Chapter 2

Registering Ebola Virus Disease (EVD) Both as a Multiple Cause of Death and as a Notifiable Disease in Africa: Comparison Between the Ideal and the Reality

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Additional information is available at the end of the chapter

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Abstract

The chapter explores the possibility of registering Ebola virus disease (EVD) as a multiple cause of death (part of the civil registration/vital statistics (CR/VS) system) in addition to being a notifiable disease (part of the disease surveillance system). The linkage between the two systems is established, followed by a framework showing how each of the systems would work in the ideal situation. A scoring system is developed and used to score each dimension of this ideal system, giving a total score of 23. This tool can be used to assess the extent to which the EVD is registered both as a multiple cause of death and as a notifiable disease in Africa. The application of the tool requires that the Ebola virus disease is coded at the fourth digit ICD-10 level and that multiple causes of death are routinely collected in the first place. The country that is closest to satisfying these criteria is South Africa. The application of the tool to South Africa data showed that South African system was "fair" (between "poor" and "good"). The results are shown, discussed and recommendations are made for improving two systems in Africa.

Keywords: Ebola virus disease, disease surveillance system, civil registration/vital statistics system, multiple causes of death, ICD-10

1. Introduction

The unexpected outbreak of the Ebola virus disease (EVD) in West Africa during 2014–2015 sadly led to over 10,000 deaths [1]. The resulting amount and diversity of EVD-related research that followed was impressive. Some tried to produce estimates of EVD cases and related deaths

[2], some tried to better understand the epidemiology of EVD [3], while others tried to analyze some of the structural factors that led to the disaster [4]. Analytical reports on the West African EVD epidemic (including a CDC report) often mention that there was no prior EVD outbreak in the main affected countries of Sierra Leone, Guinea and Liberia [5]. While this observation is true, what it fails to mention is that the region bordering the three countries was already endemic to Lassa fever, another viral hemorrhagic disease. According to published findings, Lassa fever had been detected in that region as early as the 1970s. A Lassa fever outbreak had occurred in Liberia in 1972, and in a hospital-based study in Liberia in 1976–1977, Lassa fever antibodies were found to be present in 8.4% of the 844 sera specimen studied [6]. In a serological survey carried out in Liberia in 1978–1979, it was found that of 433 sera specimen studied, 16% tested positive for Lassa fever, 6% for Ebola virus and 1% for Marburg virus [7]. The latter study concluded the following: 'the results seem to indicate that Liberia has to be included in the Ebola and Marburg virus endemic zones' [7]. Other studies subsequently confirmed the endemicity of Lassa fever in both Guinea and Sierra Leone [8]. In short, the 2014/2015 Ebola epidemic in West Africa had been preceded by decades of the endemicity of other hemorrhagic fevers in the region. This suggests that EVD may lay hidden for many years before it breaks out as an epidemic. Hence, in addition to EVD being a notifiable disease, it would make sense to search for EVD among other causes present at death, in other words, as a multiple cause of death. This would strengthen the monitoring system for long-term prediction of possible outbreaks of EVD.

The rest of the section discusses the following topics: linkage between disease surveillance system and multiple causes of death system; the setup for an ideal disease surveillance system and the setup for a practical and efficient system for collecting data on multiple causes of death. The findings of these sections are used in developing the methods section which follows. The results are presented and discussed. Subsequently, the chapter ends with some concluding remarks.

1.1. Linkage between disease surveillance system and multiple causes of death system

Figure 1 shows a simplified relationship between the disease surveillance system and the system for producing multiple causes of death statistics. When someone contracts a notifiable disease, this may or may not result in contact with the healthcare delivery system. In an ideal system, once the patient with the notifiable disease gets in contact with the healthcare delivery system, the case is notified to the authorities and the details are entered into the disease surveillance system and the necessary public health action is taken. Even if this patient does not contact the healthcare delivery system, it is possible to enter the information in the disease surveillance system via lay reporting. After the patient dies (in or out of hospital), it is only when the death is reported that it becomes a part of the civil registration/vital statistics (CR/VS) system. In the processing of the cause of death, if underlying cause of death coding is used, the notifiable disease may go unreported if it is not the underlying cause of death. Hence, it is only through multiple cause of death coding that the notifiable disease (which is

