



## Deaths at Red Cross Children's Hospital, Cape Town 1999 - 2003 – a study of death notification forms

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**Objectives.** The availability of cause-specific mortality data for children in South Africa is limited. Hospital-based data have the potential to contribute to understanding of the causation of childhood death in South Africa. The objectives of the study were to gain insights into the causes of death in a South African children's hospital.

**Design.** Prospective, descriptive study of death notification forms.

**Setting.** Red Cross War Memorial Children's Hospital, Cape Town.

**Methods.** Data from 1999 to 2003 were analysed by direct and underlying causes of death (using a modified Global Burden of Diseases (GBD) classification) and demographic variables. Death rates per 1 000 hospital admissions were calculated for certain common causes of death. Seasonal correlates of mortality were examined.

**Results.** There were 1 978 deaths. The number of deaths per year increased by 11.4% over the period. The death rate rose from

15.9 to 18.4 per 1 000 admissions from 1999 to 2002, declining to 17.4/1 000 in 2003. The death rate was higher for females than for males (18.4/1 000 versus 17.6/1 000,  $p = 0.007$ ). Sixty per cent of deaths occurred in children less than 1 year old. GBD group I diseases (infectious, nutritional, perinatal) accounted for the greatest proportion of deaths (58.6%), followed by non-communicable diseases (29.1%), and injuries (7.9%). HIV/AIDS accounted for 60% of infectious deaths (31.6% of all deaths). Diarrhoea-related mortality was 3 times higher in summer than in winter. Congenital conditions dominated GBD group II (57.5%).

**Conclusion.** The analysis shows the value of routinely recording data on childhood hospital deaths. The results mirror those of the South African Medical Research Council's Burden of Disease studies but also reflect the hospital's tertiary functions. Female children were at higher risk of death. Childhood HIV-related deaths are a major challenge to the health system.

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Knowledge of the causes of childhood death in a population is fundamental to the promotion of the health of its children. Research on the causes of childhood mortality in South Africa has focussed on national or provincial data sets,<sup>1,2</sup> individual conditions such as diarrhoea<sup>3</sup> or acute respiratory infections (ARIs)<sup>4</sup> at national level, and HIV/AIDS in hospital settings.<sup>5</sup> Recent attempts to measure remediable health service factors in the causation of childhood mortality are in the developmental phases.<sup>6</sup>

The limitations of cause-specific mortality data in South Africa have been well documented.<sup>7</sup> Specific cause of death has been missing on a large proportion of death certificates. A revised death notification form was adopted in South Africa in 1998.<sup>8</sup> This form aimed to increase the epidemiological accuracy

of death certification by allowing recording of the direct cause of death, the sequence of causation and any associated conditions that may have contributed to the death. Under optimal conditions, death certificates provide a useful source of cause-specific mortality data and there is evidence that the new form is improving the epidemiological value of death registration in South Africa.<sup>1,9</sup>

We studied the death notification forms for almost 2 000 children who died at an urban children's hospital in Cape Town. It was envisaged that this analysis would help staff improve clinical care, enable administrators to identify the most appropriate and cost-effective resource allocation, and provide a foundation from which to track the changing epidemiology of child deaths in a defined urban locality.

### Methods

Information was collected on all deaths occurring under the services of the Red Cross War Memorial Children's Hospital (RCCH) from 1999 to 2003. The RCCH is a 288-bed state teaching hospital with tertiary and regional functions. It is a referral hospital but also houses 24-hour trauma and emergency units, both of which have overnight inpatient beds. It is the only paediatric inpatient facility for the central health districts of Cape Town. Its tertiary services, including an intensive care

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unit (ICU), receive referrals from southern, central and western parts of Cape Town, the southern half of the Western Cape, other tertiary children's services in the province and other provinces and neighbouring African states. It mainly serves children under 13 years of age, most of whom are dependent on state services. Approximately 156 000 children attend the outpatient and emergency services each year, of whom about 18 000 are admitted.

