list includes selected combinations of diseases, such as HIV/AIDS and TB, which are difficult to attribute to a single underlying cause. The inclusion of selected combinations of comorbidity was to assist the coders so that they would not have to select a single cause. While simplifying the task of coding, this would enable a more detailed analysis of such data, which is becoming increasingly important.

All the clerks involved in coding COD attended a training workshop organized by the team and were trained in the ICD concept of underlying COD. The abridged classification was introduced with access to the full ICD list as back-up. A support system was established, with local health professionals becoming resource persons for difficult cases. The list was modified on the basis of their inputs during the workshop, drawing on their extensive experience. The workshop was also used to reiterate the procedures for confidential handling of the forms and the data.

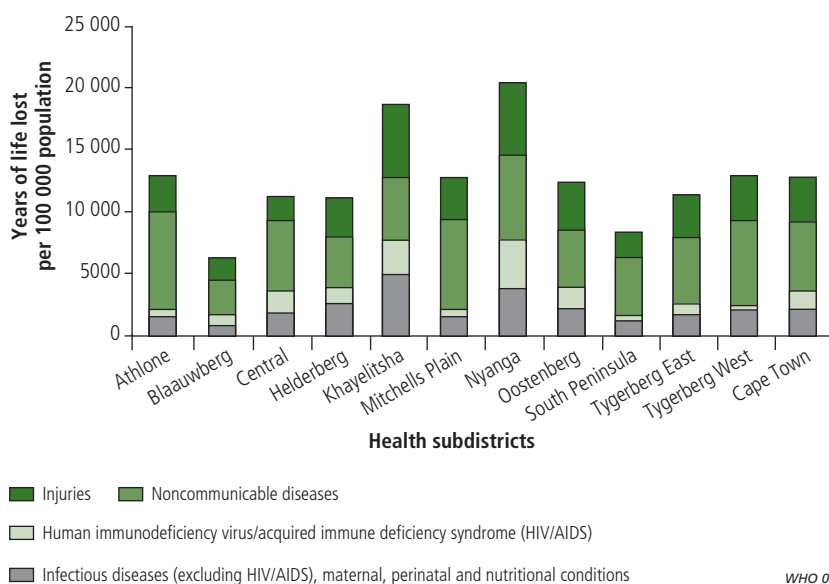
The abridged classification was implemented in all municipalities for the deaths from July 2000. Access to a medically qualified person to advise on more complicated causes of deaths was lacking in some municipalities, and this gap was resolved by providing all the coders with access to a medically trained resource person. After a period of six weeks of implementation of the new code list, the coders reported no problems.

Presentation of statistics to inform public health

The data for calendar year 2001 were examined and analysed.¹⁷ After basic cleaning of the data to remove duplicate records, 23 185 records were available for analysis. Some evidence of underregistration of deaths was observed when compared with the number obtained from a demographic projection. However, the coverage for all ages was well over 90%.¹⁷ Eight per cent of the deaths were attributable to ill-defined causes (code 2799). Although relatively high, the proportion is lower than the 13% for the country as a whole.¹⁸

There were 619 deaths attributed to both HIV/AIDS and TB (code 1020), 1088 deaths attributed to HIV/AIDS excluding TB (codes 1021–1024) and

Fig. 2. Age-standardized premature mortality rates by cause group for metropolitan Cape Town and subdistricts, 2001



WHO 06.20

752 deaths attributed to TB (codes 1011–1019). In accordance with ICD rules, HIV has been identified as the underlying cause for those deaths that are attributed to both diseases. These statistics were presented separately to allow the TB managers to access this information.

After an initial presentation of the 2001 data to health managers, it was decided to adopt one of the approaches in a burden of disease study and redistribute the ill-defined causes to specific causes on a pro rata basis by age and sex for the 2001 data set.¹⁹ This facilitates a clearer picture of the main causes of death in the city that can be used to inform evaluation and planning, and clearly demonstrates that homicide was the most common COD in Cape Town, followed by ischaemic heart disease, HIV/AIDS, hypertensive heart disease and TB (Fig. 1.). The leading causes reflect the quadruple burden that has been observed in South Africa with the traditional double burden of infections and chronic diseases experienced in many developing countries, accompanied by the additional injury burden and that of HIV/AIDS.

Together with the health managers, it was also decided that a measure of premature mortality would be useful to rank the causes of death from a prevention perspective. The years of life lost against an ideal life expectancy were calculated using the approach used by WHO in the global burden of disease study.¹⁹ It was

also decided to age standardize the rates to allow for the differences in age structure of the subdistricts and for comparative purposes the WHO standard was selected.²⁰ A comparison of the age-standardized premature mortality rates across the 11 subdistricts in Cape Town revealed striking differences in the premature mortality rates as well as the COD profile (Fig. 2). Injuries, causes related to poverty and HIV/AIDS feature prominently in the districts with large informal settlements. In contrast, noncommunicable diseases account for the majority of diseases in the more affluent subdistricts.

