Deaths at the Red Cross Children's Hospital 1999-2003

A report by:

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ABBREVIATIONS

ARV	Antiretroviral therapy
CHD	Congenital heart disease
GBD	Global Burden of Disease report
ICD-10	International Classification of Diseases version 10
MRC	Medical Research Council of South Africa
PMTCT	Prevention of Mother-to-Child Transmission of HIV
RCCH	Red Cross Children's Hospital
TB	Tuberculosis

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EXECUTIVE SUMMARY

The availability of cause-specific mortality data for children in South Africa (SA) is limited. This report, detailing a study of hospital-related childhood deaths at the Red Cross Children's Hospital (RCCH), a 288 bed referral facility in Cape Town, aims to expand our understanding of cause-specific childhood mortality. The objectives of the study were to gain insights into the causes of death and the systems that capture the data, and to provide a baseline for future data collection and analysis of trends in child mortality in the Cape Town area.

All death registration forms filled in by the RCCH's medical staff from 1999 to 2003 had been recorded in a database that formed the basis of the study. Data were analysed by direct and underlying cause of death (using a modified Global Burden of Diseases (GBD) classification), site of death and demographic variables such as age, sex and area of residence. Case fatality rates per 1000 hospital admissions were calculated for certain common causes of death. Seasonal correlates of mortality were also examined.

There were 1978 deaths registered at the RCCH from 1999 to 2003. The number of deaths per year increased by 11.4% over this period. In all, 1667 died as inpatients, the others dying outside the hospital (mostly at home) or in the Emergency areas. The death rate per 1000 admissions rose from 15.9 to 18.4 from 1999 to 2002 and then declined to 17.4 in 2003.

More male patients were admitted than females but the death rate was higher for females (18.4 versus 17.6 p = 0,007). Children less than 1 year old at death comprised 60% of all deaths. Overall mortality did not vary by season or month.

Almost half of all the children who died came from two metropolitan low income areas that the RCCH serves: Khayelitsha 26.5%, Nyanga/Guguletu 20.1%.

Most children died in the hospital's Intensive Care Unit (37.8%) or the medical wards (35.8%).

GBD Group I conditions (infectious and parasitic, nutritional, perinatal) accounted for 58.6% of deaths, Group II (non-communicable diseases) 29.1% and Group III (injuries) 7.9%. Only 4.3% of deaths were ill-defined. In GBD Group I infections dominated (89.5%). HIV/AIDS accounted for 60% of these deaths.

Of the Group II diseases, congenital conditions dominated (57.5%) reflecting the RCCH's referral and tertiary functions. Congenital cardiac causes comprised 41.4% of these congenital causes, by far the commonest single group. Notably, girls died of heart conditions at a greater rate than boys.

The 156 injury-related deaths (GBD Group III) could not be further analysed owing to the paucity of specific information.

Infants largely died of infections (69.5%) as did children who died aged between 1 and 5 years (55.5%) but, over 5 years of age, GBD Group II causes made up over half of the deaths. These differences were statistically significant ($p < 0,0001$).

HIV/AIDS accounted for 31.6% of all deaths. The number of deaths increased steadily over the study period, and the number of deaths in 2003 represented an 11.4% increase in mortality from 1999. The proportion of all deaths attributable to HIV/AIDS also declined for the first time in 2003. The death rate for girls with HIV/AIDS was higher than that for boys (6.1 versus 5,1). HIV/AIDS-associated deaths congregated in the younger age groups but their role in the older groups took on greater significance over the 5 year period, doubling in the 1 to 5 year age group. Pneumonia was the commonest cause of HIV-related death at 51.2% followed by septicaemia (16.8%).

Diarrhoea related mortality rates were three times as high in summer as in winter. Respiratory deaths aggregated in early winter.

The hospital system for capturing death-related data had changed over time and did not capture any of the non-demographic details held in the database analysed here. Even the fact that the child had died was often not reflected. The new *Clinicom* system has the potential to capture this data.

The analysis has shown the value of routinely recording data such as had been collected in the database. Trends were found, even in a 5-year period. Previously unknown and unsuspected facts were unearthed e.g. the higher in hospital mortality in females and the seasonal variation in cause-specific death rates.

This data's relevance to general mortality in SA and Cape Town is less clear, but 1 in 6 metropolitan deaths occurred at RCCH and the pattern of causes mirrored that of the Medical Research Councils Burden of Disease studies of Bradshaw and colleagues. As they showed, preventable causes of childhood death predominate in the South African population.

At 31% of all hospital deaths at a tertiary referral hospital, HIV/AIDS-related deaths clearly provide a major challenge to the health system in the terms of prevention of infection and controlling the childhood epidemic of perinatally-acquired disease.

This study should be seen as part of national attempts to improve our understanding of factors leading to avoidable deaths in childhood. Recommendations have been made regarding the capture of routine death-related data on *Clinicom*, clinical service provision and training, and for further research.

I. INTRODUCTION

The limitations of available cause-specific mortality data in South Africa have been well documented (van der Merwe S et al, 1991). Although the adoption of the revised death registration form in 1998 (Bradshaw et al, 1998) has led to an improvement in the systems for capturing the cause of death, many deaths are still misclassified or recorded simply as "unknown" or "natural causes" (van der Merwe S et al, 1991). Cause-specific mortality data for children can be even more problematic, especially when children do not die under the auspices of a health care facility. In light of these shortcomings, smaller, local death enquiries can provide valuable detail on the specific causes of death within a given population and augment larger, aggregate data sets at provincial and national level.

Given the absence of any cause of death data collected within the hospital's electronic information system and the lack of a hospital-specific mortality report generated by the Department of Health or the Department of Home Affairs, this study was undertaken to elucidate the mortality profile at the Red Cross Children's Hospital (RCCH) in Cape Town. The study is based on a data set maintained by one of the hospital consultants. By providing an understanding of the causes of child deaths at the RCCH, this study aimed to:

1. Inform RCCH clinical staff of the diseases contributing most to the mortality burden at the hospital and potentially stimulate improvement or alterations in the clinical care provided for these conditions.
2. Enhance the ability of hospital administrators to target the most appropriate and cost-effective resource allocations and staff training for an efficient and successful response to these causes of death in a resource-limited environment.
3. Provide a foundation for tracking the changing epidemiology of child deaths at the hospital, e.g. monitoring the mortality burden of HIV as the epidemic evolves, especially in light of the recent roll-out of the Prevention of Mother-to-Child Transmission of HIV (PMTCT) and antiretroviral therapy (ARV) programmes in the Western Cape Province.
4. Assess and recommend updates to the current data collection process for child deaths at the hospital in order to develop an efficient and sustainable electronic information system for capturing future child mortality data.
5. Determine the approximate proportion of Cape Metropole child deaths that occur at the RCCH to assess the extent to which the results of this study can be generalised to the larger population.

The RCCH is a 288-bed hospital affiliated to the University of Cape Town and has tertiary and regional functions. The hospital is largely funded by the State through the provincial Department of Health. It is a referral hospital but also houses 24-hour Trauma and Emergency Units, both of which have short stay in-patient beds. It is the only paediatric in-patient facility for the central health districts of the Cape Metropole. Its full range of paediatric tertiary services (including an intensive care unit) receives referrals from southern, central and western parts of the Cape Metropole, the southern half of the Western Cape Province, from the other tertiary children's services in the province and from 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.

II. METHODS

A. Study Population

Information was collected on all child deaths that occurred under the services of the RCCH from 1999 to 2003.

B. Data Collection

Death registration forms were filled out by physicians at the hospital, and they were reviewed by a single physician (Dr. A. Westwood) before being entered into a Microsoft Excel database. The following information was extracted from the death registration forms:

- hospital folder number;
- age, stratified into three groups: below 1 year of age (<1), 1-5 completed years (1-5), 5 years and over (>5);
- direct cause of death;
- underlying cause of death (when provided); and
- place of death (e.g. hospital ward).

In certain exceptions, a patient's medical record was reviewed to obtain clarity on the certified cause of death. Patient folder numbers were subsequently used to retrieve data on the sex and postal code for each death from the RCCH medical records system. Sex data was available for 98.7% of the patients in this study. Sex could not be obtained for 25 of the patients because either the sex of the patient was recorded as unknown (1) or the folder number could not be found in the computer system (24).

Similarly, postal code information could not be obtained for the 24 invalid folder numbers. Folder numbers that were invalid were believed to be transcription errors and still represented true deaths, so they were not excluded from the calculations of total deaths, but they were removed for analyses involving sex and postal code. There was no apparent systematic bias among the patients with missing sex and postal code, so analysis with these cases excluded was deemed valid.

C. Classification of Deaths

The cause of death in each case was classified by the study physician according to the International Classification of Diseases version 10 (ICD-10). In keeping with ICD-10 regulations, which specify that deaths must be assigned to one cause, the ICD-10 code was assigned based on the underlying cause of death, if given, or the direct cause if no underlying cause was recorded. For instance, for an HIV-infected patient who was admitted to the hospital and died of an opportunistic pneumonia, the direct cause of death may have been listed as pneumonia while the underlying cause was recorded as HIV infection. In this case, the ICD-10 coding would reflect a death due to HIV infection, not pneumonia.

Following ICD-10 coding, the causes of death were grouped according to a classification scheme modified from the Harvard School of Public Health Burden of Disease Unit's Global Burden of Disease report (GBD) (Murray and Lopez, 1996) and the South African National Burden of Disease study (Bradshaw et al, 2000). Under this scheme, deaths were grouped into three broad categories, with a fourth category reserved for "ill-defined" deaths:

Group I	Pre-transitional causes: communicable diseases, perinatal conditions, and nutritional deficiencies
Group II	Non-communicable diseases
Group III	Injuries
Ill-defined	Deaths of unknown or unclear aetiology

Groups I and II were further subdivided into major categories, such as infectious diseases, neoplasms, and congenital anomalies (see Appendix). Further sub-division of Group III was not possible due to the limited information regarding the specific nature of the trauma deaths. It should be noted that the original GBD classification contains an additional sub-group, maternal conditions, within Group I.

The RCCH is strictly a paediatric hospital and does not offer obstetric services, so all child deaths recorded in this study occurred after birth and none were attributed directly to a condition present in the child's mother. Two of the larger major categories, infectious diseases and congenital abnormalities, were further sub-classified to provide more detail into the precise cause of death (see Appendix). Some of the major groups and the sub-classification of infectious diseases and congenital abnormalities were altered from the GBD scheme to better represent the causes of death observed at the RCCH.

