Why, how and when do children die in a Paediatric Intensive Care Unit (PICU) in South Africa?

By

Dr Martie Wege

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Supervisors: Brenda Morrow; Beyra Rossouw ; Andrew Argent

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DECLARATION

I, Martie Wege, hereby declare that the work on which this research project is based is my original work (except where acknowledgements indicate otherwise) and that neither the whole work nor any part of it has been, is being, or is to be submitted for another degree in this or any other university.

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I would like to dedicate this work to my dearest son and husband, who loves and adores me despite the days, weeks and years I've spent on my career instead of with them. For the respect, support and admiration they've shown me through this incredible humbling experience.

You bring me so much joy and the most valuable lessons in life I've learned from you and not from my academic life.

To my supervisors – you are so much more than that. You are my inspiration, my mentors, my heroes. Prof Brenda – you are a true research champion. The only reason I've completed this is because of you.

For anyone that has ever completed a death summary on anyone of these children – thank you!

To every parent/caregiver that has lost a child in our unit, reviewing the details of the end of your dearest child's life made me realize yet again how precious life is. Once you are gifted with a child, your heart beats outside of you. Out of control, without guarantees. Your children taught me that the only thing that truly matters are the time we get to hold our loved ones. Through your losses, I've learned not just about the process and characteristics of diseases and death, but about the treasure of this brittle, harsh but yet beautiful cycle called life.

LIST OF ABBREVIATIONS

BD: Brain death

CPR: Cardiopulmonary resuscitation

Child PIP: Child Healthcare Problem Identification Programme

CCC: Complex chronic conditions (CCC)

CPAP: Continuous positive airways pressure

DNR: Do-not-resuscitate

HFNC: High flow nasal cannula

HIV: Human immunodeficiency virus

ICD 10: International Classification of Diseases, tenth revision

LOS: Length of PICU stay

LST: Life sustaining treatment

LLST: Limitation of life sustaining treatment

PIMS: Paediatric index of mortality scoring systems

PICU: Paediatric intensive care unit

RCWMCH: Red Cross War Memorial Children's Hospital

Stats SA: Statistics South Africa

TOF: Terminal organ failure

U5MR: Under-five mortality rate

WHO: World Health Organization

WLST: withdrawal of life sustaining treatment

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CHAPTER 1: INTRODUCTION

Aim and objectives of the research project

1. To determine the mode of death in children who died in the Paediatric Intensive Care Unit (PICU) at Red Cross War Memorial Children's Hospital (RCWMCH) between the 1st of January 2013 and the 31st of December 2017.
2. To describe the characteristics of children who died in the PICU at RCWMCH and to evaluate mortality trends over the 5-year study period.
3. To describe the epidemiology of death in the PICU over the 5-year period.
4. To establish the proportion of hospitalized children that die in PICU.

BACKGROUND

Modern medical therapies and technologies have advanced rapidly over the last decade. These improvements have led to a dramatic decrease in childhood mortality in well-resourced countries, despite the severity of illness in hospitalised children having increased (1, 2). Unfortunately, modern technology can also be used beyond a point where it improves outcome or preserves quality of life and can then therefore also prolong suffering (3, 4). There is a concern that the declining mortality rate observed in children is being accompanied by a rising disability rate and that children who previously would have died early because of treatment failure, now die after a prolonged hospital admission (5, 6).

Intensivists need to constantly evaluate the appropriateness of life-sustaining therapy in patients who are not responding to specific interventions. End-of-life care and planning is an integral part of paediatric intensive care medicine (2).

AIM AND OBJECTIVES OF THE REVIEW OF LITERATURE

The literature review focused on deaths occurring in the PICU. The main objectives were to review the epidemiology and characteristics of children who died in PICUs worldwide, with a specific focus on the mode of death.

METHODOLOGY

A structured literature review was conducted using PUBMED (www.ncbi.nlm.nih.gov) and Google search engines. The search was limited to human studies in English language and age limitation was customized from birth to 18 years of age. All research designs and review articles were included. Abstracts from the articles were reviewed and were only included if the full articles were available. Reference lists and related citations of identified articles were scanned for other relevant literature and if found to be relevant these were included. There was some overlap between the different searches.

