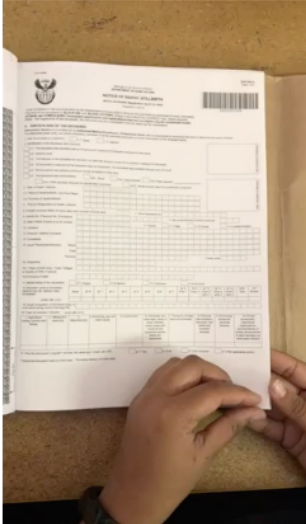


Improving Cause of Death Reporting

Module 1

Welcome to Module 1 of Improving Cause of Death Reporting.

Competencies at end of this module



- Importance of correct cause of death certification for:
 - accurate mortality statistics
 - public health policy
 - planning and allocation of resources
- Current quality of cause of death information
- Role of medical doctors
- Legal, ethical and confidentiality issues

In this first module we will discuss the importance of the correct certification of cause of death and the role of medical doctors in producing reliable causes of death statistics.

At the end of this module you should be able to demonstrate the competencies to:

- Explain the importance of correct cause of death certification for accurate mortality statistics and public health policy and the planning and allocation of resources,
- Discuss the current quality of cause of death certification in the country,
- Explain the role of medical doctors, as part of the official mortality system, for improving the quality of cause of death certification, and
- Discuss the legal, ethical and confidentiality issues related to cause of death certification.

Importance of cause of death data

This is the first page of the death certificate form, titled 'NOTICE OF DEATH / STILLBIRTH'. It includes the national emblem and the text 'REPUBLIC OF SOUTH AFRICA DEPARTMENT OF HEALTH SERVICES'. The form contains sections for 'PARTICULARS OF THE DECEASED', 'CERTIFICATE BY MEDICAL PRACTITIONER / PATHOLOGICAL CASE', and 'PARTICULARS OF FUNERAL UNDERTAKER'. It features various checkboxes, text boxes for names and addresses, and a large grid for recording the date and time of death.

This is the second page of the death certificate form, titled 'NOTICE OF DEATH / STILLBIRTH'. It continues the 'PARTICULARS OF FUNERAL UNDERTAKER' section and includes a section for 'CERTIFICATE BY MEDICAL PRACTITIONER / PATHOLOGICAL CASE'. It contains detailed checkboxes for medical conditions and a grid for recording the date and time of death.

This is the third page of the death certificate form, titled 'NOTICE OF DEATH / STILLBIRTH'. It includes the 'PARTICULARS OF FUNERAL UNDERTAKER' section and a section for 'PARTICULARS OF DECEASED'. It contains checkboxes for funeral arrangements and a grid for recording the date and time of death.

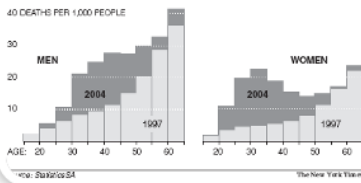
What the medical doctor writes as the cause of death on the death certificate, is as important to public health as what a doctor writes in a patient's medical records, is to patient care.

Importance of cause of death data



A Bulging Mortality Rate

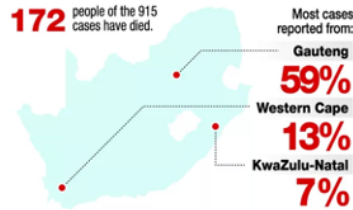
Death rates for adult South Africans rose sharply from 1997 to 2004, a trend that suggests that AIDS and H.I.V.-related diseases are claiming a growing share of men and women, especially those in their prime years.



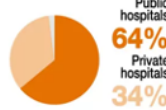
LISTERIOSIS OUTBREAK

915 laboratory-confirmed listeriosis cases have been reported to NICD from all provinces since 01 January 2017.

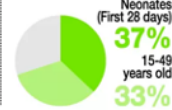
172 people of the 915 cases have died.



Healthcare sectors:



Age groups affected:



Symptoms may include: fever, muscle pain, restlessness, and sometimes vomiting or diarrhoea.

Graphic: Rowan Abrahams/African News Agency(ANA)

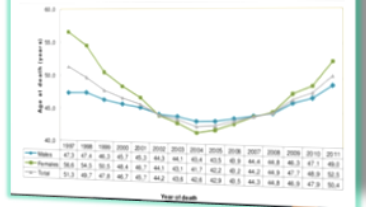
How Big Polony's lethal listeria outbreak was stopped



Mbeki is wrong about death statistics

14 March 2016. By Nathan Colloff

AIDS has for many years been by far the largest cause of death



Causes of death are analysed to detect trends. The data is used to determine public health and social policy, and for the planning and the allocation of resources for health and social care programmes.

Mortality data uses

STATISTICAL RELEASE
P0309.3

**Mortality and causes of death in South Africa:
Findings from death notification**

2017

Embargoed until:
26 March 2020
11:00

ENQUIRES:	FORTHCOMING ISSUE:	EXPECTED RELEASE DATE:
User information services	2018	October 2020

012 319 2600

Mortality and causes of death in South Africa, 2017: Findings from death notification

Articles

Mortality trends and differentials in South Africa from 1997 to 2012: second National Burden of Disease Study

Yvonne Pleyer and Rik Willem Steyn, Debra Luchner, Ashi D. Chingola, Peter Giesecke, Tracy Gibbs, Andrea Agrippa, Ines D'Amico, Alison Hutchinson, Sagar Chandra, Malini Srinivas, Anandharajasekaran, Thiruv, Nandha Kumar Sankaranarayanan, Prasad Venkatesh, Anurag Choudhary, Suresh Kumar, Sankar Ghoshal

Summary

The past health of South Africans is known to be associated with a quadruple disease burden. In the second National Burden of Disease (NBD) study, we aimed to analyse cause of death data for 1997–2012 and develop national, population group, and provincial estimates of the burden and causes of mortality.