D. Mortality Analysis

To calculate a case fatality rate, the number of discrete hospital admissions was approximated by summing the total discharges and total deaths for each year of the study. A composite of discharges and deaths was used as a proxy for formal admissions, because admission data are complicated by transfers between wards within the hospital, which are classified as separate "admissions" in the RCCH computer system, thereby potentially diluting the death rate.

E. Rankings

As causes of death can be aggregated on different levels of specificity, decisions were made when ranking the "specific" causes of death to compare roughly equivalent groups while still emphasising the causes of death that are most prevalent at the Red Cross Children's Hospital. The injuries (Group III) were not disaggregated beyond the broad group level due to a lack of complete information on the specific nature of the trauma. Group I causes were unpacked to the next level of detail (Major Category), and infectious causes were further disaggregated into specific diseases. Group II conditions were unpacked to the level of organ system (e.g. cardiovascular diseases) except for congenital abnormalities which were further disaggregated to "congenital heart disease" (CHD) and "other congenital abnormalities" to highlight the high prevalence of CHD in this population.

F. Health District Analysis

The deaths were classified according to Metropolitan Health Districts based on the postal code.

G. Seasonal Analysis

Certain diseases are known to have a strong seasonal incidence in Cape Town. Seasonal variation was examined for two categories of death: diarrhoeal diseases and respiratory infections. Any patient with either a direct or underlying cause of death attributed to diarrhoeal disease (e.g. gastroenteritis, dysentery) or an acute respiratory infection (e.g. pneumonia, lower respiratory tract infection) was classified as a case. For instance, if a patient with underlying HIV infection died from acute gastroenteritis, the ICD-10 code for cause of death reflected HIV infection but the patient would be included as a case of diarrhoeal disease. Including all cases avoided washing out the possible seasonal effect by removing patients with underlying immunodeficiency, malnutrition, or central nervous system disorders.

H. Statistical Analysis

The SPSS software package was used for all statistical calculations.

III. RESULTS

A. TOTAL DEATHS

1. General Total Deaths

A total of 1 978 deaths were registered at the RCCH for the period of 1999 – 2003, occurring either in the hospital or under the hospital's aegis. The number of deaths increased steadily over the study period, and the 414 deaths in 2003 represented an 11.4% increase in mortality from 1999 (Table I).

Table I: Total deaths under the aegis of the Red Cross Children's Hospital from 1999 to 2003, by age and sex

	All Deaths	**Males**		**Females**		**< 1**		**1 – 5**		**> 5**	
Year	#	#	%	#	%	#	%	#	%	#	%
1999	367	204	55.6	160	43.6	215	58.6	83	22.6	69	18.8
2000	392	204	52.0	181	46.2	242	61.7	94	24.0	56	14.3
2001	395	209	52.9	177	44.8	237	60.0	97	24.6	61	15.4
2002	410	233	56.8	175	42.7	247	60.2	95	23.2	68	16.6
2003	414	215	51.9	195	47.1	242	58.5	98	23.7	73	17.8
Total	1 978	1 065	53.8	888	44.9	1 183	59.8	467	23.6	327	16.5

Of the total deaths, 139 occurred outside the hospital and consisted of patients who died at home, were certified 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 in-patient deaths during the study period.

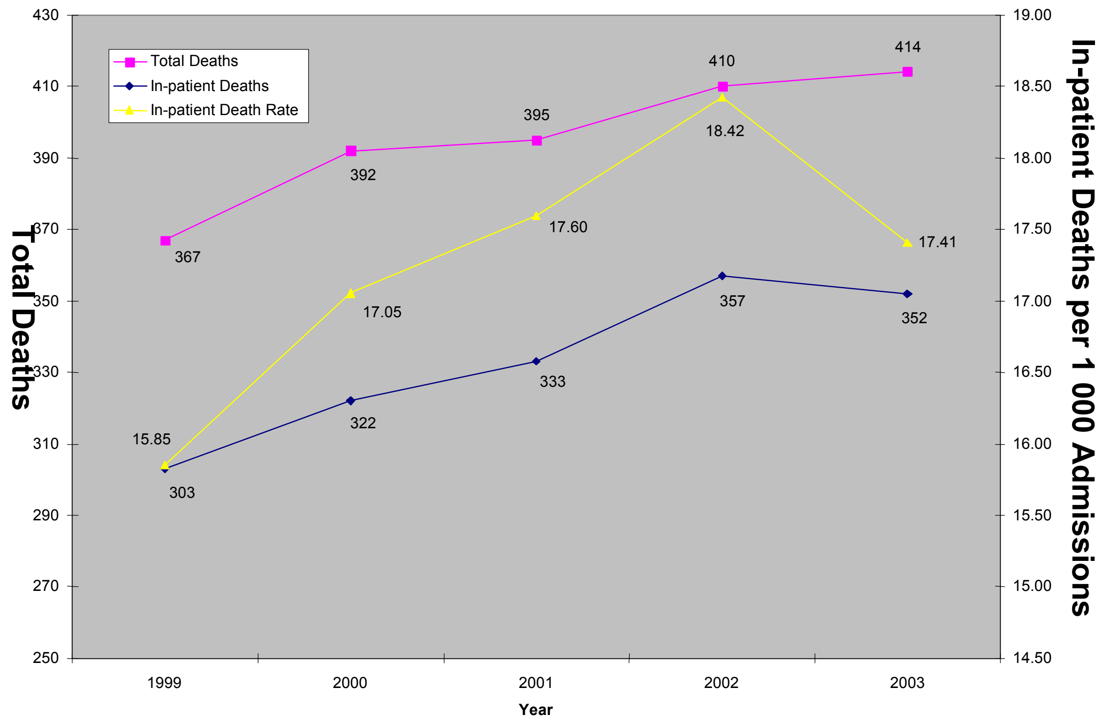
Case fatality rates were calculated for these 1 667 deaths. Total in-patient admissions ranged from 18 562 in 2000 to 19 870 in 2003, a 6.6% increase. The absolute number of in-patient deaths as well as the rate of death per admission to the hospital increased steadily from 303 deaths (15.9 per 1 000 admissions) in 1999 to 357 deaths (18.4 per 1 000 admissions) in 2002 (Table II and Figure 1, on the next page).

A child admitted to the RCCH was approximately 16% more likely to die in 2002 than in 1999 (Odds Ratio = 1.165, 95% CI: 0.998 – 1.360) and this difference almost achieved statistical significance (Pearson chi-square = 0.052). The case fatality rate dropped to 17.4 in 2003, marking the only decrease in the rate during the study period.

Table II: Case fatality rates by sex for children at the Red Cross Children's Hospital from 1999 to 2003

Year	Total In-patient Deaths	Deaths/1 000 Admits	Male In-patient Deaths	Male Deaths/ 1 000 Admits	Female In-patient Deaths	Female Deaths/ 1 000 Admits	Female/ Male Odds Ratio	95% CI	Pearson Chi - Square
1999	303	15.9	163	14..6	138	17.3	1.189	0.946 – 1.494	0.138
2000	322	17.1	172	15.6	146	18.6	1.200	0.960 – 1.498	0.109
2001	333	17.6	180	16.3	145	18.4	1.130	0.907 – 1.410	0.276
2002	357	18.4	203	18.2	152	18.5	1.017	0.823 – 1.258	0.874
2003	352	17.4	185	15.9	163	19.0	1.202	0.972 – 1.486	0.089
Total	**1 667**	**17.3**	**903**	**17.6**	**744**	**18.4**	**1.144**	**1.037 – 1.261**	**0.007**

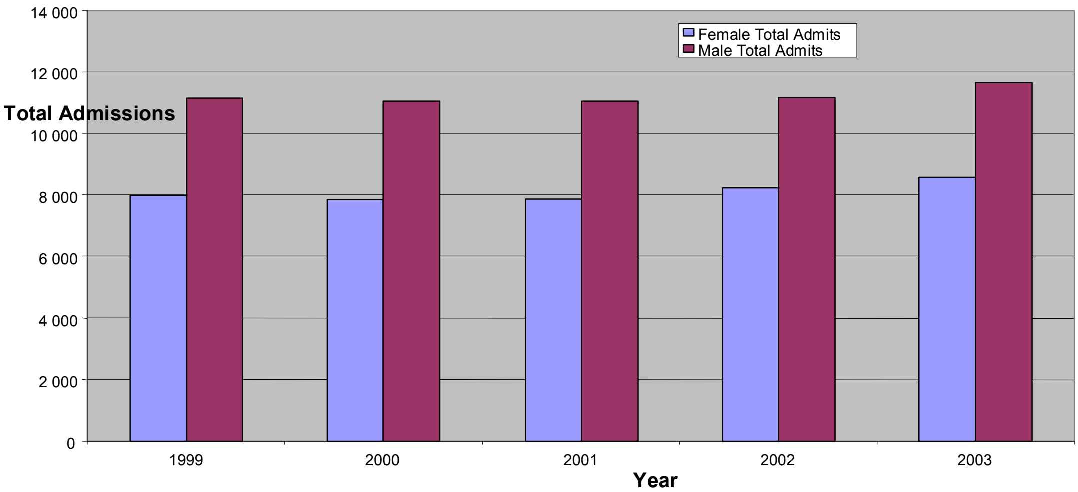
Figure 1: Total deaths, in-patient deaths, and in-patient death rate (per 1 000 admissions) at the Red Cross Children's Hospital from 1999 to 2003



2. Total Deaths by Sex

There were clear discrepancies in mortality between males and females as well as the number of patients treated at the hospital. During the course of the study, the RCCH treated over 15 000 more male patients than female patients, an average of roughly 3 000 more per year (Figure 2).