A full report of the data was distributed to the health managers and public health practitioners.¹⁷ Profiles for each district were compiled,²¹ as well as an analysis of inequalities in health.²² On the basis of feedback, a summary report was compiled to give an overview of the COD in Cape Town and our interpretation of the statistics.²³ This was circulated widely. The findings were presented to several management forums, including the health portfolio committee of the elected metropolitan council.

Conclusion

A standard classification of diseases and injury is essential for the systematic collection and study of causes of death — a fact recognized as early as the 17th century.²⁴ The rapid appraisal of the coding practice of a well-established system has led to the development of an

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abridged classification based on ICD-10 and compatible with the South African national burden of disease list. The list, to be used for coding, was considered easier to apply than the full ICD-10 list and better matched to the quality of the certification. By creating codes for selected comorbidities that occur frequently, the task of coding has been simplified and is easier to standardize, yet allows for the analysis of common multiple conditions. Analysis of the data based on the abridged list demonstrates that it is feasible to implement, and attention to the presentation of the statistics has enhanced access to the information by health planners and other stakeholders.

The abridged list has provided a practical tool for use at district level as demonstrated by its implementation in the adjacent health region. Within a year, the semi-rural health region of Boland Overberg has, with limited additional resources, set up a system and — for the first time ever — obtained a COD profile for the health districts in the region.²⁵ This has generated interest from the province to extend the system

to all six health districts. While the classification was designed for use in a particular setting, the national public health surveillance requirements were kept in mind. Nonetheless, the list may require further adaptation as it is adopted in additional settings.

The quality of the COD statistics depends largely on the details provided by the medical practitioners. The need to improve this information is a major challenge that has also been identified by Bah at a national level.²⁶ The problem is ubiquitous, even in well-resourced settings.^{27,28} It is possible that, as data are seen to be used to inform policy, doctors might provide more details on the death certificate. However, there is a need for a more proactive strategy to train doctors about the public health importance of such data and how to certify accurately the COD. As has been pointed out previously, it is important that the timing of the training curriculum is appropriate and that use is made of the programme of continued professional education.^{29,30} Efforts to develop resource materials to support such training are likely to have

a wide impact.

This initiative has demonstrated that the action research model is an extremely successful approach to assess a routine health information system and has enabled effective implementation of the recommendations of the research. Such an abridged classification is designed for public health surveillance and may not meet the needs of all research. Until such time as the quality of certification improves, the abridged list could provide a practical tool that is appropriate for local level surveillance and can be used in other settings that have the necessary foundation but limited resources. ■

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Competing interests: none declared.

Résumé

Rendre les statistiques relatives aux causes de décès exploitables à des fins de santé publique à l'échelle d'une ville, le Cap en Afrique du Sud

Objectif Étudier la qualité du codage des statistiques relatives aux causes de décès et évaluer les besoins en matière de données de mortalité de la ville du Cap.

Méthodes Une étude a été organisée selon une démarche de recherche pragmatique pour évaluer la qualité des données relatives aux causes de décès, l'exactitude de leur codage et la cohérence des procédures de codage dans les sous-districts sanitaires les plus étendus. Les besoins en matière de données de mortalité, ainsi que la meilleure manière de présenter ces statistiques pour aider les gestionnaires dans le domaine sanitaire, ont été examinés.

Résultats 75 % des certificats de décès contenaient des informations utiles, mais seulement 60 % environ de ces certificats indiquaient une cause de décès unique et certifiée et 55 % des formulaires étaient codés avec exactitude. Les problèmes résultaient principalement du fait que les personnes chargées du codage de mortalité de routine enregistraient sous forme codée la cause immédiate du décès au lieu de la cause sous-jacente. Une classification sommaire des causes de décès, reposant sur

l'importance de ces causes sous l'angle de la santé publique, sur leur prévalence et sur une sélection de pathologies associées, a été introduite, en parallèle avec une formation à l'identification des causes sous-jacentes. L'analyse des données pour l'année 2001 a permis de déterminer les causes principales de décès et de mortalité prématurée et a fait ressortir des différences frappantes entre les charges et les profils de morbidité des différents districts sanitaires.