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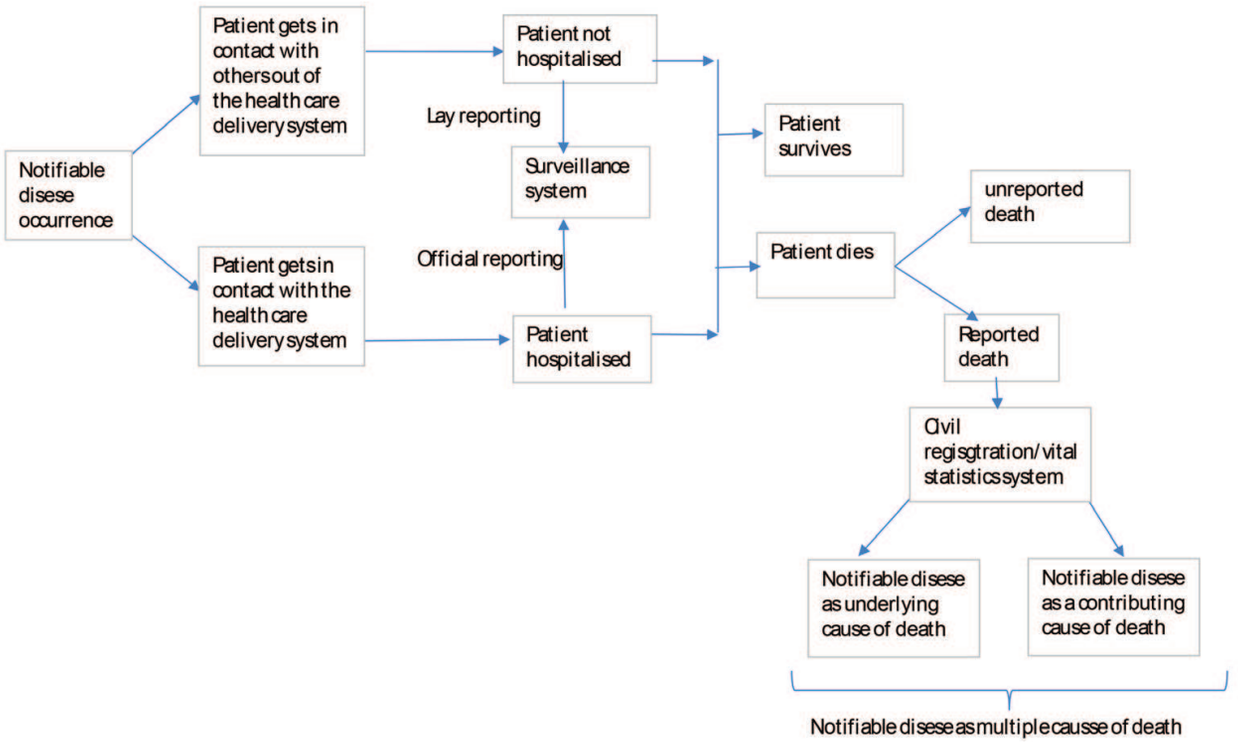

Figure 1. Linkage between disease surveillance system and multiple causes of death system.

not the underlying cause of death) present at death would appear in official vital statistics. The implication of this schema is that for notifiable diseases in general, the expectation is that the number of cases reported in the surveillance system should be more than the number of deaths with the notifiable disease as a multiple cause of death. However, for diseases with very high fatality rate and situations in which the surveillance systems and the vital registration systems are working very well, the two figures would be close to each other. The wider the difference between the data coming from the two systems, the more departure from the ideal, for either of the systems or both systems.

1.2. The setup for an ideal disease surveillance system

Figure 2 shows the framework for an ideal disease surveillance system in developing countries. While disease surveillance systems are in place in most countries, their efficiency varies markedly. The reasons for the marked variation are many. The first is the scope of entities included in the disease notification system. For many, the emphasis is mostly on government hospitals, laboratories and clinics. Private entities are either not properly integrated or not given due importance, as was found in a 2013 study in Iran [9]. The second is the complication or perceived complication of the notification process. The more complicated the process is, and the less incentives there are, the lower the reporting of notifiable diseases. The third is the lack of penalty (or low penalty) for failing to report. All of these factors contribute toward low reporting rates for notifiable diseases.