Figure 2: Admissions at Red Cross Children's Hospital from 1999 to 2003, by sex

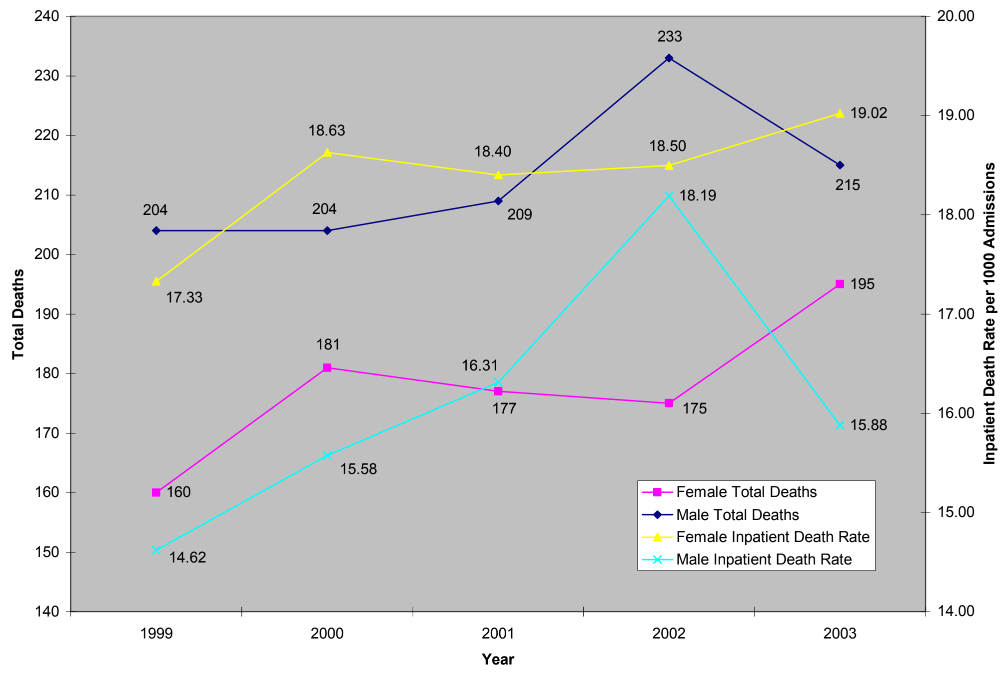


Probably as a result of this discrepancy in admissions, there were 903 male in-patient deaths compared with only 744 female in-patient deaths. This trend was similar when deaths outside the hospital were included, with 1 065 male deaths and 888 female deaths.

However, while there were more absolute male deaths in the hospital, female patients were dying at a greater rate per admission. The average case fatality rate for females was 18.4 deaths per 1 000 admissions, compared with 17.6 per 1 000 admissions for male children.

This difference was statistically significant (Pearson chi-square = 0.007, Figure 3 on the next page). The largest discrepancy in case fatality occurred in 2003, when there were 19.0 female deaths per 1 000 admissions and only 15.9 male deaths per 1 000 admissions. Over the five years study period, a female patient admitted to the hospital was approximately 14% (Odds Ratio = 1.144) more likely to die than a male patient.

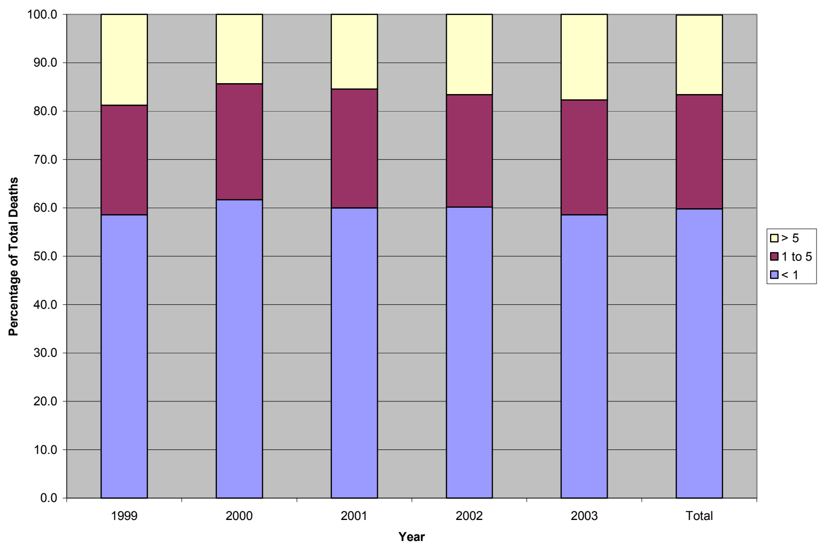
Figure 3: Crude deaths and in-patient death rate by sex



3. Total Deaths by Age

The absolute number of deaths per age group declined as children grew older. Children <1 comprised nearly 60% of the deaths in the 5-year period while children in the 1-5 age group and >5 group made up approximately 24% and 16% of the deaths respectively. These proportions remained relatively constant over the study period as seen in Figure 4.

Figure 4: Proportion of total deaths by age for 1999 to 2003



4. Total Deaths by Month and Season

Admissions to the hospital varied substantially through the months, tending to be higher in the summer and early autumn and lowest in the winter (Figure 5). Over the five years studied, March had the greatest number of admissions (9 526) while January had the fewest (6 896). Admissions in December and January were particularly low, which is likely to reflect both the holiday season and the relatively low levels of infectious diarrhoeal and respiratory diseases in those months (see below).

However, there was no clear pattern in total deaths or the rate of in-patient deaths for the different months, nor was there a distinct pattern within a given month over the five years studied (See Table III on the next page).

Figure 5: Total admissions per month for 1999 to 2003

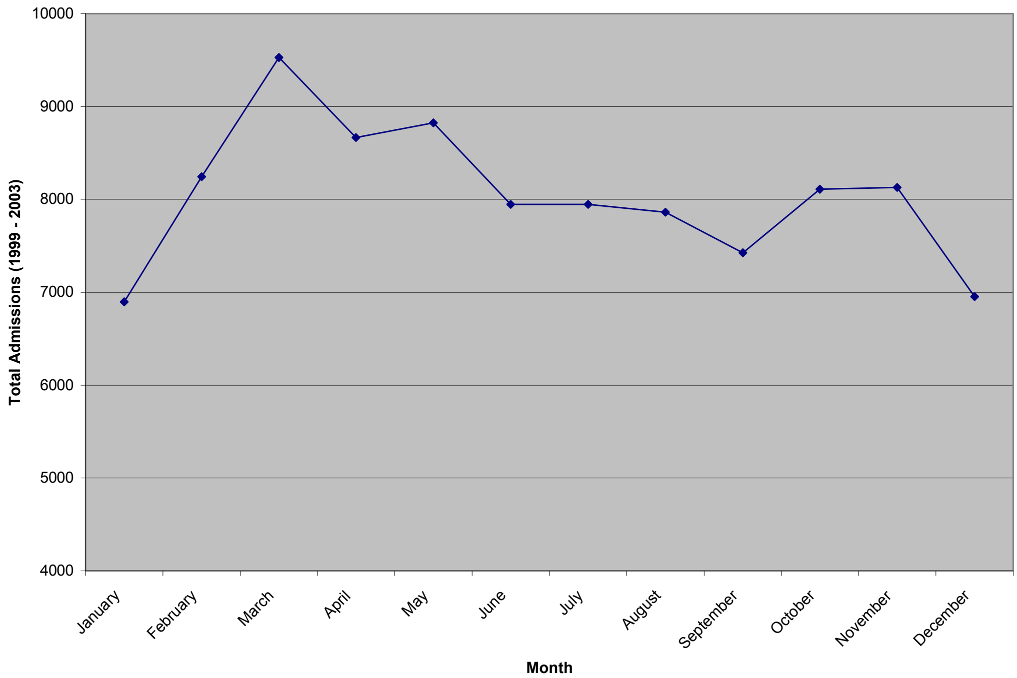


Table III: Monthly deaths per 1 000 admissions from 1999 to 2003

	YEAR										TOTAL	
	1999		2000		2001		2002		2003			
MONTH	#	Rate	#	Rate	#	Rate	#	Rate	#	Rate	#	Rate
January	15	12.4	21	15.2	17	12.2	32	22.7	24	16.0	109	15.8
February	34	20.4	26	15.3	37	24.4	36	21.2	33	19.8	166	20.1
March	34	17.1	35	19.1	21	12.5	34	17.4	43	20.8	167	17.5
April	28	16.1	20	11.8	34	20.9	33	19.2	34	18.0	149	17.2
May	29	16.4	34	19.1	30	17.3	36	21.8	28	14.9	157	17.8
June	29	17.6	35	22.3	28	17.4	36	24.3	26	15.9	154	19.4
July	23	14.3	27	17.2	29	19.0	18	11.6	25	14.8	122	15.4
August	16	10.4	23	14.6	23	15.1	29	17.9	35	21.9	126	16.0
September	26	18.4	32	21.9	29	19.2	29	19.1	22	14.5	138	18.6
October	26	17.1	21	13.9	35	20.2	27	16.6	36	21.0	145	17.9
November	20	13.2	30	19.1	21	12.1	22	13.2	27	16.5	120	14.8
December	23	15.5	18	14.5	29	21.7	25	16.8	19	13.6	114	16.4

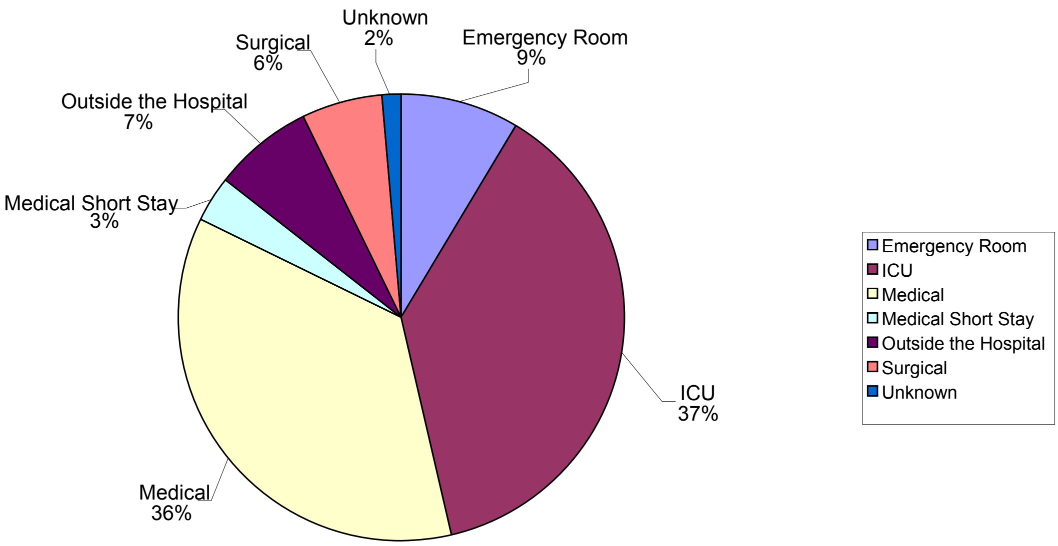
5. Total Deaths by Health District

Using the postal codes for each patient, the deaths were divided into the major Metropolitan Health Districts that were meant to refer patients to the RCCH. Nearly half of all the deaths at the hospital came from two districts, Khayelitsha (26.5%) and Nyanga (20.1%). A significant number of the deaths also came from Athlone (9.6%) and Mitchell's Plain (9.5%). The Central Health District only contributed 13 deaths (0.7%) during the entire study. Although not in the RCCH referral system, Langa was the third most common origin of patients who died (11%).