Death notification forms completed by physicians at the hospital were reviewed every month by a senior physician (TW). The following information was derived from the forms: the hospital folder number, the child's age (stratified into those less than 1 year of age (< 1), 1 - 5 completed years (1 - 5), 5 years and over (> 5)), the direct and underlying causes of death (when provided) and the place of death (e.g. ICU, home). Folder numbers were used to retrieve data from the RCCH medical records system on the sex and postal code for each patient who died.

The direct and underlying cause of death was classified by the physician according to the *International Classification of Diseases* version 10 (ICD-10). Following ICD-10 coding, the underlying cause of death or the direct cause where no underlying cause was recorded was classified according to a modified version of the Global Burden of Disease (GBD) report<sup>10</sup> and the South African National Burden of Disease study.<sup>1</sup> Under this scheme, deaths were grouped into broad categories, with a fourth category reserved for 'ill-defined' deaths: (i) group I - pre-transitional causes, viz. communicable diseases, perinatal conditions, and nutritional deficiencies; (ii) group II - non-communicable diseases; and (iii) group III - injuries.

Groups I and II were subdivided into major categories, such as infectious diseases in the former, and neoplasms and congenital abnormalities in the latter. Two of the larger major categories, infectious diseases and congenital abnormalities, were further subclassified to provide more detail on the precise cause of death. Some of the major groups and the subclassification of infectious diseases and congenital abnormalities were altered from the GBD scheme to better represent the causes of death observed at the RCCH.

Data were analysed for the whole period as well as for individual years. Mortality rates per 1 000 hospital admissions were calculated for the whole data set, individual years and individual causes of death. The roles of sex and age group were examined for certain common causes of death. Seasonal variation was examined for two categories of death that have a strong seasonal incidence in Cape Town, viz. diarrhoeal disease and ARI. Deaths of patients who had been living in Cape Town were classified according to metropolitan health districts based on the postal code. The SPSS software package was used for all statistical analyses.<sup>11</sup>

Permission to study the death notification forms was granted by the RCCH Medical Superintendent.

## Results

There were 1 978 deaths registered at the RCCH. The annual number rose from 367 in 1999 to 414 in 2003, an 11.4% increase (Table I). One hundred and thirty-nine deaths occurred outside the hospital (at home, dead upon arrival at the hospital, or died at a primary care facility but registration took place at RCCH). In addition, 172 deaths occurred in the emergency room, leaving a total of 1 667 inpatient deaths. The absolute number of inpatient deaths as well as the rate of death per 1 000 admissions increased from 303 deaths (15.9 per 1 000 admissions) in 1999 to 357 deaths (18.4 per 1 000 admissions) in 2002. The odds ratio of the death rate in 2002 compared with 1999 was 1.16 (95% confidence interval (CI): 1.0 - 1.4,  $p = 0.052$ ). The rate dropped to 17.4 per 1 000 admissions in 2003.

Female inpatients died at a greater rate than males (18.4 versus 17.6 deaths per 1 000 admissions,  $p = 0.007$ ). Over the 5 years, a female patient admitted to the hospital was approximately 14% more likely to die than a male patient.

The absolute number of deaths declined as age rose (Table I).

More than half of all the deaths occurred in children who came from three very low-income health districts in Cape Town, viz. Khayelitsha (26.5%), Nyanga (20.1%) and Langa (11%).

The most common locations for deaths within the hospital were the ICU (37%) and the medical wards (36%). The vast majority (96.4%) of the deaths outside hospital occurred at home.

GBD group I diseases accounted for the greatest proportion of deaths (58.6%), followed by non-communicable diseases (29.1%), and injuries (7.9%). Ill-defined deaths made up 4.3% of the deaths (86 cases). Included in this category were 7 cases of sudden infant death syndrome.

Overall the mortality profile was similar for males and females. The profile of death for each of the age groups was distinct (Fig. 1).

The group I causes of death were predominantly infectious diseases (89.5%), with perinatal conditions contributing 5.7% and malnutrition 4.8%. Of the deaths attributed to malnutrition, 60.7% were due to kwashiorkor.