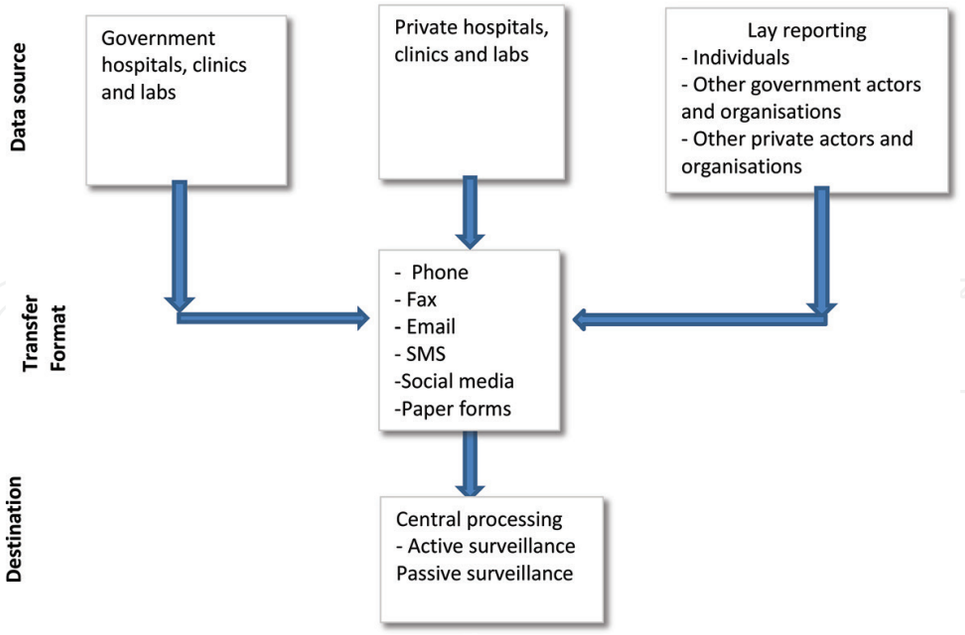

Figure 2. Framework for an ideal disease surveillance system in developing countries.

1.3. The setup for a practical and efficient system for collecting data on multiple causes of death

Unlike disease surveillance systems, there is no 'ideal system' for collecting data on multiple causes of death. This is because the vital statistics systems are a by-product of the civil registration system, which has diverse arrangements in different countries. A CR/VS system that produces the desired outcome is an acceptable system, irrespective of the arrangements used. The desired outcome of acceptable system for producing statistics on multiple causes of death is as follows:

1. Timely production of statistics, not more than 1 year after the end of the reference year
2. Regular official tabulation of multiple causes of death tables
3. The use of software for the automatic selection of underlying causes of death
4. The use of ICD-10 (at the four digit level) for coding causes of death
5. The negligible proportion of 'ill-defined causes of death'

The fourth point is mentioned because EVD is only properly coded at the four-digit level in ICD-10 (A98.4).

In passing, it is worth mentioning that the country that best satisfies all these criteria is arguably Australia. Australia regularly publishes official tables on multiple causes of death. It uses ICD-10, at the fourth digit level, to code causes of death. It uses IRIS software for the automatic selection of underlying causes of death. Its proportion of ill-defined causes of death is negligible. Lastly, the 2016 statistics on multiple causes of death was published in 2017. As such, the Australian system for producing multiple causes of death is the closest to the ideal.

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2. Methods

2.1. Criteria for comparing surveillance and multiple causes of death systems against the ideal

The features of the ideal systems described above have been converted into a table (**Table 1**) with scores given for the different dimensions. Each dimension is scored as either binary (0 or 1) or ordinal (from 0 to 3). Using this scoring system, the maximum score (the ideal system) is 23. Any system scoring 18 or over can be rated as good. Any system scoring between 13 and 17 can be rated as fair, and any system rating below 13 can be rated as poor. Information on dimensions from 1.1 to 3.1 can be obtained from the literature, by studying the working of the surveillance system and the multiple causes of death system. The dimension 3.2, however, could only be assessed through analysis of data, through the direct comparison of the number of cases from the surveillance system and the number of deaths from the multiple causes of death system for the same year and the same cause.