6. Total Deaths by Location within Hospital

Figure 6 shows that the most common locations for deaths within the hospital were the intensive care unit (37.8%) and the general medicine wards (35.8%). The vast majority (96.4%) of the deaths outside of the hospital occurred at home.

Figure 6: Location of deaths certified under the aegis of the Red Cross Children's Hospital for 1999 to 2003



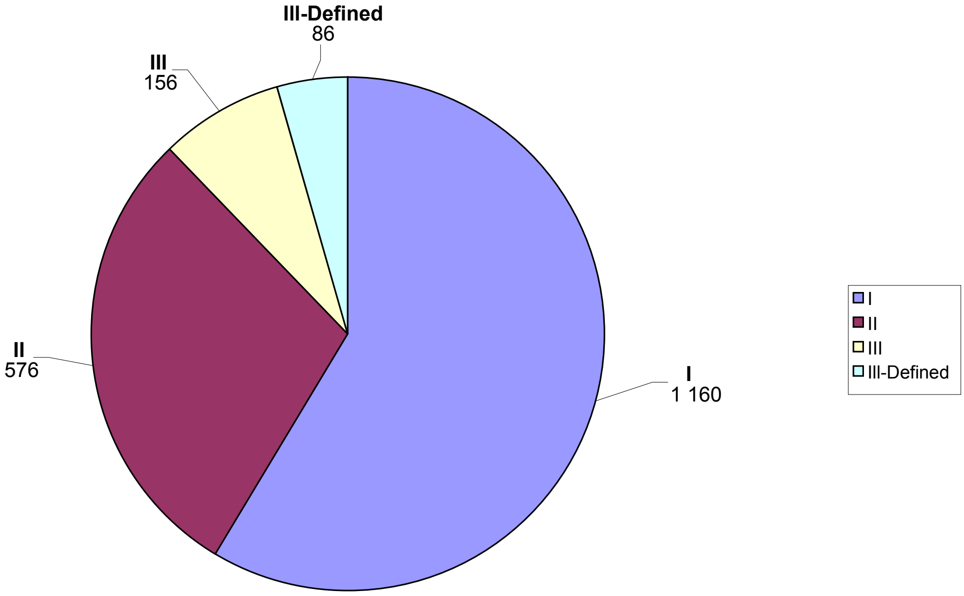
B. SPECIFIC CAUSES OF DEATH

1. Broad and Specific Causes of Death

The causes of death were first divided into three large groups according to the scheme developed for the GBD. Group I diseases (Pre-transitional causes: communicable diseases, perinatal conditions and nutritional deficiencies) accounted for the greatest proportion of deaths (58.6%), followed by the non-communicable diseases in Group II (29.1%), and then the injuries in Group III (7.9%). See Figure 7 on the next page.

Only 4.3% of the deaths were classified as ill-defined where the physician did not have any reliable information on the cause of death (e.g. "natural causes", "unknown", "shock", "dead on arrival"). Included in the ill-defined category were seven cases of Sudden Infant Death Syndrome, or cot death, and these children died at home (2), in the emergency room (4), or in the ICU (1).

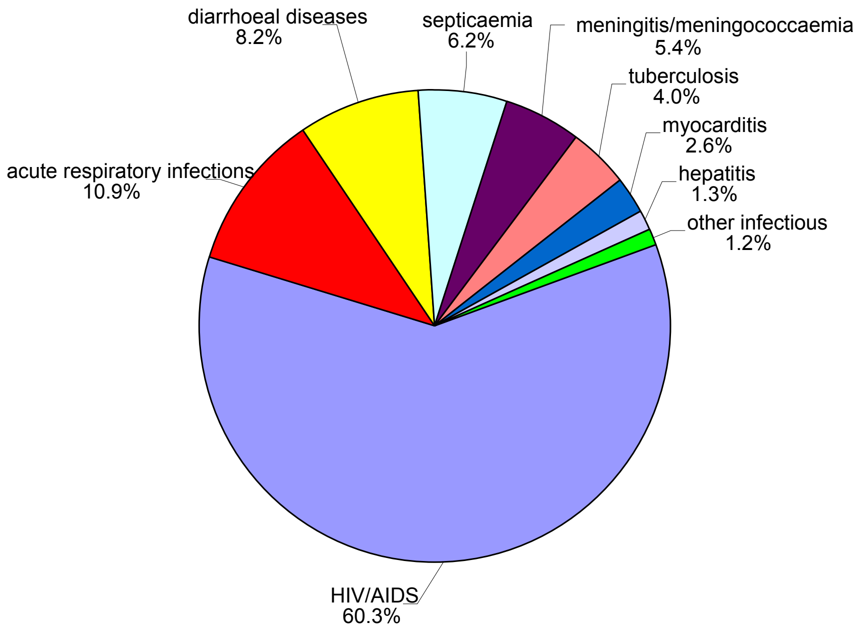
Figure 7: Distribution of broad causes of deaths at Red Cross Children's Hospital from 1999 to 2003 (total number of deaths within each group)



The Group I causes of death were predominantly infectious diseases (89.5%), with perinatal conditions (5.7%), and malnutrition (4.8%) contributing to a lesser extent. Prematurity comprised 48 of the 66 perinatal deaths, while other sources of mortality in this group included birth asphyxia (3), necrotizing enterocolitis (3), neonatal infections (8), and other perinatal conditions (4). Of the deaths attributed to malnutrition, 60.7% were due to kwashiorkor.

HIV/AIDS constituted over 60% of the deaths within the infectious and parasitic diseases, and was by far the most prevalent specific cause of death in this population. Figure 8 on the next page shows the breakdown of infectious causes of death. After HIV infection, acute respiratory infections, diarrhoeal diseases, and meningitis/meningococcaemia were the most common forms of infectious death in children at the RCCH.

Figure 8: Infectious causes of death at the Red Cross Children's Hospital from 1999 to 2003

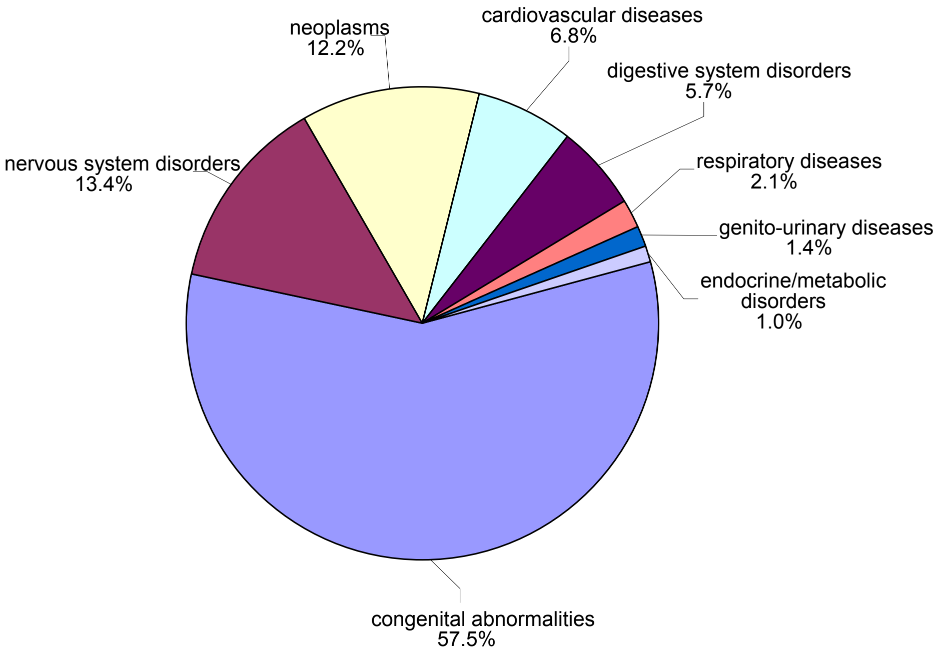


Non-communicable causes of death (Group II) accounted for 29.1% of all deaths during the study period. Figure 9 provides a sub-classification of these deaths based largely on organ systems.

Congenital abnormalities comprised nearly 60% of the mortality attributable to non-communicable conditions. Disorders of the nervous system, neoplasms, cardiovascular diseases, and disorders of the digestive tract also made significant contributions to child mortality.

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 produced by cancers of the central nervous system (e.g. brain tumours) or cancers of the blood or immune system (e.g. leukaemia and lymphoma).

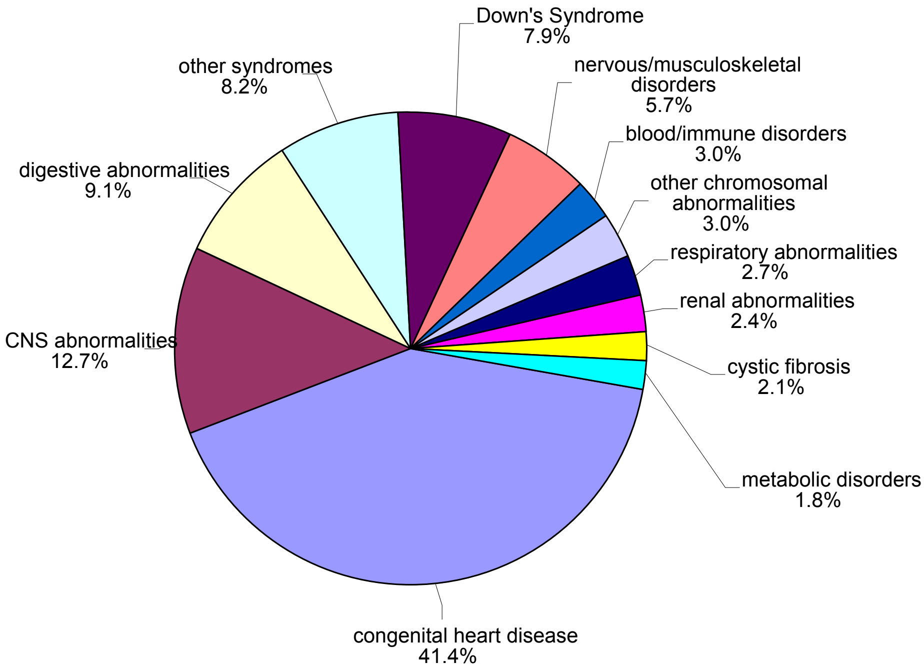
Figure 9: Group II causes of death at Red Cross Children's Hospital from 1999 to 2003



Congenital abnormalities were responsible for so many deaths that this group warranted further sub-classification. Figure 10 on the next page provides a breakdown of the congenital causes of death. CHD was the predominant modality of congenital death, followed by abnormalities of the central nervous system, abnormalities of the digestive system, and Down's syndrome.