Methods We used underlying cause of death data from death notifications for 1997–2012 obtained from Statistics South Africa. These data were adjusted for completeness using indirect demographic techniques for adults and compared with survey and census estimates for child mortality. A regression approach was used to estimate unexplained HIV/AIDS deaths and so-called garbage codes were proportionally redistributed by age, sex, and population group population group (black African, Indian or Asian descent, white European descent), and adjusted for residual mortality according to the prevailing categories. Injury deaths were estimated from additional data sources. Age-standardised death rates were calculated with indirect population estimates and the WHO age-standard Institute of Health Metrics and Evaluation Global Burden of Disease (IHME GBD) estimates for South Africa were obtained from the IHME GBDs website for comparison.

Findings All-cause age-standardised death rates increased rapidly since 1997, peaked in 2006 and then declined slightly by changes in HIV/AIDS. Mortality from tuberculosis, non-communicable diseases, and injuries decreased slightly in 2012. HIV/AIDS caused the most deaths (27.7%) followed by cardiovascular disease (7.7%) and lower respiratory infections (4.7%). All-cause age-standardised death rates were 1.7 times higher in the province with the highest death rate compared to the province with the lowest death rate, 2.5 times higher in black Africans compared to whites, and 3.4 times higher in males compared with females. Comparisons with the IHME GBD estimates for South Africa revealed substantial differences for estimated deaths from all causes, particularly HIV/AIDS and interpersonal violence.

Interpretation This study shows the reversal of HIV/AIDS, non-communicable disease, and injury mortality trends in South Africa during the study period. Mortality differentials show the importance of social determinants, raise concerns about the quality of health services, and provide relevant information to policy makers for addressing inequalities. Differences between GBD estimates for South Africa and this study emphasize the need for more careful calibration of global models with local data.

Funding South African Medical Research Council's Flagships Awaraz Project

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Introduction

South Africa has poor health outcomes given its level of economic development. Despite being an upper middle-income country, South Africa has high mortality levels resulting from a unique quadruple disease burden, described in the first National Burden of Disease study in 2000: "The 2000 Lancet focus on health in South Africa" revealed the poor health status in the country's history of colonisation and apartheid, which resulted in over 50% of its total health expenditure, expenditure of the working class, high poverty and unemployment, and a high burden of HIV/AIDS (1).

Although the beginning of democracy in 1994 led to efforts to build a nation with social equality, gaps persisted that necessitate policies that focused on social economic growth that can "wealth inequality." The 2012 update of the Lancet Series acknowledged improved access to water, sanitation, and electricity, and increased provision of social grants but noted the large social differentials in social determinants of health. The health service faces considerable challenges, including inefficiencies and inequities: "More than half of the country's health care financing, and more than 70% of the country's doctors are employed in the private sector serving about 20% of the population."

The health services' Government is moving towards national health insurance to provide accessible, quality health care to all. Understanding the disease burden currently and addressing it to reach nationally equitable and monitor changes and differentials in health status through improvements in the quality of vital registration data have occurred, these data are not complete and cause

Mortality data - routinely collected for every death - is used frequently. Cause of death statistics are particularly informative as they come directly from the cause of death reported by the medical doctor caring for the decedent.

Mortality data uses

- Indicate community health concerns and priorities
- Justify health spending
- Track infant and maternal deaths
- Make pension and life insurance calculations
- In the next 4 pages we will discuss a few examples of how mortality data are used, in more detail

It indicates the overall health of a community, drive health and social policy decisions.

The information is also used to determine funding for health and social interventions.

The health department uses cause of death data to identify needs, measure results and allocate resources, for example in infant and maternal care .

Actuaries calculate pensions and life insurance premiums based in part on mortality data.

Cause of death: Mortality data uses

Indicate community health concerns and priorities



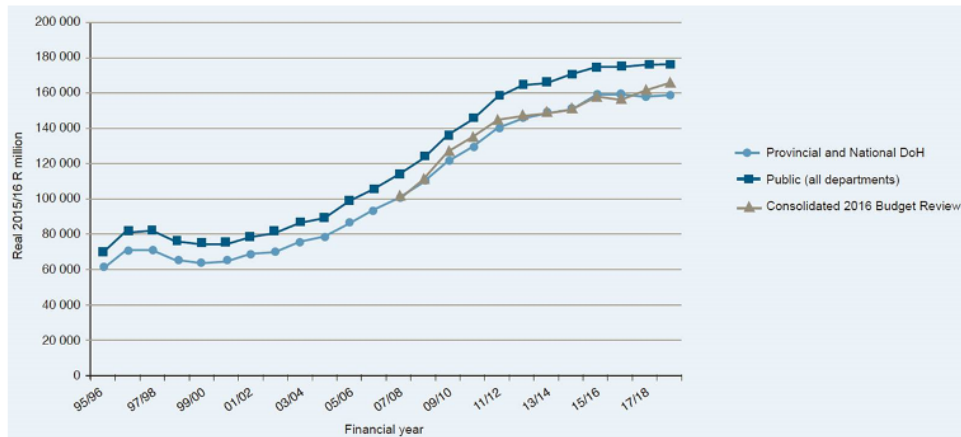
Deaths by disease category for males (N = 276,378) and females (N = 252,568), South Africa 2012

Source: Msemburi W et al. *Second national burden of disease study for South Africa: Cause-of-death profile for South Africa, 1997–2012*. Cape Town: South African Medical Research Council, 2016. ISBN: 978-1-928340-06-5.

Mortality data is used to indicate community health concerns and priorities. In these graphs you can see deaths by disease category for males and females in South Africa in 2012. HIV and TB account for 33% of deaths in both males and females. Injuries account for 14.4% of deaths amongst males versus only 4.4% in females. Cardiovascular deaths account for 22% amongst women and 15.2% amongst men.