The following search terms were used:

Search 1: "intensive care unit AND mortality AND end-of-life AND pediatrics" = ("intensive care units"[MeSH Terms] AND ("mortality"[MeSH Terms]) AND end-of-life[All Fields] AND ("paediatrics"[All Fields] OR "pediatrics"[MeSH Terms] OR "pediatrics"[All Fields]) AND ("humans"[MeSH Terms] AND ("infant"[MeSH Terms] OR "child"[MeSH Terms] OR "adolescent"[MeSH Terms]))

Search 2: "modes of death AND pediatrics" = (modes[All Fields] AND ("death"[MeSH Terms] OR "death"[All Fields])) AND ("paediatrics"[All Fields] OR "pediatrics"[MeSH Terms] OR "pediatrics"[All Fields]) AND ("humans"[MeSH Terms] AND ("infant"[MeSH Terms] OR "child"[MeSH Terms] OR "adolescent"[MeSH Terms]))

Search 3: "mortality AND intensive care unit AND South Africa" = ("mortality"[All Fields] OR "mortality"[MeSH Terms]) AND ("intensive care units"[MeSH Terms] OR ("intensive"[All Fields] AND "care"[All Fields] AND "units"[All Fields]) OR "intensive care units"[All Fields] OR ("intensive"[All Fields] AND "care"[All Fields] AND "unit"[All Fields]) AND ("south africa"[MeSH Terms] OR "south africa"[All Fields]) AND ("humans"[MeSH Terms] AND ("infant"[MeSH Terms] OR "child"[MeSH Terms] OR "adolescent"[MeSH Terms]))

Search 4: "death AND end-of-life" = ("death"[MeSH Terms] OR "death"[All Fields]) AND end-of-life[All Fields] AND "humans"[MeSH Terms] AND ("infant"[MeSH Terms] OR "child"[MeSH Terms] OR "adolescent"[MeSH Terms]))

The following articles were excluded:

1. Studies that described mortality and mode of death in neonatal intensive care units.
2. Studies that focused on deaths in the paediatric intensive care unit due to a specific disease, like pneumonia.
3. Studies from a focused, single discipline paediatric intensive care unit, for example neurosurgical, post-operative cardiac unit, trauma, burns or oncology units.
4. Studies from mixed adult and paediatric intensive care units.

Mode of death (Table 1)

The mode of death is defined as the manner or way of dying. Previous reports divided the mode of death into the following categories (Table 1):

1. Death after limitation of life sustaining treatment (LLST), including a do-not-resuscitate (DNR) order
2. Death after withdrawal of life sustaining treatment (WLST)
3. Failed cardiopulmonary resuscitation (CPR) or
4. Brain death (BD).

Most reports have grouped withdrawal and limitation of life-sustaining treatment (LLST) together (3, 4, 7-15). Some reports have an additional category for DNR (3, 4, 7, 8, 11, 12, 14-16) and one had a category for terminal organ failure (TOF) (Table 1) (8).

The mode of death, end-of-life decision-making and family involvement varies greatly between countries (3). Recent publications report the rate of Paediatric Intensive Care Unit (PICU) deaths after withdrawing or withholding LST to range between 15-75% (2, 8, 14, 16). Active WLST and LLST was found to be the most common mode of death in patients from North America, Europe, United Kingdom, Australia, Canada and Pakistan (Table 1). In some South American countries, failed CPR was still found to be the most common mode of death, attributable in part to differing ethical attitudes amongst both families and physicians across the world (7, 9).

End-of-life treatment in children is complex and involves ethical and legal considerations (10). The decision makers do not only have to make a decision based on the best interest of the patient, but also need to consider the families' interests and wishes. In the South African context, the ethical principle of distributive justice – doing the best for the most within resource constraints -

comes into play. With limited available PICU resources, more specific attention and resource utilization may need to be focused on other patients with better prognoses, especially those awaiting major elective surgery (2, 17, 18). In South Africa there is a wide variety of cultures and religions, and these different beliefs and traditions need to be respected and considered in the end-of-life care of all patients.

There is no published information on the mode of death in South African PICUs, therefore we set out to document this within our PICU. The PICU at Red Cross War Memorial Children's Hospital (RCWMCH) has a mortality rate that is lower than described in some other low and middle income countries and on par with PICU's in some high income countries, when using standardized Paediatric Index of Mortality scoring systems (PIMS 2 or 3) (19-22).

Table 1: Publications on Modes of Death in PICU

Lower Middle-income countries								
Article	**Year**	**Location**	**Failed resuscitation**	**Withdrawal of LST**	**Limitation of LST including (DNR) order**	**DNR as separate outcome**	**Terminal organ failure**	**Brain death**
Siddiqui et al (4)	2007 - 2012	Pakistan	28.2% (70)	22.6% (56)	41.1% (102)	-	8.1% (20)	-
Upper Middle-income countries (South American countries)								
Kipper et al (9)	1988 - 2000	Brazil	73.5% (374)	18.1% (92)	-	-	8.4% (43)	-
Althabe et al (7)	2000 - 2001	Argentina	52% (232)	20% (92%)	16% (72)	-	11% (52)	-