No.	Dimension	Scoring system (Binary or ordinal)
1.	**Disease surveillance system**	
1.1	Collections of data from government hospitals, clinics and laboratories	0-Absent 1-Low 2-Moderate 3-High
1.2	Collections of data from private hospitals, clinics and laboratories	0-Absent 1-Low 2-Moderate 3-High
1.3	Use of lay reporting	0-Absent 1-Present
1.4	Multiple transfer format for reporting	0-None 1-One format 2-Two formats 3-Three or more formats
1.5	Central processing	0-Absent 1-Present
1.6	Using of active surveillance for highly infectious disease	0-Not used 1-Used
1.7	ICD-10 coding	0-Not used 1-Used
1.8	Use of four-digit coding	0-Not used 1-Used

No.	Dimension	Scoring system (Binary or ordinal)
2.	**Multiple causes of death system**	
2.1	Timeliness of reporting of causes of death	1-After 4 or more years
		2-Within 3 years
		3-Within 2 years
		4-Within 1 year
2.2	Regular official tabulation for multiple causes of death	0-Absent
		1-Present
2.3	Software for automating the coding of causes of death and the selection of underlying cause of death	0-Absent
		1-Present
2.4	ICD-10 coding	0-Absent
		1-Present
2.5	Use of four-digit coding	0-Absent
		1-Present
3.	**Overlap between the surveillance system and the multiple causes of death system**	
3.1	Official linkage between the surveillance system and the multiple causes of death system	0-Absent
		1-Present
3.2	The number of reported cases in the surveillance system being equal to, or more than the reported multiple causes of death for the same disease for the same reporting year	0-No
		1-Yes

Table 1. Criteria for comparing surveillance and multiple causes of death systems against the ideal.

3. Results

The application of the criteria to Africa starts with some inclusion criteria. Since we are discussing EVD and multiple causes of death, the main inclusion criteria for African countries to be included in this study are two: the official collection and publication of data on multiple causes of death and the use of ICD-10 coding. According to the data included in the global health data exchange (GHDx), the only African countries submitting mortality data to WHO using ICD-10 coding are as follows: Egypt, Morocco, Tunisia, Cape Verde, Zambia, Mauritius, Seychelles and South Africa. Of these countries, only South Africa collects and publishes data on multiple causes of death.

The South African national statistics office, Statistics South Africa (Stats SA), routinely collects, analyses and publishes data on multiple causes of death. It has been routinely publishing data on multiple causes of death, starting from the 1997 data. The causes of death coding were initially done at the three-digit level, but recently, it has moved on to four-digit coding. South Africa also has decades-old functional disease notification system for reporting and analyzing notifiable diseases (the South African Institute for Medical Research was established in 1912). The number of notifiable diseases in South Africa is over 40 and includes Crimean-Congo hemorrhagic fever (CCHF) (ICD-10: A98.0) and 'other hemorrhagic fevers of Africa,' which

No.	Dimension	Score	Source/note
1.	**Disease surveillance system**		
1.1	Collections of data from government hospitals, clinics and laboratories	2	The surveillance system has been independently assessed and rated as being 64% complete [11]
1.2	Collections of data from private hospitals, clinics and laboratories	1	'There are no legal provisions for laboratories to notify communicable diseases.' [11]
1.3	Use of lay reporting	0	Not mentioned in the reporting mechanism
1.4	Multiple transfer format for reporting	2	'The NDSS in South Africa is a paper-based system…'[11] 'All suspected VHF cases require an immediate telephonic notification' [12]
1.5	Central processing	1	The National Institute for Communicable Diseases (NICD) is responsible for disease surveillance
1.6	Using of active surveillance for highly infectious disease	1	
1.7	ICD-10 coding	0	The description used 'other hemorrhagic fevers of Africa' in disease surveillance is not part of the ICD-10 description
1.8	Use of four-digit coding	0	
2.	**Multiple causes of death system**		
2.1	Timeliness of reporting of causes of death	2	[13]
2.2	Regular official tabulation for multiple causes of death	1	
2.3	Software for automating the coding of causes of death and the selection of underlying cause of death	1	
2.4	ICD-10 coding	1	
2.5	Use of four-digit coding	1	
3.	**Overlap between the surveillance system and the multiple causes of death system**		
3.1	Official linkage between the surveillance system and the multiple causes of death system	0	Not mentioned
3.2	The number of reported cases in the surveillance system being equal to, or more than the reported multiple causes of death for the same disease for the same reporting year	1	Indirectly assessed as shown in the Appendix
	Total	14	

Table 2. Rating of the south African system for registering Ebola virus disease (EVD) both as a multiple cause of death and as a notifiable disease based on 2015 data.

includes EVD (ICD-10: A98.4). According to the South African disease notification system, any notifiable disease resulting in death must be doubly notified, first as a case and second as death. Thus, if one of these notifiable hemorrhagic fevers occurred, it would result in death.

It should be reflected in either the disease surveillance system or the causes of death data from the CR/VS system. If any cause of death is recorded in the CR/VS system, an analysis of the data using the multiple-cause approach has more chance of detecting the cause than the one based on underlying-cause approach.