Cause of death: Mortality data uses

Justify health spending



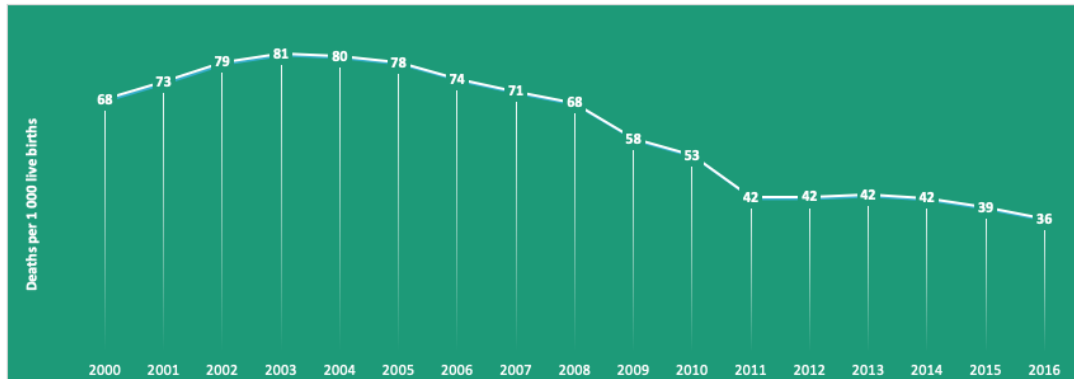
Source: Blecher M et al. HIV and AIDS financing in SA, SA Health review 2016.

Mortality data is used to justify health spending. This graph shows the public health expenditure trend between 1995 and 2018.

The marked increase in expenditure from 2005 onwards reflects the roll out of the antiretroviral treatment programme to combat the HIV epidemic.

Cause of death: Mortality data uses

Track infant and maternal deaths: Under 5 mortality rate



Source: Rapid Mortality Surveillance Report 2017. (Dorrington et al., 2019). Available from <http://www.mrc.ac.za/reports/rapid-mortality-surveillance-report-2017>.

Mortality data is used to track infant and maternal deaths. This graph shows the under 5 mortality rate from 2000 until 2016.

The increase in under 5 mortality between 2000 and 2003 is largely due to the impact of the HIV epidemic.

The marked decline in under 5 mortality after 2004 is due to the impact of the Prevention of Mother to Child Transmission and the rollout of the ARV programme, which has dramatically reduced mother to child transmission.

However, after 2011 the decline in mortality in this age group has levelled off.

Cause of death: Mortality data uses

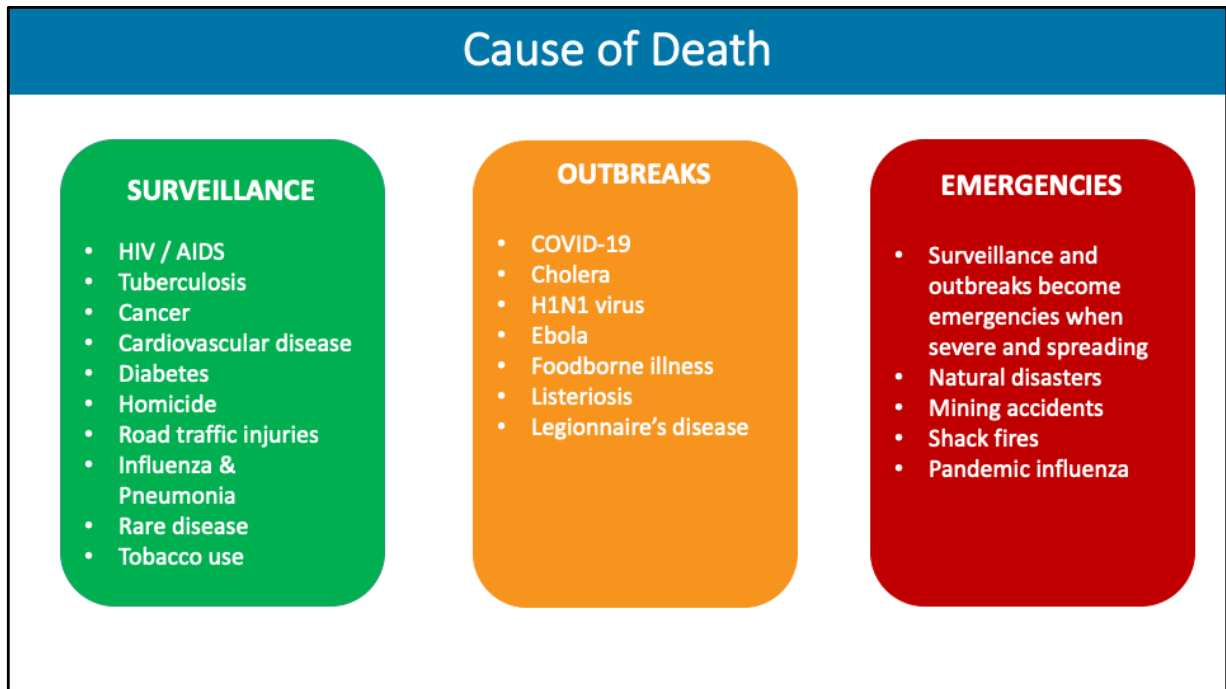
Make pension and life insurance calculations

**Expectation
(in years), of
life by
gender, South
Africa 2019**

Age	Persons	Male	Female
0	63.8	60.2	67.4
10	56.2	52.6	59.7
20	46.7	43.2	50.2
30	38.2	34.8	41.6
40	30.7	27.5	33.8
50	23.8	20.9	26.4
60	17.4	15.1	19.3
70	12.0	10.4	13.0
80	7.3	6.3	7.8
90	3.4	2.8	3.6

Source: Dorrington RE, et al (2019). Rapid mortality surveillance report 2017. Cape Town: South African Medical Research Council.

This table shows the life expectancy (in years), for males and females of different ages in 2019 which are used in calculating rates for life assurance premiums.



Death certificates can be used for surveillance, outbreaks and emergencies, such as those listed on the screen.

Rapid reporting of deaths are required by law. Cause of death information alerts local and national agencies – and the healthcare community at large – to epidemics and severe medical complications of infectious and environmental exposures. Accurate and complete reporting of cause of death ensures this surveillance is effective. If it is not effective, it can be disastrous, as was the case with reporting HIV as cause of death in South Africa.