**Table I. Number and proportion of deaths by year and age group (N (%))**

Year	Age group (yrs)			Total
	< 1	1 - 5	> 5	
1999	215 (58.6)	83 (22.6)	69 (18.8)	367
2000	242 (61.7)	94 (24.0)	56 (14.3)	392
2001	237 (60.0)	97 (24.6)	61 (15.4)	395
2002	247 (60.2)	95 (23.2)	68 (16.6)	409
2003	242 (58.6)	98 (23.7)	73 (17.7)	413*
Total	1 183 (59.8)	467 (23.6)	327 (16.5)	1 977*

\*Age unknown for 1 patient.



Fig. 2 shows the infectious causes of death. HIV/AIDS caused over 60% of the 1 038 deaths and, causing 31.6% of all deaths, was by far the most prevalent specific cause of death. There were 95 deaths attributable to the disease in 1999, the number rising each year to peak at 148 deaths in 2002 and dropping to 135 deaths in 2003. The mortality rate for HIV/AIDS per 1 000 hospital admissions peaked at 6.5 in 2002, dropping to 5.8 in 2003. The proportion of total hospital deaths attributed to HIV/AIDS increased from 26.2% in 1999 to 36.1% in 2002 before falling to 32.6% in 2003. Of the 626 HIV-related deaths, 72% occurred in children < 1, 22% in the 1 - 5 group, and 6% in the > 5 group. The age-related mortality burden from HIV infection decreased with increasing age: 451 (38.1%) of deaths in children < 1, 138 (29.6%) of deaths in the 1 - 5 group, and 37 (11.3%) of deaths in the > 5 group. The proportion of deaths due to HIV infection increased in all age groups over the study period. This was particularly evident in the 1 - 5 group; 19.3% of the deaths were associated with HIV in 1999 compared with 36.7% in 2003.

Fig. 3 provides a subclassification of the 576 deaths due to non-communicable disorders, based largely on organ systems.

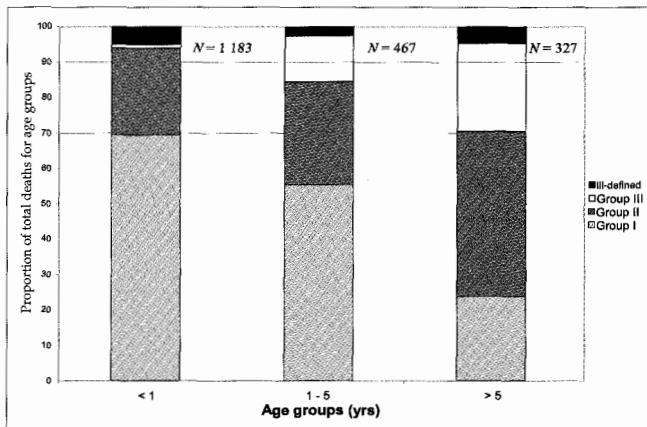


Fig. 1. Proportion of deaths within each age group in relation to the 4 Global Burden of Disease categories of causes.

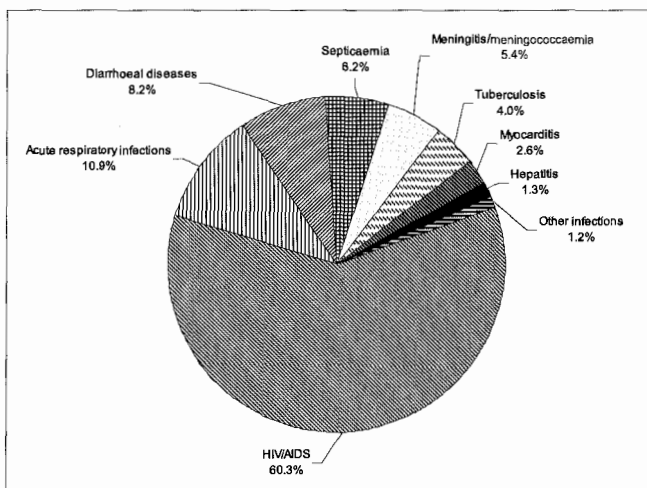


Fig. 2. Infectious causes of death at the Red Cross Children's Hospital from 1999 to 2003 (N = 1 038).