Using the criteria developed above, the rating of the South Africa system for registering EVD both as a multiple cause of death and as a notifiable disease is given in **Table 2**. Based on latest available data at the time of writing (2015 data), The total score for South Africa is 14 of the maximum of 23. According to the definition defined earlier, this is 'fair' (in between 'poor' and 'good'). While the multiple causes of death component are excellent, the overall ranking is rated down because of the lesser performance of the surveillance system.

In **Table 2**, the dimension 3.2 could not be assessed directly as there is no case of EVD for latest year 2015. Since in the absence of outbreaks EVD is a very rare disease, one would need to collect data over several years to enable the comparison of the two systems. This is done in Appendix 1.

4. Discussion

The major challenge faced in this chapter is the irony in which the countries affected by EVD are the same ones with weak vital registration systems that are neither likely to collect data using ICD-10 nor likely to submit causes of death data to the WHO. Of all African countries, only South Africa collects and publishes data on multiple causes of death and has been doing so since 1997. But in South Africa, EVD is very rare. This rarity plus the use of three-digit ICD-10 coding in the early 2000s frustrated attempts at comparing data on EVD based on disease notification and those based on multiple causes of death. An indirect approach had to be used based on another viral hemorrhagic fever, which is endemic to South Africa, CCHF [10]. This indirect approach helped to establish complementarity of the disease surveillance system and the multiple causes of death statistics system.

The chapter has tried to argue that the system of multiple causes of death complements that of disease notification. Under the ideal conditions, for highly fatal notifiable diseases, the number of cases reported in the disease notification system should be close to the number of deaths due to that disease when reported as a multiple cause of death. This complementary relationship has several implications. The first is that, in the early stages of the development of two systems, one can be used to check on the accuracy of the other. The second is that, through record linkage methods, the data from the disease surveillance system can be linked with the data from the multiple causes of data for more in-depth analysis. The third is that the spread of the disease can be better understood through analysis of the place of disease notification against the place of death as obtained from the death statistics. The fourth is that both systems help to establish accurate endemic levels against that to gauge the start of epidemics.

With some concerted efforts, African countries can set up the ideal systems described in this chapter. Some recommendations for doing so are as follows:

1. Exploit the use of mobile phones (mHealth) in the disease notification process.
2. Embark on training the trainer program by selecting a few officers with medical background (e.g., nursing) and train them in ICD-10 coding. Through request for training assistance, one experienced trainer can be invited to come and train the trainers.
3. As automatic coding software are available free of charge, the software can be obtained, and through request for training assistance, one experienced trainer can be invited to come and train the trainers on using the software
4. Again through request for training assistance, one experienced official statistics officer can assist the African countries in analyzing data on multiple causes of death.

5. Conclusion

The chapter has shown how to set up systems capable of registering EVD both as a notifiable disease and as a multiple cause of death. The chapter has given arguments in favor of the benefits of such systems. Through a program of training the trainers, it is possible for African countries to achieve this within a few years, if concerted efforts are made.

Appendix 1

Comparing data from the disease notification system and the multiple causes of death statistics system in South Africa

To compare data from the disease notification system and the multiple causes of death statistics system, we need (1) comparable period, (2) comparable geography and (3) comparable diseases (causes of death). Since EVD is a rare disease in South Africa, a group of years should be chosen instead of a single year. For this purpose, the period 2000–2005 has been chosen. For this period, causes-of-death coding is done at the three-digit ICD-10 level. The three-digit level, as opposed to the four-digit level, loses some specificity in disease classification. For example, since the four-digit code for EVD is A98.4, under three-digit coding, this is appropriately coded as A98 ('Other viral hemorrhagic fevers, not elsewhere classified'). This category includes the following, Crimean-Congo hemorrhagic fever (CCHF) (A98.0), Omsk hemorrhagic fever (A98.1), Kyasanur hemorrhagic fever (A98.2), Marburg hemorrhagic fever (A98.3), Ebola virus disease (A98.4) and hemorrhagic fever with renal syndrome (A98.5). Of these above-mentioned hemorrhagic fevers, only CCHF is endemic to South Africa [12].

Based on the data available, the closest comparison one could make is between disease notification for CCHF (A98.0) and multiple causes of death due to 'Other viral hemorrhagic fevers,

not elsewhere classified' (A98). The data used in the comparison are data from the South African disease surveillance system for 2000–2005 and the national vital registration data on causes of death for the same period.