TAKE A STAND
AGAINST
AIDS/HIV
Advocate
AWARENESS

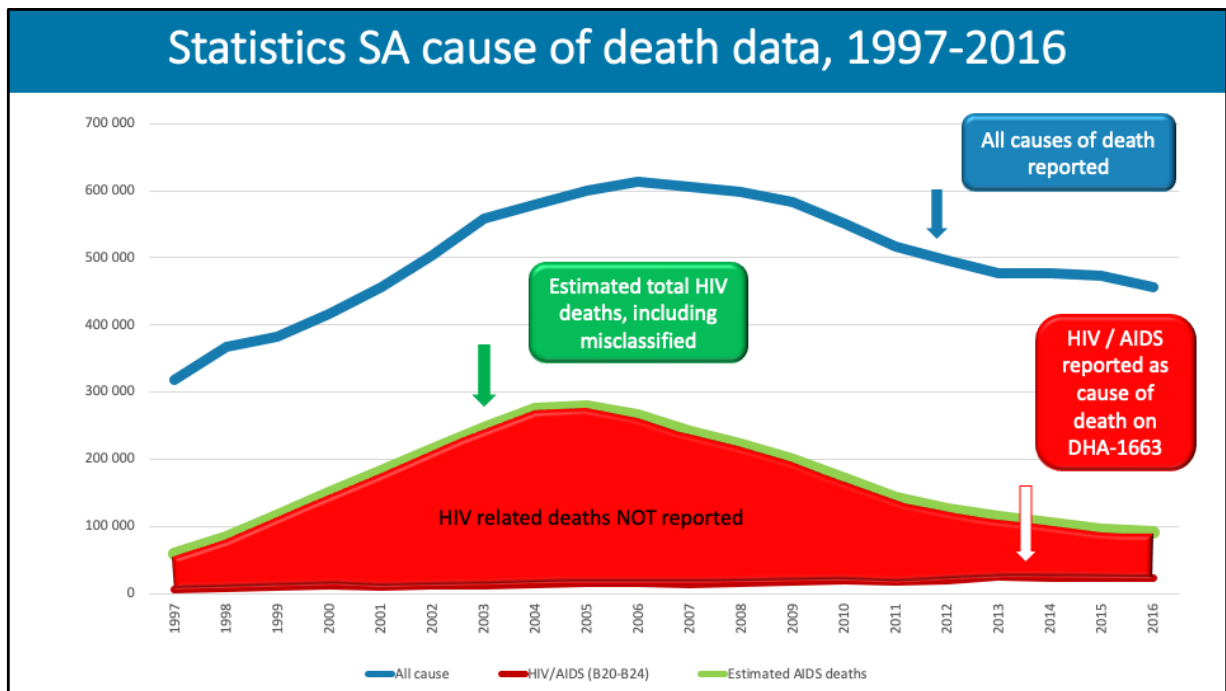
Myths

Denial

Stigma

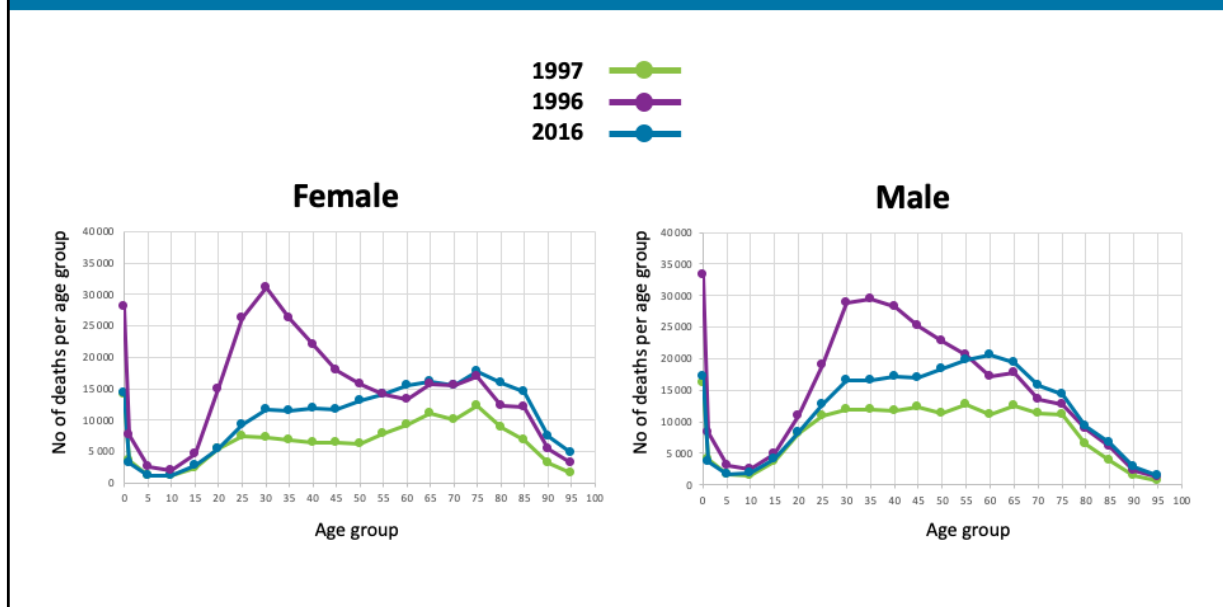
Cost of drugs

HIV-related deaths became a reality in millions of South African households. Besides the obvious increase in mortality, there was a problem. The president said that the increase in deaths in the country was not as a result of HIV, because Statistics South Africa showed that only about 10 000 people died of HIV per year. This is because the incorrect cause of death information was reported by doctors on the death notification form. They reported the immediate cause of death – such as TB, pneumonia or gastroenteritis - without reporting HIV as the underlying cause. Or they reported euphemisms, such as “RVD”, “retroviral disease”, immune-deficiency” or “immuno-compromised”. RVD or retroviral disease is not coded to HIV - it is coded to “other retroviruses”. And “immuno-compromised” or “immuno-deficiency” is coded to “immune disorders” rather than to HIV.