Cerebral palsy constituted more than 75% of the nervous system disorders, and cardiomyopathy accounted for a similar proportion of the cardiovascular mortality. Neoplastic deaths were most commonly caused by cancers of the nervous system and of the blood or immune systems.

Fig. 4 provides a breakdown of the 331 congenital causes of death. Congenital abnormalities contributed significantly to the overall mortality, with 'other congenital conditions' comprising nearly 10% of all deaths and congenital heart disease (CHD) making up nearly 7% of all deaths. Given the frequent co-morbidity of Down's syndrome and CHD (16 of the 26 Down's syndrome patients had some form of CHD), any patient whose cause of death was attributed to both of these conditions was classified as Down's syndrome for the purposes of this analysis. Females had a greater number of CHD deaths than males ( $p = 0.003$ ). Mortality rate for CHD per 1 000 hospital admissions was 65% higher for female children (OR 1.65, 95% CI: 1.18 - 2.32) than that for male children.

There were 156 deaths (7.9% of all deaths) attributed to injuries. There was insufficient information on the nature of

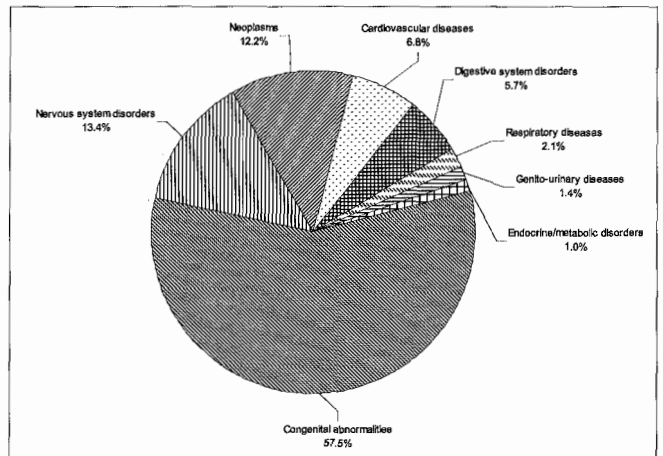


Fig. 3. Non-communicable causes of death at Red Cross Children's Hospital from 1999 to 2003 (N = 576).

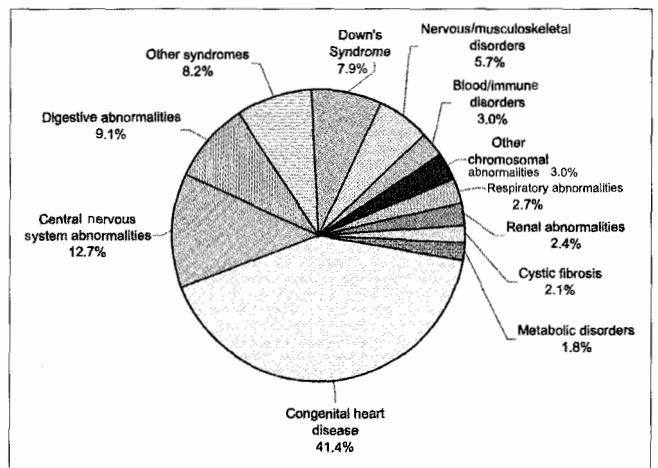


Fig. 4. Congenital causes of death at Red Cross Children's Hospital from 1999 to 2003 (N = 331).



the trauma to further subclassify these deaths. From the data available, it appeared that motor vehicle accidents were the most common form of fatal trauma.