High-income countries (Include European, Australia, New Zealand and North-American countries)								
Article	**Year**	**Location**	**Failed resuscitation**	**Withdrawal of LST**	**Limitation of LST including (DNR) order**	**DNR as separate outcome**	**Terminal organ failure**	**Brain death**
Moore et al (3)	2006	Australia	19% (5)	56% (15)	19% (5)	-	7% (2)	-
Moynihan et al (22)	2006 - 2016	New Zealand and Australia	21%	51%	12%	-	-	16%
Garros et al (11)	1995 - 1996	Canada	27.3% (27)	39.4% (33)	20.2% (20)	-	13.1% (13)	-
Fontana et al (10)	2008 - 2010	Canada	6% (4)	81% (55)	-	-	13% (9)	-
Martinot et al (23)	1993 - 1994	France	26% (24)	27% (25)	27% (25)	-	20% (18)	-

Article	Year	Location	Failed resuscitation	Withdrawal of LST	Limitation of LST including (DNR) order	DNR as separate outcome	Terminal organ failure	Brain death
Ten Berge et al (8)	2000 - 2005	Netherlands	18.4% (16)	27.6% (24)	4.6% (4)	26.4% (23)	23% (20)	-
Launes et al (16)	2001 - 2008	Spain	-	19.6% (61)	9.6% (30)	2% (6)	-	26.4% (82)
Sands et al (18)	1997 - 2007	United Kingdom	10.8% (22)	54.9% (112)	9.8% (20)	-	-	24.5% (50)
Vernon et al (14)	1993	United States	19% (57)	32% (95)	26% (78)	-	23% (70)	-
Zawistowski et al (12)	1997 - 2001	United States	16% (20)	40% (50)	25% (31)	-	19% (24)	-
Burns et al (13)	2010 - 2011	United States	14% (26)	70% (133)		-	-	16% (30)
Keele et al (24)	2011 - 2013	United States	19.3% (53)	51.3% (141)	16.7% (46)	-	-	12.7% (35)

DNR = Do-not-resuscitate
LST = Life sustaining therapy
LLST = Limitation of life sustaining therapy
PICU = Paediatric intensive care unit

Characteristics of patients who die in PICU (Table 2)

It is inevitable that some children admitted to PICU will die. Publications show that a greater proportion of hospitalized children die in an intensive care environment than in general wards. Ramnarayan et al showed an increase in the proportions of death occurring in ICU from 80.1% in 1997 to 90.6% in 2003 compared to hospital admissions outside of the ICU setting (1, 10, 16). Previous work done at RCWMCH, during the HIV epidemic when there was no access to ARV's, showed that 37% of hospital deaths occurred in the PICU and 36% in the medical wards (25).

Table 2 summarises the published literature describing the characteristics of children who die in PICUs across the world.

Age

The median age at death in the reviewed studies varied between 9 and 70 months. Younger age groups were more likely to die from failed CPR, whereas withdrawal or limitation of LST were more likely to be the mode of death in older children. Most of these studies were done in high income countries but some of them were from upper-middle income economies, which might be more applicable to the South African patient profile (3, 7, 8).

Gender

Most reports on in-hospital deaths from South Africa and the rest of the world, suggest a slightly higher mortality in males, at 52-60% (4, 8, 9, 12, 13, 19, 22, 26, 27). In contrast to these reports, a study previously conducted at RCWMCH found that a female patient admitted to hospital was 14% more likely to die than a male counterpart (25).

Source of admission

PICUs from high income countries admit more than two thirds of their patients from other referral hospitals and from wards within the hospital (3, 7, 8, 22). There is also one study from a low-income country, Mozambique, that described similar findings (32). Previous data from RCWMCH PICU suggests that 32-41% of admissions are elective surgical cases (17). This is much higher than described in units from upper-middle and high income countries, where only 4-19% of admissions were from theatre (3, 7, 8, 13). The predicted mortality for elective patients is likely to be substantially lower than for emergency admissions (17, 19).

At RCWMCH implementation of high flow nasal cannula (HFNC) and non-invasive continuous positive airways pressure (CPAP) therapy in the medical wards at RCWMCH appears to have made a huge difference to the number of children referred from the emergency department and medical wards for invasive ventilation (17). This may impact the amount of admissions to the PICU for respiratory failure, but may also increase the predicted mortality of the cases referred to PICU as the patients admitted to the PICU with respiratory failure are likely to be sicker.

Underlying complex chronic conditions (CCC)

PICU resources and services need to be used in the best possible way. Policies previously developed by the PICU at RCWMCH, when the unit was under immense pressure for beds, suggested that preference should be given to children who have a condition that is amendable to therapy, preferably with a relatively short anticipated PICU stay (17). However with advances in medical care, children with complex chronic conditions (CCC) who previously might have had a very limited medium term prognosis, are now surviving acute intercurrent illnesses with a reasonable prognosis. Admission policies have adapted to this changing patient profile (4, 10, 35).