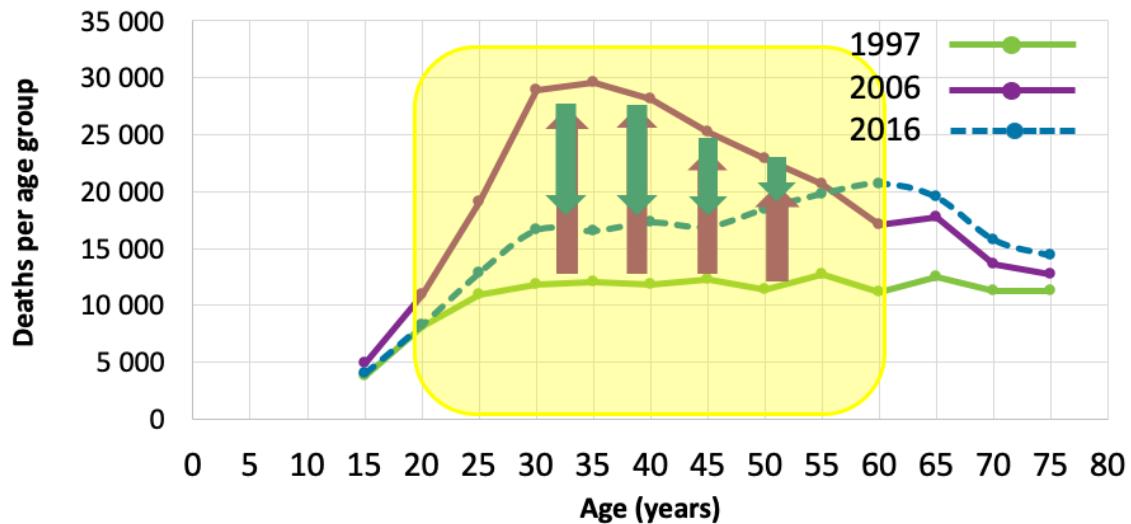
Here is another angle to look at causes of death statistics for South Africa. The blue line shows the number of deaths reported annually between 1997 until 2016. The red line shows the number of HIV-related deaths reported on the death notification form over the same period... Whereas, the green line shows our estimated number of HIV-related deaths. The gap between the red and green line reflects deaths that should have been reported as HIV-related. The consequence of inaccurate statistics on HIV-related deaths was that the government had reason to delay rolling out anti-retroviral treatment resulting in an estimated 1 million deaths that could have been averted.

Deaths in South Africa: 1997 - 2016



These two graphs show the age distribution of all registered deaths for males and females in South Africa between 1997 and 2016

Male deaths in South Africa: 1997 - 2016



Let's have a closer look at the graph for males, as an example.

- You can see a large year on year increase in the number of deaths between 1997 and 2006
- It was followed by a steady decrease between 2006 to 2016
- The main increase was recorded in the age groups, 20 to 60 years of age. The increase in deaths in young children and in adults between 15 and 50 years is typical of an HIV epidemic with no interventions. The decrease in deaths after 2006 demonstrates the impact of the ARV roll out in the public sector.

Current challenges in cause of death data in South Africa

Major challenges with cause of death are compromising its use for health policy purposes

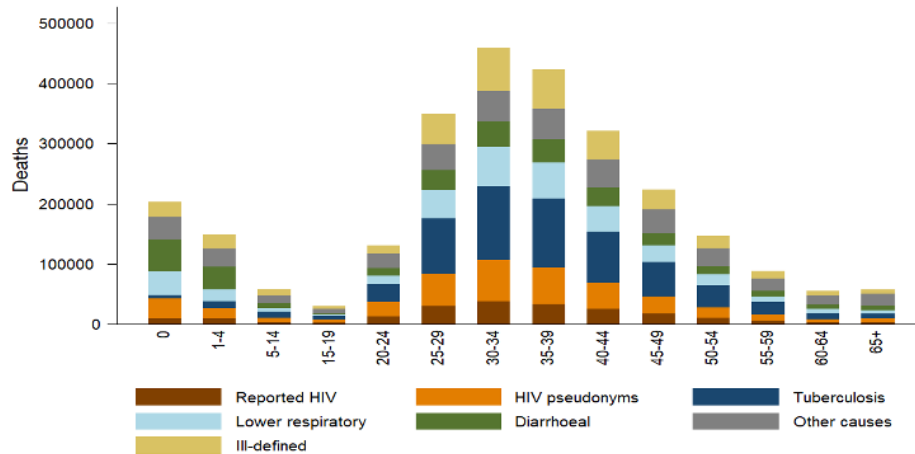
- Under-reporting of HIV deaths
- High proportion of deaths with ill-defined (unusable) causes
- Injury mortality profile inaccurate

There are other major challenges with cause of death certification, which compromise the use of the official mortality data for health policy purposes. This is in addition to the underreporting of HIV-related deaths - due to misclassification to other causes, such as TB and diarrhoea – and the use of euphemisms like “RVD”.

Additional challenges include the high proportion of deaths with ill-defined or vague causes, and an inaccurate injury mortality profile.

Current challenges in cause of death data in South Africa

Misclassification of HIV deaths to other causes



Source: Bradshaw et al., AIDS 2015; Pillay-van Wyk et al, BODRU Technical Report 2015

The Burden of Disease Research Unit of South African Medical Research Council has estimated the misclassification of HIV deaths. This figure shows the extent of the misclassification by age group, as well as the causes the HIV is misattributed to. Reported HIV deaths are indicated in brown closest to the x-axis with the numbers of misattributed HIV deaths to other causes shown in other colours. The largest proportion of HIV deaths were misattributed to TB - dark blue.