Following [14], if $n_{ab}^{cd(j)}$ represents the number of deaths belonging to the sex *a*, age group *b*, with underlying cause *c*, a multiple cause *d* whose order of mention is *j*, then 'any mention' of a specific cause, d (irrespective of position of mention) is given as:

$$n_{\bullet\bullet}^{d(\bullet)} = \sum_{i=1}^{N}\sum_{j=1}^{m} k_i^{d(j)}$$

where *i* stands for any record out of N death records and k_i^x 's are indicator variables defined as follows:

$$k_i^{d(j)} = \begin{cases} 1 \text{ when } d = d^*(\text{the selected multiple cause (s) with order of mention } j) \\ 0 \text{ otherwise} \end{cases}$$

where j = 1,…m (the maximum number of causes per death) [14]

This expression makes up the core of the software Cause-limp 1.1 used for extracting the multiple cause data from the death records. The records were searched to any mention of 'Other viral hemorrhagic fevers, not elsewhere classified') (A98). The variables used in the analysis are the following: year of death, sex, and all the multiple causes listed on the certificate (five causes in all) including the underlying cause of death. The program routinely eliminates all still births and all those with missing recording of sex. It is restricted to those whose place of residence and death is South Africa.

Over the study period, 2000–2005, the total number of reported deaths analyzed was over 2.7 million (2,702,710). This was the number of records remaining after eliminating still births, and a number of deaths of unknown and unspecified sex were eliminated.

Of these records analyzed, the total number of deaths with any mention of hemorrhagic fever (A98) was 12. In 2000, seven deaths were recorded with A98 as a multiple cause of death. For each of the remaining years, only one death was recorded. The number of deaths with A98 as a multiple cause was highest in Free State (five), while only one multiple cause death was recorded for each of the provinces, with the exception of Limpopo where no multiple cause death was recorded.

There is a very little chance that these fevers could be of Asiatic origin (e.g., Omsk hemorrhagic fever (A98.1) or Kyasanur Forest disease (A98.2)). As mentioned in a South African manual on hemorrhagic fevers, 'Omsk hemorrhagic fever is a tick-borne virus of Siberia and Kyasanur forest disease is a tick-borne virus of the Indian subcontinent. These infections are unlikely to be seen in Africa' [15]. This makes it very likely that the disease could be CCHF as it is the only endemic one in the remaining list. As the two figures are comparable, this confirms that the two systems are comparable.

Source: Reformatted output from Cause_limp v 1.1 [16].

Over the same period, the number of notifications for CCHF was 21, and of these, the number that died was 11, close to what was obtained above based on the CR/VS system.

	Province of residence of deceased									
	Gauteng	Free State	Northern Cape	Western Cape	Eastern Cape	Mpuma-langa	Limpopo	North West	KwaZulu-Natal	SA
2000	1	2	1	0	1	1	0	1	0	7
2001	0	1	0	0	0	0	0	0	0	1
2002	0	1	0	0	0	0	0	0	0	1
2003	0	0	0	0	0	0	0	0	1	1
2004	0	1	0	0	0	0	0	0	0	1
2005	0	0	0	1	0	0	0	0	0	1
TOTAL	1	5	1	1	1	1	0	1	1	12
Total death records	504,425	249,430	60,972	218,908	374,387	202,084	290,924	242,230	628,559	2,702,710

Source: Reformatted output from Cause_limp v 1.1 [16].

Table A1. Trends in multiple causes of death in South Africa due to hemorrhagic fevers (ICD-10: A98) for both males and females in different provinces of residence, 2000–2005.

	Gauteng	Free State	Northern Cape	Western Cape	Eastern Cape	Mpuma-langa	Limpopo	North West	KwaZulu-Natal	All cases	All deaths
2000	1	3	2	0	1	0	0	1	0	8	5
2001	0	1	2	1	0	0	0	1	0	5	2
2002	0	1	2	0	0	0	0	0	0	3	1
2003	0	0	0	0	0	0	0	0	0	0	0
2004	0	1	1	0	0	0	0	2	0	4	2
2005	0	0	0	1	0	0	0	0	0	1	1
TOTAL	1	6	7	2	1	0	0	4	0	21	11

Source: [11].

Table A2. Trends in laboratory confirmed cases of Crimean-Congo hemorrhagic fever (CCHF) (A98.0) for both males and females in different provinces, 2000–2005.

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