Analysis of the specific causes of death by age group revealed some clear differences in the mortality profiles. HIV infection was the leading cause of death for children <1 and 1 - 5. In children > 5, it was the third most common cause of death following injuries and disorders of the nervous system (largely cerebral palsy). Infectious diseases accounted for over 60% of deaths in children < 1, 50% in children 1 - 5, but 24% in children > 5. In children < 1, 5 of the top 10 causes of death were infectious diseases, with HIV infection, ARI and diarrhoeal disease accounting for just over half of the deaths. Non-communicable conditions such as neoplasms, nervous system disorders, and cardiovascular diseases became more prominent in the older age groups. Injuries did not appear in the top 10 causes of death for children < 1 yet were the second most common cause in children 1 - 5 and the leading cause of death in children > 5.

Admissions to the hospital were particularly high in the summer and early autumn and lowest in the winter. However, there was no seasonal pattern in total deaths or the rate of inpatient death (data not shown). Seasonal fluctuation was observed in two specific categories of death, viz. diarrhoeal disease and ARI. Deaths due to diarrhoeal disease consistently peaked in mid-summer to early autumn, with nearly 60% of these deaths over the 5 years occurring between February and May. The death rate from diarrhoea per 1 000 hospital admissions was 3 times as high during these months as in the other 8 months (3.0 v. 1.0).

Deaths due to ARI exhibited a different pattern, tending to peak in early winter (May - June), with the lowest incidence in the late spring and summer (November - January). There appeared to be a second peak in mortality rates per 1 000 hospital admissions for all respiratory deaths occurring in the late winter and early spring (August - October) (Fig. 5). This

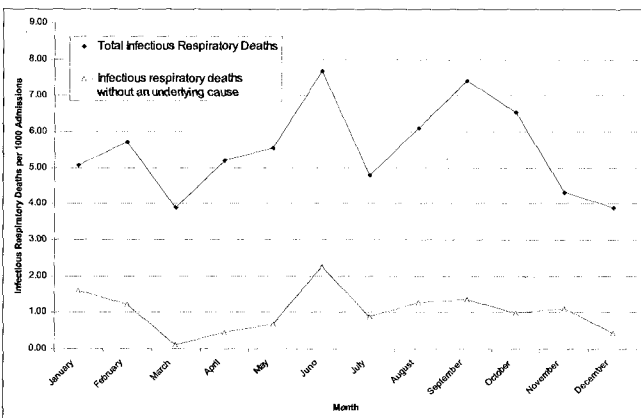


Fig. 5. Seasonal variation in mortality rate per 1 000 hospital admissions - infectious respiratory diseases.

disappeared when patients at increased risk of respiratory infection (underlying HIV/AIDS, malnutrition, disorders of the blood or immune system, cerebral palsy, CHD) were excluded from the analysis (Fig. 5).

## Discussion

This study has shown the value of keeping routine data on deaths in a hospital. The data were systematically recorded over 5 years, allowing an analysis that can inform managers, planners and clinicians. For example, the demonstration that there is a tripling of in-hospital mortality from diarrhoea in the summer months requires investigation. The magnitude of the effect of HIV/AIDS on childhood in-hospital death demands a response in terms of health resource provision. However, although this study used both direct and underlying cause of death, which allowed more detail than the Burden of Disease studies for South Africa<sup>1</sup> and for Cape Town,<sup>12</sup> this method is still limited by the lack of detail on other factors (e.g. health service factors) that contributed to the deaths. Nevertheless if simple data such as those collected here were routinely recorded, valuable information on trends and patterns of hospital-related deaths would be available. Indeed it is notable that 'ill-defined' causes of death were considerably fewer than in other South African death certification studies,<sup>7,13</sup> reflecting the potential value of hospital-related mortality data. Simple guidelines on filling in the second page of the death notification form have been supplied to most new medical staff at the RCCH since the late 1990s. These have been reinforced by the clerical staff responsible for collating the forms.

While the RCCH's large referral base complicates the drawing of conclusions on the relevance of these data to child mortality in general, comparison of these figures with a study of mortality in Cape Town in 2001<sup>12</sup> shows that 1 in 6 of the 1 845 deaths under the age of 14 years in metropolitan Cape Town in 2001 were registered at the RCCH. Similarly the preponderance of deaths from the metropolitan areas that refer children with primary- and secondary-level health problems to the RCCH enables conclusions to be drawn regarding common causes of death in childhood in these largely low-income communities. The leading causes of death in this study are congruent with the South African and Cape Town Burden of Disease studies,<sup>12,14</sup> supporting the potential utility of the RCCH data in drawing conclusions on mortality in the surrounding population. The differing rates of perinatal (lower) and congenital (higher) causes of death reflect the RCCH's position in the health care system.