Current challenges in cause of death data in South Africa

Unusable cause of death codes used in 2014

Unusable codes classification		Number of deaths with unusable codes	% of total causes
Category 1	Symptoms, signs and ill-defined conditions	58,342	12.3
Category 2	Impossible as underlying cause of death	5,282	1.1
Category 3	Intermediate cause of death	47,544	10.0
Category 4	Immediate cause of death	4,560	1.0
Category 5	Insufficiently specified causes within ICD chapters	92,853	19.6
Total unusable and insufficiently specified causes		208,581	44.1

An analysis of South African mortality data for 2014 reveals that unusable codes are used for up to 44% of all deaths.

Almost half of these are insufficiently specified causes of death, such as cancer with no primary site specified.

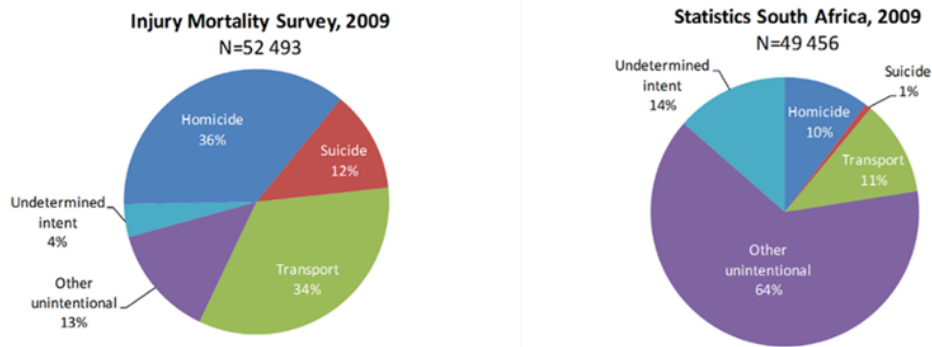
Symptoms and signs – like headache, cough and so on - which provide no clues on the underlying cause of death, account for 12.3% of all deaths.

Invalid causes of death such as glaucoma or warts account for 1%.

And intermediate and immediate causes of death – such as heart failure or renal failure - account for 11% of total deaths. Since many conditions can cause heart failure or renal failure it is important that the underlying cause of death for these are stated on the death certificate.

Current challenges in cause of death data in South Africa

Injury profile inaccurate



Left: Matzopoulos R et al, BODRU Technical report, 2013; Right: Statistics SA, 2011. Mortality and causes of death in South Africa, 2009

In South Africa, injury deaths are legally required to undergo a post mortem investigation and some also require an inquest to establish the cause of death and/or culpability.

The Inquests Act states that anyone who pre-empts the finding of an inquest can be subject to a fine or imprisonment.

For this reason many forensic pathologists do not state the manner of death - homicide, suicide, accident or natural - on the death notification form, even though they may have this information.

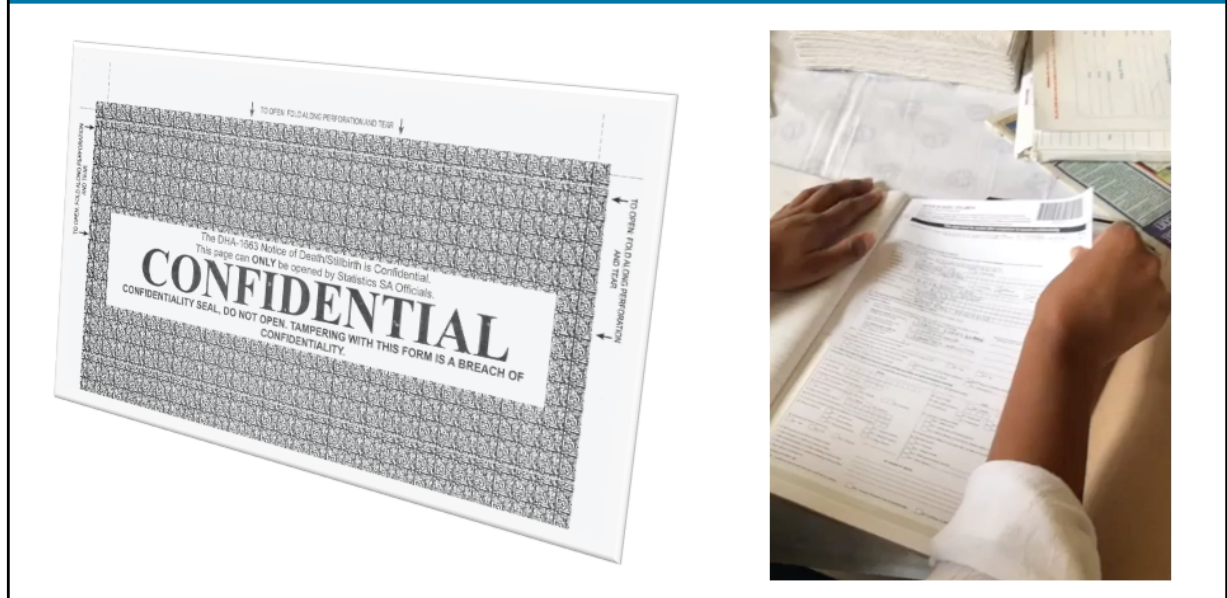
The ICD-10 coding rules for assigning the manner of death caused by injury, defaults to "accidental", if no manner is listed.

Therefore, if you have a case with a gunshot wound to the chest, without the manner of death indicated, it would be coded as an "accidental gunshot wound".

The South African Medical Research Council undertook an injury mortality survey at a national sample of forensic mortuaries in 2009 and compared the injury mortality profile obtained through the survey. See the pie graph on the left, with the national injury mortality statistics on the right.

It is clear that the official injury statistics are very inaccurate.

Legal record and confidential information



We have emphasised thus far the importance of death certification to accurate mortality statistics, public health policy planning and the allocation of resources. Aside from the public health importance, cause of death is part of a permanent legal record.