Given the frequent co-morbidity of Down's syndrome and CHD (16 of the 26 Down's syndrome patients in this study 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.

Figure 10: Congenital causes of death at Red Cross Children's Hospital from 1999 to 2003



There were 156 deaths attributed to injuries (Group III). At the time of this analysis, there was insufficient information about the nature of the trauma to further sub-classify them. From the data available, it appears that motor vehicle accidents were the most common form of trauma leading to the death of children.

2. Broad Causes by Sex

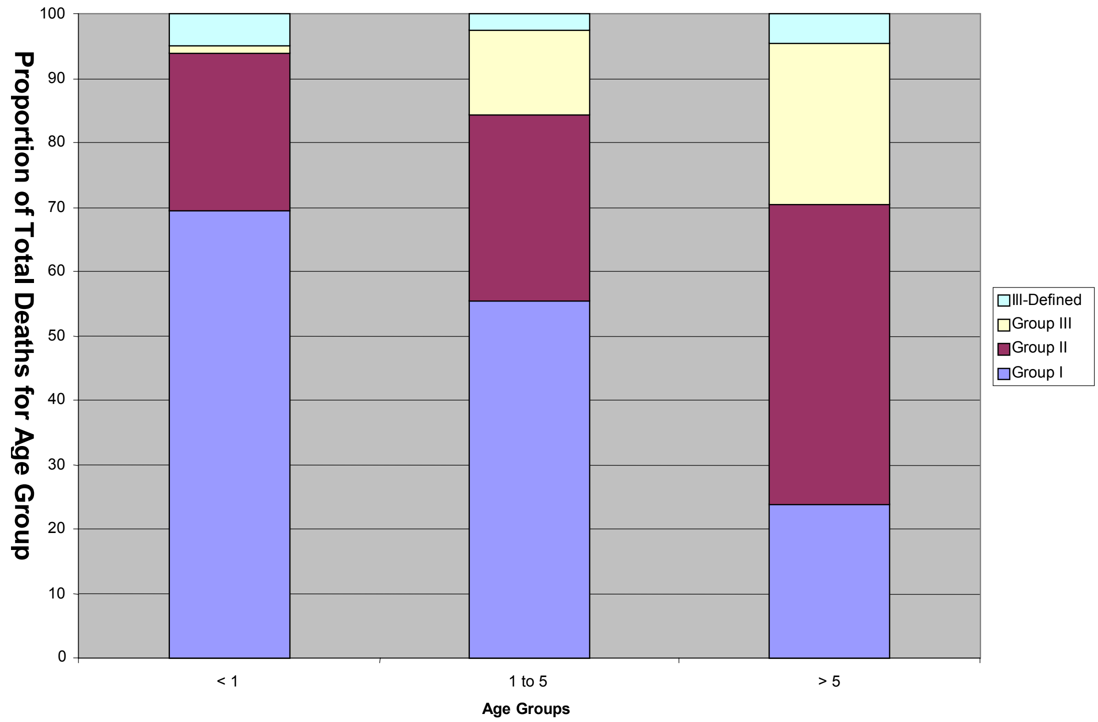
The mortality profile, based on the broad groups of death, was similar for males and females. For both sexes, roughly 60% of the deaths were attributable to Group I causes and 30% to Group II causes. There was some discrepancy in injury-related deaths, with only 6% of female children dying from injuries compared with nearly 9% of male children. However, this difference was not statistically significant given the larger proportion of males treated (Pearson chi-square = 0.158).

3. Broad Causes by Age

The profile of death for each of the age groups was quite distinct. Children <1 were most likely to die of Group I causes (69.5%), followed by non-communicable diseases (24.4%), and then injuries (1.1%). Children 1-5 had the same general pattern, but the proportion of deaths from Group I conditions was reduced to 55.5%, with Group II and Group III deaths increasing to 28.9% and 13.1% respectively. Once children were >5 non-communicable diseases became the predominant modality of death, accounting for 45.7% of mortality. The Group

I conditions only accounted for 24.4% of the deaths in this age group, with injuries constituting 25% of mortality. When the total trauma deaths for each age group were compared with the chi-square "goodness of fit" test, the differences were found to be statistically significant ($p < 0.0001$). Unfortunately, discharge data by age was not available, making it impossible to calculate rates of death and analyse whether older children were statistically more likely to die of injuries, which would be the intuitive conclusion. The cases of ill-defined death were disproportionately allocated amongst the younger patients, with 67% of ill-defined deaths occurring in children in the <1 group.

Figure 11: Proportion of deaths within an age group in relation to the four broad categories of causes



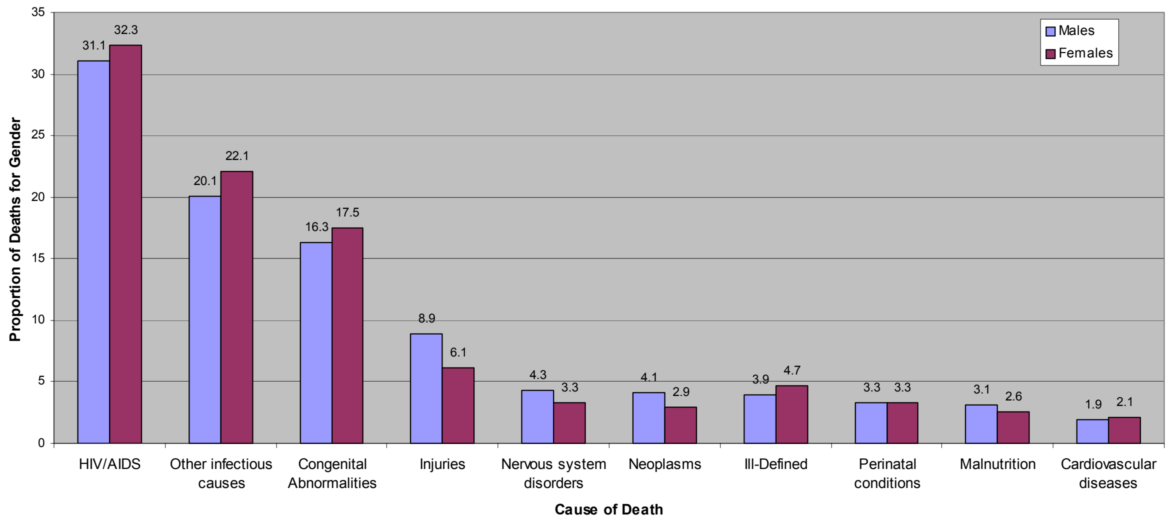
4. Specific Causes of Death for All Children

HIV infection was by far the leading specific cause of death in children at the RCCH, accounting for 31.6% of the total deaths. Congenital abnormalities contributed significantly to the overall mortality, with "other congenital conditions" comprising nearly 10% of the deaths and CHD making up nearly 7% (see Appendix). The large number of deaths from congenital causes can probably be attributed to the RCCH's role as a referral centre for children with congenital disorders, and the proportion of deaths due to these conditions is almost certainly higher than the proportion in the general population. Injuries were the third leading cause of mortality, making up nearly 8% of the deaths.

5. Specific Causes by Sex

For most specific causes of death there were no major disparities between male and female children. Figure 12 provides the proportion of deaths by sex, and which are attributable to specific conditions. As noted previously, a larger proportion of male children died of injuries than female children, but this difference was not statistically significant. Interestingly, females had a greater proportion of CHD deaths than male children, and this difference was significant (Pearson chi-square = 0.003). In fact, when looking at the case fatality rate for CHD deaths based on total admission for sex, female children are roughly 65% more likely to die of CHD (Odds Ratio = 1.649, 95% CI: 1.176 – 2.3193) than male children.

Figure 12: Specific causes of death by sex



6. Specific Causes by Age

Analysis of the specific causes of death by age group reveals some clear differences in the mortality profiles. HIV infection was the leading cause of death for both children <1 and 1–5. However, in children >5, it was only the third leading cause of death behind both injuries and disorders of the nervous system. In general, infectious diseases represented a larger proportion of the mortality burden in younger children, but became less important in the older age groups.

Infectious diseases accounted for over 60% of deaths in children <1, 50% in children 1–5, and only 24% in children >5. In children <1, five of the top 10 causes of death were infectious diseases, with HIV infection, acute respiratory infections, and diarrhoeal diseases accounting for just over half of the total deaths for that age group. Non-communicable conditions such as neoplasms, nervous system disorders, and cardiovascular diseases become more prominent in the older age groups. Injuries did not even make the top 10 causes of death for children <1, but were the second leading cause in children 1-5, and the top cause of death in children >5.

7. Infectious Causes for All Children

Of the infectious causes of death, HIV infection was by far the most common, accounting for over 30% of the child deaths. Acute respiratory infections, diarrhoeal diseases, and septicaemia were the other most common infectious causes.

Tuberculosis (TB) was not as prominent as expected, accounting for only 2.1% of the deaths in male and female children. These cases were those where TB was the cause of death without another underlying condition such as HIV infection. If the cases of TB with underlying HIV are also included, TB still only accounted for 2.5% of the deaths.

8. Infectious Causes by Sex

There was very little difference in the profile of infectious deaths between male and female children.