Conclusion La recherche pragmatique se révèle particulièrement utile pour améliorer les systèmes d'information et met en lumière la nécessité de normaliser les procédures de codage désignant la cause sous-jacente. Les certificats de décès actuellement disponibles ne permettent pas d'atteindre le niveau de détail requis par la classification CIM intégrale. L'utilisation d'une classification sommaire pour le codage offre un outil pratique et adapté à la surveillance en santé publique au niveau local. Il importe de veiller à ce que la présentation des statistiques relatives aux causes de décès permette aux décideurs d'utiliser ces données.

Resumen

Estadísticas sobre las causas de defunción: utilidad para la salud pública a nivel local en Ciudad del Cabo

Objetivo Examinar la calidad de la codificación de las estadísticas sobre las causas de defunción (CDD) y evaluar las necesidades de información sobre la mortalidad en Ciudad del Cabo.

Métodos Utilizando un enfoque de investigación-acción, se puso en marcha un estudio para investigar la calidad de la información sobre las CDD, la exactitud de la codificación de las CDD y la coherencia de las prácticas de codificación en los subdistritos de salud de mayor tamaño. Se estudiaron las necesidades de información sobre la mortalidad y la mejor manera de presentar las estadísticas para ayudar a los administradores sanitarios.

Resultados Un 75% de los certificados de defunción contenían información útil, pero en casi un 60% de los casos sólo se certificaba una sola causa; el 55% de los formularios se habían codificado con precisión. Las discordancias se debían principalmente a que los codificadores codificaban la causa inmediata, no la subyacente. Se aplicó una clasificación abreviada de CDD, basada en causas relevantes para la salud pública, causas prevalentes y determinadas

combinaciones de enfermedades, con capacitación para determinar la causa subyacente. El análisis de los datos de 2001 permitió identificar las causas principales de muerte y mortalidad prematura y puso de relieve diferencias sorprendentes en la carga y la distribución de la morbilidad entre los subdistritos de salud.

Conclusión La investigación-acción, una alternativa particularmente valiosa para mejorar los sistemas de información, reveló la necesidad de normalizar las prácticas de codificación seguidas para identificar las causas subyacentes. La especificidad del conjunto de la clasificación CIE supera el nivel de detalle de los certificados de defunción actualmente disponibles. Una clasificación abreviada de la codificación brinda un instrumento práctico adecuado para vigilar la salud pública a nivel local. Es importante prestar atención a la presentación de las estadísticas sobre las CDD si se desea que las autoridades basen sus decisiones en datos sólidos.

ملخص

الإفادة من إحصائيات أسباب الوفيات في الصحة العمومية

وجهة نظر الصحة العمومية، والأسباب الواسعة الانتشار وبعض الأمراض المنتشرة التي قد تصحبها مع التدريب حول الأسباب الدفينة. وأوضح تحليل المعطيات الخاصة بعام 2001 الأسباب الرئيسية للوفيات والموت الباكر، والفروق الواضحة في المرسمات وفي أعباء المرض في مختلف التقسيمات الإدارية الصحية. **الاستنتاج:** إن البحوث العملية ذات فائدة خاصة في تحسين نظم المعلومات، وهي توضح الحاجة لوضع معايير موحدة لممارسات الترميز والتعرف على الأسباب الدفينة للموت. إن نوعية التصنيف الدولي للأمراض المتكامل تتجاوز مستوى التفاصيل المتاحة حالياً في شهادات الوفيات. إلا أن تصنيف الترميز يتيح أداة عملية ملائمة للترصد في الصحة العمومية على الصعيد المحلي. إن إيلاء الاهتمام إلى عرض إحصائيات أسباب الوفيات ذو أهمية كبيرة في إيصال المعطيات إلى أصحاب القرار السياسي.

الهدف: استعراض جودة ترميز إحصائيات أسباب الوفيات وتقييم الاحتياجات من المعلومات على الصعيد المحلي في مدينة كيب تاون **الطريقة:** أجريت دراسة لتقصي جودة المعلومات حول أسباب الوفيات ودقة ترميزها ومماشاة الممارسات المتبعة في الترميز للتقسيمات الإدارية الصحية الكبيرة، مع استقصاء الاحتياجات من المعلومات حول معدل الوفيات وأفضل الطرق لعرض المعطيات التماساً لمساعدة المديرين.

الموجودات: كانت المعلومات المفيدة متضمنة في 75% من شهادات الوفيات، إلا أن 60% منها تتضمن سبباً واحداً فقط، و 55% منها تتضمن رموزاً صحيحة. وكانت مواطن الاختلافات الرئيسية ناجمة عن إثبات المختصين بالترميز السبب الفوري للموت بدلاً من السبب الدفين. وقد تم تدريب المختصين بالترميز على تصنيف أسباب الوفيات بالاستناد إلى الأسباب الهامة من

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