Legal record and confidential information

STAATSKOERANT, 26 FEBRUARIE 2014

No. 37373 5

GOVERNMENT NOTICE

DEPARTMENT OF HOME AFFAIRS

No. R. 128

26 February 2014

BIRTHS AND DEATHS REGISTRATION ACT, 1992

REGULATIONS ON THE REGISTRATION OF BIRTHS AND DEATHS, 2014


The Minister of Home Affairs has, in terms of section 32 of the Births and Deaths Registration Act, 1992 (Act No. 51 of 1992), made the Regulations in the Schedule.

The Births and Death registration Act 51 of 1992 requires that all deaths are registered with the Department of Home Affairs using the prescribed form: DHA1663.

Legal record and confidential information

G.P.S. 0970

DHA-1663 A
Page 1 of 3



REPUBLIC OF SOUTH AFRICA
DEPARTMENT OF HOME AFFAIRS

NOTICE OF DEATH / STILLBIRTH

(Births and Deaths Registration Act 51 of 1992)
(Regulations 11 and 14)

To be completed in full and submitted at the Department of Home Affairs office by the informant or authorised funeral undertaker. The form to be completed in **BLACK INK with BLOCK LETTERS**. Please mark with ✓ the CORRECT box, where required. All fields are **COMPULSORY**. Incomplete applications and applications that are not legible may be considered invalid. (Note: The fingerprints of the deceased, the informant and the undertaker must be taken by the undertaker)

A. PARTICULARS OF THE DECEASED

Instructions: Section A to be filled out by Authorised Medical Practitioner / Professional Nurse, who is responsible for examining the body to determine the cause of death. The informant must verify, and where necessary, complete in full the personal particulars and other information of the deceased below.

1. Was this a death or a stillbirth? 1.1 Death 1.2 Stillborn

2. Identification of the deceased (tick one box):

2.1 The deceased was identified with an ID document / passport (if foreigner) produced by the family

2.2 Stillborn child

2.3 The features of the deceased do not seem to match the features on the ID document or passport of deceased

2.4 ID document or passport of the deceased was not presented. The deceased was identified through word of mouth

2.5 The deceased was already buried prior to the completion of this form

2.6 The deceased was unidentifiable: 2.6.1 Burnt 2.6.2 Decomposed 2.6.3 Other (specify) _____

2.6.4 DNA samples retrieved for identification purposes 2.6.5 Dental records taken for identification purposes

3. Date of Death / stillbirth: Y Y Y M M D D

4.1 Place of Death/stillbirth (City/Town/Village)

4.2 Province of Death/stillbirth

5. Place of Registration of Death / stillbirth

11

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Left (Informant of deceased)

Right (Funeralist of deceased)

Prescribed form: DHA1663.

Legal record and confidential information

CHAPTER III REGISTRATION OF DEATHS (ss 14-22)

14 Death due to natural causes

(1) (a) In the case of a death due to natural causes any person who was present at the death, or who became aware thereof, or who has charge of the burial concerned, shall give, as soon as practicable, by means of a certificate mentioned in section 15 (1) or (2), notice thereof to a person contemplated in section 4.

15 Certificate by medical practitioner

(1) Where a medical practitioner is satisfied that the death of any person who was attended before his death by the medical practitioner was due to natural causes, he shall issue a prescribed certificate stating the cause of death.

Where a medical practitioner is satisfied that the death was due to natural causes, he or she is required to issue the prescribed cause of death certificate stating the cause of death.

Legal record and confidential information

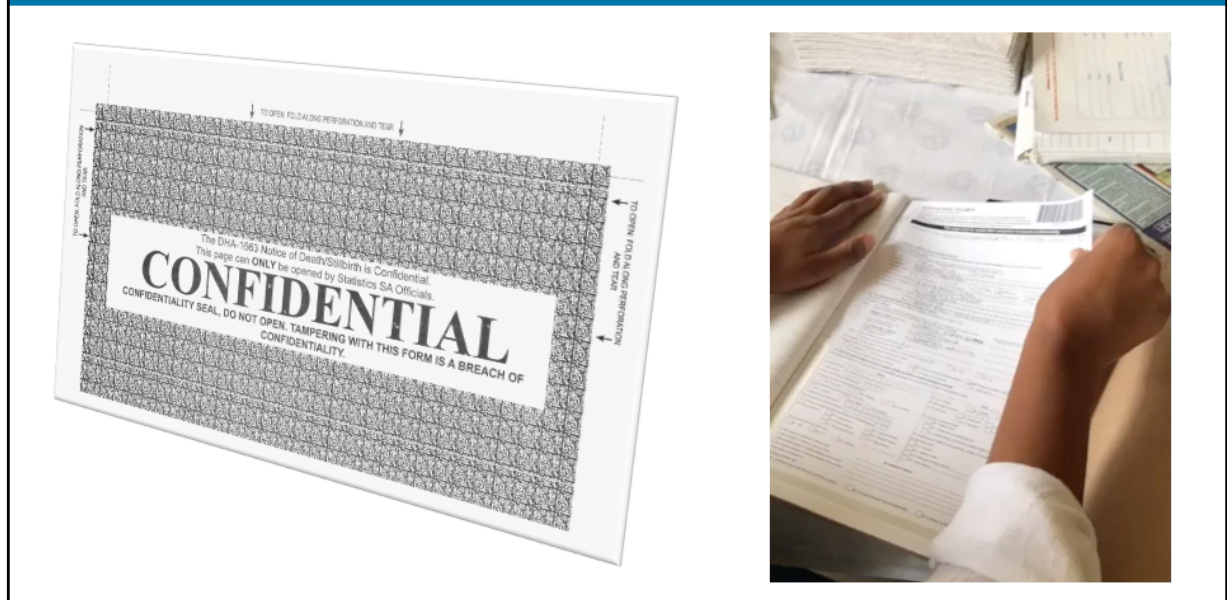
CHAPTER III REGISTRATION OF DEATHS (ss 14-22)