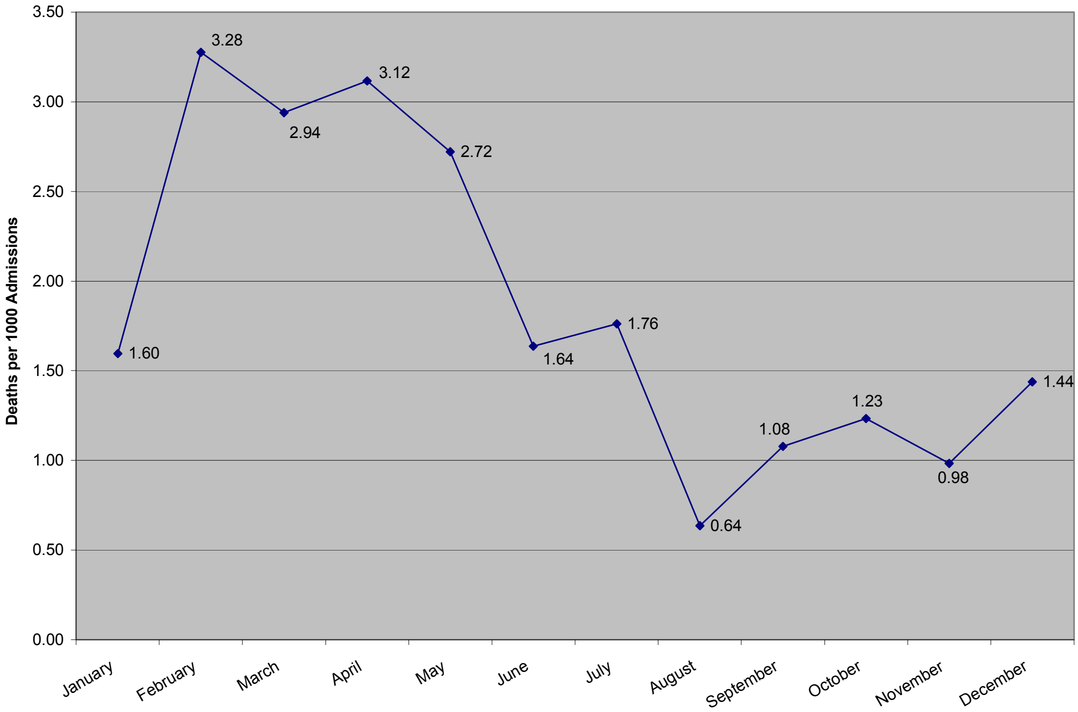
9. Infectious Causes by Age

There was some variation in the infectious death profile between age groups. HIV infection was the leading infectious cause of death for all age groups. However, after HIV infection, children <1 suffered most from acute respiratory infections and diarrhoeal diseases while children 1-5 and >5 suffered most from TB and meningitis. As children <1 accounted for a large proportion of the total deaths, TB and meningitis are not as prominent when considering cumulative deaths over the entire study, but they were still important sources of infectious mortality for older children.

10. Seasonal Variation

Seasonal fluctuation was observed in two specific categories of death: infectious diarrhoeal diseases and respiratory infections. Deaths due to infectious diarrhoeal diseases consistently peaked in mid-summer to early autumn, with nearly 60% of the cases over the five years occurring between February and May (Figure 13 on the next page). Mortality due to gastroenteritis was particularly high in 1999, 2002, and 2003.

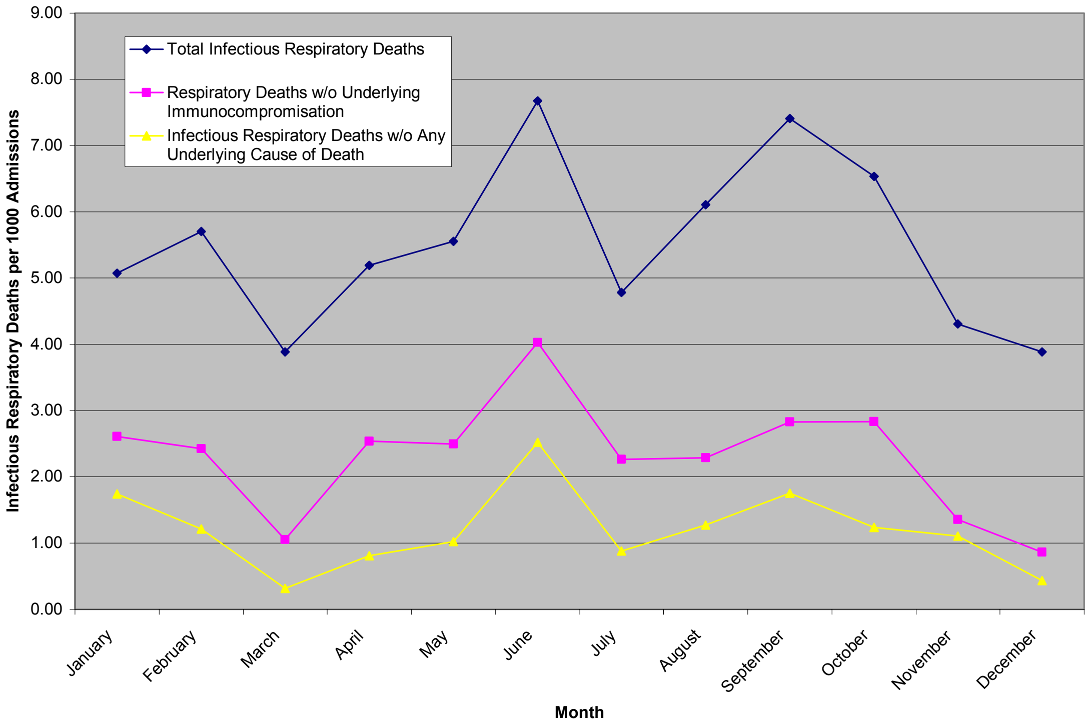
Figure 13: Seasonal variation in case fatality rate for infectious diarrhoeal deaths



Respiratory infections exhibited a different pattern, tending to peak in early winter (May to June), with the lowest incidence in the late spring and summer (November to January). There appears to be a second peak in case fatality rates for all respiratory deaths, including patients who died of respiratory infections with or without underlying conditions, occurring in the late winter and early spring (August to October, see Figure 14 on the next page). However, when immuno-compromised patients – those with underlying HIV/AIDS, malnutrition, or disorders of the blood or immune system – were removed from the analysis for possible blunting or alteration of the natural seasonal variation, this second peak disappeared. Blunting of the second peak was also observed when looking only at patients who died directly of respiratory infections where there were no underlying conditions.

This last analysis removed patients with conditions such as cerebral palsy that do not constitute immuno-suppression but nonetheless put the patient at greater risk of acquiring respiratory infections. It is possible that the original bimodal seasonal distribution may be an artefact of the large population of children with immune disorders (especially HIV), abnormalities of the nervous system, or other underlying conditions that make them more susceptible to respiratory infections at all times of the year and produced an incidence peak in spring that does not actually reflect an increased exposure to respiratory infections experienced by the general population.

Figure 14: Seasonal variation in case fatality rate for infectious respiratory deaths

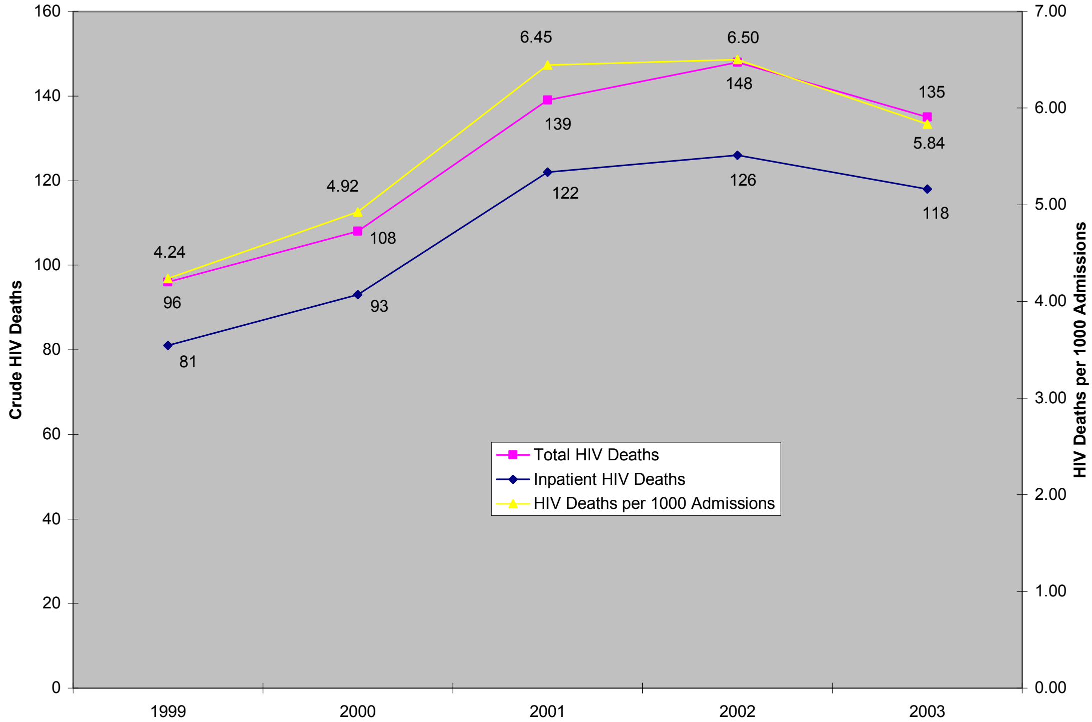


11. HIV-Related Deaths

HIV infection was the leading cause of death in children. Over the entire study period, HIV/AIDS deaths accounted for 31.6% of the total hospital mortality. The total number of deaths as well as the case fatality rate for HIV infection steadily increased over the study period until 2003, when it declined.

There were 95 deaths attributable to the disease in 1999 and 148 deaths at its peak in 2002, before dropping to 135 deaths in 2003. Similarly, the case fatality rate peaked at 6.5 deaths per 1 000 admissions in 2002 and then dropped to 5.8 in 2003. Also, the proportion of total hospital deaths attributable to HIV steadily increased from 26.2% in 1999 to 36.1% in 2002 before falling to 32.6% in 2003 (Figure 15 on the next page).