Causing at least 1 in 3 deaths, HIV/AIDS stands out as by far the most common cause of death. This figure is likely to be an underestimate of HIV's role in causing death as to some extent doctors remained reluctant to certify it as the cause of death.<sup>9,15</sup> The predominance of HIV parallels the findings of the Burden of Disease studies of the South African Medical



Research Council in which HIV accounted for 40% of under-5 deaths.<sup>14</sup> This method of collecting data cannot prove that the children certified as dying of HIV/AIDS and its complications were indeed infected by the virus since infection was not confirmed with laboratory assays for the virus, but it is likely that disease severe enough to kill the children reflected true infection in most cases. Its dominance is a challenge to the health system to prevent mother-to-child transmission of HIV and to provide antiretroviral therapy to infected children. In this way, a considerable impact could be made on infant and under-5 mortality rates. An increasing proportion of older children died from HIV/AIDS, a sign of a maturing childhood epidemic in Cape Town. It is possible that the decrease in HIV-related mortality in 2003 is indicative of the efficacy of moves to control this epidemic in the Western Cape. Another potential explanation for this phenomenon – that more patients were being sent home to die – is not supported as there was no increase in out-of-hospital HIV-related deaths in 2003.

The contribution of malnutrition to mortality will have been underestimated using this methodology. Only the most severe forms of malnutrition are likely to have been recorded as causes of death, and even then only where other severe conditions were not present. An unpublished study of HIV/AIDS deaths at the RCCH showed that over half of the children were severely malnourished (T Westwood and L Henley – personal communication, 2002).

The higher death rate in female children was an unexpected finding. This phenomenon in HIV/AIDS and CHD, both of which accounted for a large number of deaths, may simply reflect an inability to demonstrate a similar difference for less common conditions. The higher mortality among female children undergoing cardiac surgery for CHD has been described in California, USA<sup>16</sup> but an equivalent risk in HIV/AIDS has not been described before. This phenomenon requires investigation.

The demonstration of a distinct seasonal profile for death rates attributable to diarrhoea and ARI is further proof of the value of routinely analysing child deaths. The higher death rate in certain seasons might reflect higher acuity or, alternatively, the inability of the health system to cope with increased numbers of sick children. The two possibilities would have different solutions. Further research will be necessary. These findings have led to a concerted drive to prevent summer diarrhoea in children in Cape Town and to improve its management.

Deaths due to injury require further analysis. Injuries represented a significant cause of childhood mortality in this population, especially in the older age groups. The current system of data collection around injury-related deaths provides insufficient detail to allow for meaningful clinical or public health intervention. However, many of the trauma-related deaths at RCCH have forensic postmortem examinations, so a system to marry the forensic details with the current mortality

database would allow a more complete assessment of injury-related deaths.

Childhood deaths are largely preventable. It is therefore important to have as much detail as possible on their causes in order to implement appropriate and timely responses. Current and sufficiently detailed information is therefore critical. Many approaches are being employed to improve child mortality information systems in South Africa. The 'Morbidity and Mortality' approach recommended by the Western Cape Department of Health is now being implemented at the RCCH. This is staff-intensive and is not carried out consistently in all departments. The large number of deaths each month complicates complete data capture, but the system could be useful in providing a forum for preventable causes of mortality to be identified and remedial actions to be taken. A more extensive approach involving detailed classification of factors that lead to the death of children who present to hospitals has been explored in the North West province.<sup>6</sup> Further refinements of the methodology are taking place. Its practicality and value for routine collection in a large urban environment such as Cape Town have yet to be demonstrated. This study has clearly demonstrated that, with clinical supervision, the collection and analysis of simple routine hospital data on childhood deaths can lead to useful outputs.

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