17 Death due to other than natural causes

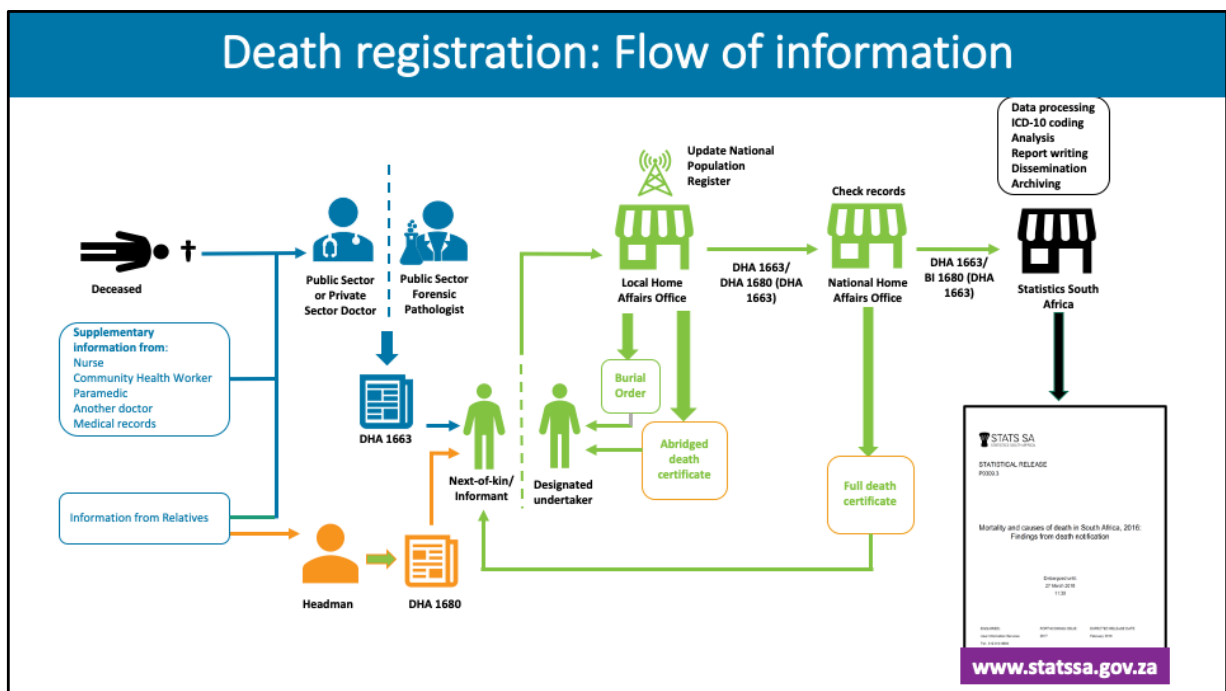
(1) After an investigation as to the circumstances of a death due to other than natural causes in terms of section 3 of the Inquests Act, 1959 (Act 58 of 1959), the medical practitioner concerned shall, as soon as he is satisfied that the corpse concerned is no longer required for the purposes of an examination mentioned in the said section 3, issue a prescribed certificate to that effect and deliver it to the police officer concerned.

Where the death is due to other than natural causes, an investigation into the circumstances of the death is required under section 3 of the Inquests Act 58 of 1959.

Legal record and confidential information



In South Africa, the cause of death section is considered confidential information. The Regulations on the Registration of Births and Deaths were amended in 2014, to include a self-sealing page for Section G of the medical certificate of cause of death. The certifying medical doctor is required to seal this page after completing Section G to ensure confidentiality. Thereafter it is only available to Statistics South Africa for official purposes.



Now that we've discussed the importance and legal status of cause of death reporting, let's have a look at the official mortality statistics system and the role of the medical doctor for improving quality of death certification in the country.

When someone dies, there are a few people that could play an important role to assist the doctor – who is completing the Death Notification Form - to obtain the necessary information to report on the cause of death.

This include other members of the healthcare team, such as the nurse caring for the person, the community health worker who regularly visited the person at home, the paramedics who provided emergency care prior to admission to hospital, or the doctor who usually looked after the person. Clinic or hospital medical records may also provide information on the deceased's medical history. Then there is the family, who may be able to provide valuable information.

In South Africa, medical doctors in public or private health facilities, and forensic pathologists at forensic mortuaries, certify deaths on the DHA-1663 Death Notification Form.

Headman in traditional areas can also complete a form to certify death: the DHA-1680 Form.

These forms are taken by the funeral undertaker or a relative of the deceased to a local or regional Home Affairs office, where the death is registered prior to burial.

The Home Affairs office will update the population register, and issue a burial order and an abridged death certificate to the funeral undertaker or relative.

From here the DHA-1663 form is sent to the National Department of Home Affairs in Pretoria, where they are checked, and a Full death certificate issued.

The DHA-1663 form is finally sent to Stats SA for ICD-10 coding of cause of death, analysis, reporting and archiving.

An annual Mortality and Cause of death report is issued by Stats SA and can be downloaded from the Stats SA website.

Summary

- Importance of correct death certification to
 - accurate mortality statistics
 - public health policy and planning
 - allocation of resources
- Quality of death
- Role of medical doctors
- Legal, ethical and confidentiality issues related to death certification.

In this first module we discuss the importance of the correct certification of cause of death and the role of a medical doctor in producing reliable causes of death statistics.

You should now be able:

- To explain the importance of correct death certification to accurate mortality statistics, to public health policy and planning, as well as the allocation of resources.
- To discuss the quality of death certification in South Africa.
- To explain the role of medical doctors, as part of the official mortality system, for improving quality of death certification.
- And to discuss the legal, ethical and confidentiality issues related to death certification.

You have now come to the end of Module 1



The next step is your self-assessment for Module 1.

Note:

- This is only a self-assessment and not part of the final assessment at the end of the course.
- The final assessment is a summative assessment which covers all the modules and in order to successfully complete the course, you must obtain a mark of 80%.

You have now come to the end of Module 1.

The next step is your self-assessment for Module 1.

Note:

- This is only a self-assessment and not part of the final assessment at the end of the course.
- The final assessment is a summative assessment which covers all the modules and in order to successfully complete the course, you must obtain a mark of 80%.