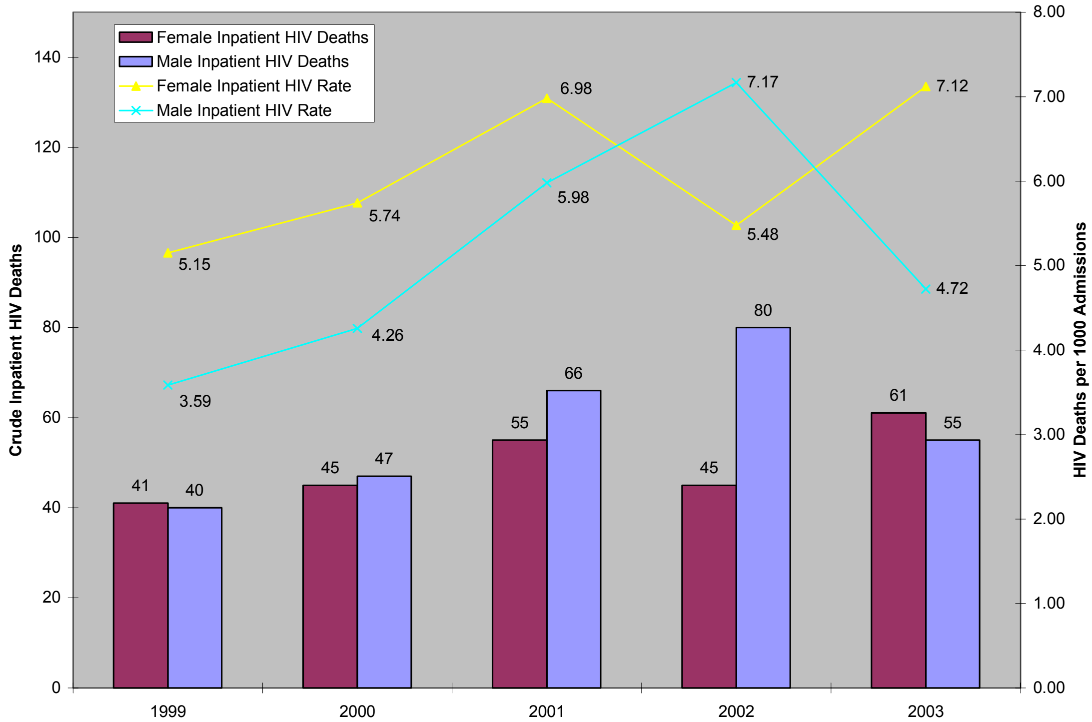
Figure 15: Total deaths, in-patient deaths, and in-patient death rate per 1 000 admissions due to HIV/AIDS for 1999 to 2003 at the Red Cross Children's Hospital



There were some sex discrepancies in the HIV-related deaths. There were more male HIV deaths (331) than female HIV deaths (287) over the study period. The sex discrepancy was almost entirely attributable to a drastic difference in HIV death in 2002, where 94 male children died of the disease compared to only 53 female children. Figure 16 illustrates this trend, although the numbers presented are in-patient deaths.

However, the HIV case fatality rate for male children was 5.1 deaths per 1 000 admissions while for female children it was 6.1 deaths per 1 000 admissions. Female children were approximately 20% more likely to die of HIV at RCCH than male children (Odd Ratio = 1.202, 95% CI: 1.026 – 1.409) and this difference was statistically significant (Pearson chi-square = 0.023).

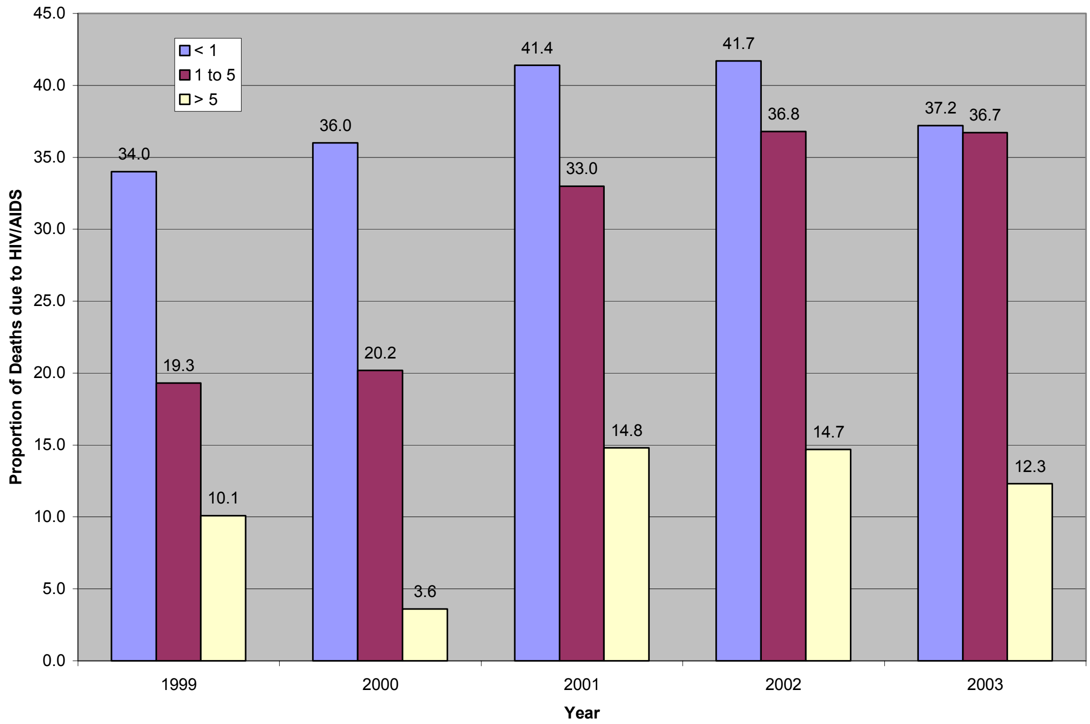
Figure 16: In-patient HIV deaths and case fatality rate by sex for 1999 to 2003 at the Red Cross Children's Hospital



HIV-related deaths exhibited a clear age pattern, with HIV infection constituting a much higher proportion of the deaths in younger children (Figure 17 on the next page). The mortality burden of HIV infection within an age group decreased with increasing age, with HIV infection accounting for 38.1% of the deaths in children <1; 29.6% of deaths in children 1-5; and only 11.3% of deaths in children >5. In addition, looking at the total HIV-related deaths, 72% occurred in children <1 year old; 22% in the 1-5 age group; and only 5.9% in the >5 group.

Figure 16 also illustrates that the proportion of deaths due to HIV infection within a given age group generally increased over the study period. This was particularly evident in the 1–5 group where only 19.3% of the deaths were due to HIV infection in 1999 but 36.7% was attributable to the disease in 2003. This is almost a doubling of the mortality burden within a 5-year period.

Figure 17: Proportion of deaths due to HIV for each age group from 1999 to 2003 at the Red Cross Children's Hospital



HIV was listed as the underlying (as opposed to direct) cause of death in more than 90% of the 626 deaths attributed to HIV/AIDS. For patients whose underlying cause of death was HIV infection, the most common direct causes of death were pneumonia (290 cases, 51.2%), septicaemia (95 cases, 16.8%), and diarrhoeal diseases (80 cases, 14.1%). *Pneumocystis carinii* pneumonia constituted 77 of the 290 pneumonia deaths in the HIV-infected population. TB was listed as the direct cause of death in only 2.8% of the HIV-related deaths.

12. Data System for Capturing Deaths

Prior to 2002, patient deaths occurring in the hospital or under the hospital's aegis were recorded both in a written log as well as on an electronic database (exact type unknown). Among the data recorded was demographic information, including patient name, date of birth, sex, race, hospital folder number, parents' names and address, as well as data about the death including date and time of death, location of death (i.e. specific hospital ward or home), physician's name, serial number of the death registration form, causes of death transcribed from the death registration form, date and time of body removal, and name and telephone number of the undertaker. The electronic database was not linked to the computerised clinical information system (HIS) used by the hospital at that time. The electronic database for death collection crashed in 2000, and from that point forward death-specific data was captured only in the written log.

On December 14, 2001, the RCCH rolled out a new computerised clinical information system, *Clinicom*, and the method of capturing data on deaths electronically was altered. In-patient deaths are now recorded on the system as discharged patients, with "death" indicated as the type of discharge. The date and time of death of these patients must be recorded, while there is a field for "diagnosis", which is the diagnosis upon discharge. The "diagnosis" field does not necessarily represent the cause of death and has no direct connection to the information recorded on the death registration form. Patients who died at home or in the emergency room cannot be discharged since they were never formally admitted to the hospital at the time of death, so these deaths are recorded on a special "details of death" field in *Clinicom*. In these cases, the system requires a date and time of death, but no other information can be entered.

Ultimately, the specific causes of death, as reported on the death registration form, are not entered into *Clinicom*, making it impossible to track trends in causes of death within the hospital without mining through the written log of deaths. A further complication in the information has been caused by the way in which patient information from the old, clinical computer system was entered into *Clinicom*. With a few exceptions, patients who died outside of the hospital, either at home or in the emergency room, but who had their deaths certified at the RCCH, were not entered as dead into the new system. Those patients' records can be found on the system, but there is no indication that the patients have died. Therefore, statisticians using *Clinicom* to generate reports on the number of patients dying under the hospital's aegis will not produce accurate results for any years prior to 2002 because the deaths occurring outside the hospital will not be counted.

Information on deaths is furthermore not electronically linked to the Department of Home Affairs. Firstly, a death registration form is completed by the physician and the death entered into the written log. Thereafter the patient is registered as dead on *Clinicom* and the body is cleared for removal. And undertaker, when coming to remove the body, takes the top copy of the death registration form with. The second page of the form, which contains the cause of death, is sealed in an envelope and the undertaker takes this to the Department of Home Affairs, where the death certificate is issued. The Department of Home Affairs is responsible for passing on the information to the National Health Information System.

The remaining copy of the death registration form remains at the RCCH. These copies were entered into a database from 1999 to 2003 for the purposes of this study. However, this database does not represent a recognised or sustainable part of the data capture system at the hospital.

The RCCH does not issue any formal mortality data beyond the monthly number of in-hospital deaths. The intra-departmental Morbidity and Mortality (M&M) data has yet to cover most deaths and has not been validated or analysed.

IV. DISCUSSION

This study has shown the value of keeping routine data on deaths in a hospital. The data were systematically recorded over five years, allowing an analysis that can inform managers, planners and clinicians. For example, the demonstration that in-hospital mortality from diarrhoea in the summer months triples, requires investigation. The magnitude of HIV/AIDS on childhood in-hospital death demands a response in terms of health resource provision. Although this study used both direct and underlying causes of death, which provided more detail than the Burden of Disease studies for the country and for Cape Town, this method is still limited by the lack of detail of other factors that led to the deaths, especially remediable ones. Nevertheless, if simple data such as used in this study was routinely recorded, valuable information on trends and patterns of hospital-related deaths would be available. Indeed, it is notable that, in this study, 'ill-defined' causes of death were considerably fewer than in other South African death certification studies (van der Merwe et al, 1991; Meel, 2003). It is believed that this reflects the potential value of hospital-related data.

While the large referral base of the RCCH complicates drawing conclusions about the relevance of this dataset to child mortality in general, it is notable that one in six of the 1845 deaths under the age of 14 years in Metropolitan Cape Town in 2001 took place at the RCCH (Groenewald et al, 2003). Similarly, the preponderance of deaths from the metropolitan areas that refer children with primary and secondary level health problems to the RCCH enables conclusions regarding common causes of death in childhood in these largely low income communities.

The top ten causes of death in this study are congruent with the SA and 2001 Cape Town Burden of Disease studies (Bradshaw et al, 2003; Groenewald et al, 2003), adding to the verisimilitude of this data. The differing rates of perinatal (lower) and congenital (higher) causes reflect the RCCH's position in the health system.

In causing one in three deaths, HIV/AIDS stands out by far as the most common cause of death. As demonstrated in an earlier study (Westwood, 2000), this figure is likely to be an underestimate of the role of HIV in causing deaths, as some doctors remain reluctant to certify it as the cause of death. This method of collecting data cannot prove that the children certified as having died of HIV/AIDS and its complications were indeed infected by the virus as opposed to having maternal antibody to it. However, it is likely that disease severe enough to kill the children reflected HIV infection in most cases.

The dominance of HIV/AIDS poses a challenge to the health system to prevent mother-to-child transmission of the virus and to provide antiretroviral therapy to infected children. In this way, a considerable impact could be made on infant and under-5 mortality rates. It is possible that the decrease in HIV-related mortality in

2003 shows the efficacy of moves to control this epidemic. Another potential explanation for this decrease in HIV-related mortality in that year is that more patients were being sent home to die. However, this is not supported by the lack of increase on out-of-hospital HIV-related deaths in 2003.

The methodology used in this study would have under-estimated the contribution of malnutrition to mortality. Only the most severe forms of malnutrition were 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 (Westwood & Henley, personal communication).

The higher death rate in female children was an unexpected finding. The presence of this finding in HIV/AIDS and CHD-related deaths, which both accounted for a large number of associated deaths, may simply reflect an inability to demonstrate a difference in less common conditions. The higher mortality among female children undergoing cardiac surgery for CHD has been described in California, USA (Chang et al, 2002), but an equivalent risk in HIV/AIDS mortality has not been described before.

The demonstration of a distinct seasonal profile for death rates attributable to diarrhoea and acute respiratory infections is further proof of the value of this data. It also poses the question as to whether the higher death rate in certain seasons reflect higher acuity, or an inability of the health system to cope with increased numbers of sick children. The two possibilities would have different solutions and further research to answer this question will be necessary.

Trauma deaths also require further analysis. Since the RCCH is a referral centre and trauma is a large contributor to preventable childhood deaths, more detail on this cause of death is required. Detailed information will be available for most such deaths as most cases would have involved forensic post mortems. An initiative to collect routine statistics on trauma deaths is currently under discussion with the Child Accident Prevention Foundation of South Africa.

Childhood deaths are largely preventable. It is thus important to have as much detail as possible on their causes. A number of approaches is underway to improve child mortality information systems in South Africa. What has been demonstrated in this study is that the simple collection of routine data can lead to useful outputs. The M&M approach recommended by the Western Cape Department of Health is now being implemented at the RCCH. However, this is a staff-intensive process and is not carried out consistently in all departments. The large number of deaths per month prevents complete data capture, but the system will be useful in allowing 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 individual children has been explored in the North West province (Krug et al, 2004). Further refinements of that methodology are taking place and its practicality and value in a large urban environment such as Cape Town has yet to be demonstrated.

V. CONCLUSIONS

1. Data from the death registration form filled in by the paediatrician has yielded invaluable information and the variables collected on this form must be integrated into the current official record system in order to track child deaths in the hospital. The current *Clinicom*-based method of record-keeping of hospital deaths is inadequate for this purpose.

2. Up to 2003, both the number of deaths and the death rate have been rising.

3. The greatest increase has been in deaths due to HIV/AIDS, which now constitute almost one third of all deaths.

4. A decrease in hospital mortality in 2003 may be attributable to a decrease in deaths from HIV/AIDS.

5. Infectious causes (GBD Group I) are the dominant causes of death.

6. The high proportion of congenital causes of death, dominated by CHD, reflects the hospital's specialist function.

7. GBD Group III deaths (injuries) are common especially among older children but further detail is required before useful analysis can take place.

8. Cause of death varies with age group, with GBD Group I causes dominating under the age of five years. Groups II and III take on more significance in the older children.

9. There is a marked seasonal variation in in-hospital mortality from common infectious diseases such as diarrhoeal disease.

10. There is a higher mortality for females, especially from CHD and HIV/AIDS.

11. All cause mortality is dominated by children from the local metropolitan health sub-districts (largely low income areas).

VI. RECOMMENDATIONS

1. Improving the Data Collection System

While it appears that *Clinicom* has been a welcome improvement to data collection and patient processing at the RCCH, the system is not being utilised to its full capacity to capture information on patient deaths.

The *Clinicom* system should be extended to all hospitals in the Western Cape Province. This expansion will represent an important opportunity to implement a consistent, sustainable electronic system for mortality data captured at the RCCH and in the entire Western Cape – however, the system would need to be appropriately and fully utilised for the purposes of keeping track of child deaths.

It is recommended that an expanded "details of death" field be introduced onto the system to capture all patients who die either as in-patients or outpatients, including home deaths that are certified at the hospital. This field would capture the following information from the death registration form:

- date and time of death,
- causes of death (both primary and underlying),
- ICD-10 code for cause of death,
- location of death,
- age at death,
- serial number from the death registration form, and
- an indication of whether a post-mortem examination was performed.

The use of the serial number from the death registration form might allow future electronic linkage with the Department of Home Affairs and potentially eliminate or at least support the current paper system. By capturing this data, statisticians and epidemiologists would be able to generate more detailed reports on the causes of death at specific hospitals. In addition, analysis of the mortality profile at all the health care facilities in a particular region, or ultimately the entire Western Cape Province may be possible as the scope of *Clinicom* expands.

The potential role of the audit system in this hospital and province is currently being explored by Dr Krug and colleagues through a separate research study that has the potential to alter whether, and how, child deaths are audited in hospitals around the country. Lessons learnt at the RCCH could provide valuable insight to this process.

2. Clinical Service Provision and Training

a. *PMTCT and ARV roll-out programmes*
There are the first indications that these programmes are improving child mortality from HIV infection. The HIV-related data need to be fed back to the Directorate for HIV/AIDS and TB in the Western Cape Province.

b. *Diarrhoeal season*
The three-fold increase in diarrhoea-related mortality in the first half of the year represents a challenge to the hospital, the health system and the provincial government in terms of a common, preventable cause of death. Further research in this field is urgently needed. There is a need for a focus on the prevention and management of diarrhoeal disease in the summer months, and the health service response to it.

c. *Nutrition*
The limited data on the role of nutrition in the deaths at the RCCH is noted. Malnutrition remains a significant problem in this region and its contribution to child mortality needs closer scrutiny. It is unlikely that the death registration form will be the best way to record this, given the training that would need to be provided to a constantly changing staff component. It is recommended that the RCCH M&M process focus on this aspect when examining each childhood death.

d. *Citation of cause of death – quality assurance, training on classification*
This data is not entirely based on the raw death registration form data. Where possible, Dr Westwood interpreted causes of death from the data on the form where the registering doctor had either given a mechanism of death as cause of death, or had not put the direct sequence of causes of death or contributory causes in logical order. This clearly indicates that more effort needs to be directed at training medical staff in filling in the death registration form to ensure routine data collection that can prove as useful as presented in this study (see Recommendation 1).

3. Further Research

a. *Further investigations into female death rates*
The unexpected finding of greater mortality for females in certain categories of cause of death should be studied to uncover its potential sociological or health system antecedents. As with any other demographic variable, non-biological reasons for an associated higher mortality should be sought and attempts made to counter them.

b. *CHD-related deaths*
Congenital heart disease is the most common, single congenital cause of death at the RCCH. Further analysis must be done to elucidate the preventable causes of death. This will involve the further breakdown of causes, e.g. in-operable, delayed diagnosis, excessively long surgical waiting lists, operative misadventure etc. The existence of the Children's Heart Unit makes a province-wide analysis feasible. However, hospital-related analysis of mortality related to CHD will also provide valuable data to enable appropriate health services aimed at children with CHD.

VII. REFERENCES

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APPENDIX

PROTOCOL FOR CATEGORISATION OF CHILD DEATHS AT THE RED CROSS CHILDREN'S HOSPITAL FROM 1999-2003

Based on the "Global Burden of Disease" and "National Burden of Disease" classification model, with some sub-categories modified to reflect more child-specific causes of death prevalent at Red Cross Children's Hospital.

- Roman numerals = Broad group
- Letters = Major groups within each broad group
- Numbers = Sub-groups within each major group (where applicable/necessary)
- Brackets next to each group indicate the number of cases in that category

I. COMMUNICABLE DISEASES, MATERNAL CONDITIONS, PERINATAL CONDITIONS, NUTRITIONAL DEFICIENCIES [1160]

A. Infectious and Parasitic [1038]
1. Acute respiratory infections [113]
2. Diarrhoeal diseases [85]
3. HIV/AIDS [626]
4. Meningitis/Meningococcaemia [56]
5. Myocarditis [27]
6. Septicaemia [64]
7. Tuberculosis [42]
8. Hepatitis [13]
9. Other infectious [12]

B. **Maternal conditions** = [0] (there are no causes of death linked to the mother)

C. **Perinatal conditions** [66]
1. Birth asphyxia [3]
2. Necrotising Enterocolitis [3]
3. Neonatal infections [8]
4. Prematurity [48]
5. Other perinatal [4]

D. **Malnutrition** [56]

II. NON-COMMUNICABLE DISEASES [576]

A. Cardiovascular diseases [39]

B. Digestive system disorders [33]

C. Endocrine/Metabolic disorders [6]

D. Genito-Urinary disorders [8]

E. Neoplasms [70]

F. Nervous system disorders [77]

G. Respiratory diseases [12]

H. Congenital Abnormalities [331]

1. Blood/immune disorders [10]
2. Congenital heart disease [137]
3. Cystic fibrosis [7]
4. Digestive abnormalities [30]
5. Down's Syndrome [26] (children with Down's and CHD were classified as Down's)
6. Central nervous system abnormalities [42]
7. Nervous/musculoskeletal disorders [19]
8. Other chromosomal abnormalities [10]
9. Respiratory abnormalities [9]
10. Renal abnormalities [8]
11. Metabolic disorders [6]
12. Other syndromes [27]

III. INJURIES [156]

No further sub-classification was possible based on the limited information surrounding the specific nature of trauma-related deaths.

IV. ILL-DEFINED [86] (includes dead on arrival, natural causes, shock, sudden infant death syndrome/cot death, unknown).