A systematic literature review done in Australia by Moore et al reported that 45-81% of patients who died in PICU had an underlying chronic disease. Several of the studies included in the review found that withdrawal or limitation of treatment was more likely in patients with underlying chronic conditions (3). A study from a low resourced unit in Ethiopia also suggested that children with underlying comorbid conditions were ten times more likely to die (28).

We set out to investigate the proportion of children with underlying CCC who are dying in our PICU and to compare this to reports from other centers.

Conditions associated with death

The main cause of death at RCWMCH was previously reported under the category of infectious diseases (25, 29, 30). This is different from high income countries where the two most common conditions associated with death were respiratory failure and underlying congenital malformations (1). The above analysis from RCWMCH was done in 2003, whilst a more recent review at RCWMCH found that the most common cause of death was still pneumonia and diarrhoea (30). A report from the Child Healthcare Problem Identification Programme (Child PIP) recorded deaths in South African hospitals for 2012/2013. This report confirmed that pneumonia was still the

primary cause of death for children in SA, responsible for 19.4 % of all deaths, followed by acute diarrhoea with hypovolaemic shock and sepsis (17.2%) (29).

Length of PICU stay (LOS)

Most paediatric deaths have been reported to occur within the first 24 hours of admission to hospital (29). More children die from failed resuscitation during the first three days of PICU admission (22). Althabe and Kipper et al both reported that one third of deaths occurred on day one of admission (7,9). Children who died after 14 days in PICU were more likely to die from limitation or withdrawal of life support (7, 9). The mean length of stay for children admitted to PICU before death has been reported to range from three to five days (Table 2).

Nupen et al recently studied long-stay patients at RCWMCH PICU. Only 4.8% of patients admitted to the PICU were defined as long-stay patients (LOS>19days). This small group of patients used almost a third of the available PICU bed-days, had a much higher mortality than short-stay patients (29.6% vs. 12% respectively) and consumed a disproportional amount of PICU resources (20).

Table 2: Published articles on characteristics of deaths in PICU

Low Income Countries									
Location Total admissions	**Article *Year of publication***	**Mortality rate % (n)**	**Median age of death (months)**	**Gender (Male)**	**Source of admission**	**Most common cause of death**	**Median LOS**	**Comorbid**	**Postoperative**
Ethiopia (400)	Haftu (28) *2015*	8.5% (34)	-	-	-	Multiorgan failure 42.9%	-	-	-
Mozambique (n=987)	Punchak (32) *2018*	25 % (242)	24	-	ER 25% (60) In-patient ward/OR 13% (32) Another facility 58% (140)	Sepsis 59%	-	-	-
Lower-middle Income Countries									
Nigeria (n=302)	Embu (31) *2011*	36.1 (109)	-	59% (179)	OR 51.7% Trauma 31.6%	-	5.5 days	-	51.7 %
Pakistan (n=1919)	Siddiqui (4) *2015*	12.9% (248)	34	60.5% (150)	ER 57.7% In-patient ward 37.1% OR 5.2%	Sepsis (17.3%)	-	39.5% (98)	-

Upper-middle income countries									
Location Total admissions	**Article *Year of publication***	**Mortality rate % (n)**	**Median age of death (months)**	**Gender (Male)**	**Source of admission**	**Most common cause of death**	**Median LOS**	**Comorbid**	**Postoperative**
Brazil (n=6233)	Kipper (9) *2005*	9.2% (575)	11	55% (278)	-	Infectious disease 35%	4 days	-	-
Brazil (n=428)	Piva (33) *2010*	-	52	54% (234)	-	Shock 59%	12.1 days	-	-
South Africa (n=529)	Ballot (19) *2016*	16.2% (86)	-	-	-	-	3 days	-	-
Turkey (2187)	Ayar (34) *2019*	18.02% (394)	70	61.7% (243)	-	Respiratory disease 24.5 %	5 days	-	-

High income countries									
Location Total admissions	**Article *Year of publication***	**Mortality rate % (n)**	**Median age of death (months)**	**Gender (Male)**	**Source of admission**	**Most common cause of death**	**Median LOS**	**Comorbid**	**Postoperative**
France (n=712)	Martinot (15) *1998*	13% (92)	9	-	-	Respiratory Failure 21.7%	4 days	45%	-
Argentina (n=6358)	Althabe (7) *2003*	7.2 % (457)	17	53%	-	Respiratory failure 33% (147)	3 days	65% (290)	20% (90)
Canada (n=1458)	Garros (11) *2003*	7.3% (99)	9	56% (56)	-	Cardiac disease 46.5%	5 days	-	-
Netherlands (n=1995)	Ten Berge (8) *2006*	4.4 % (87)	26	56% (49)	ER 28% In-patient ward 23% OR 10% Another facility 39%	Congenital malformations 22%	4 days	-	10 % (9)

Location Total admissions	**Article *Year of publication***	**Mortality rate % (n)**	**Median age of death (months)**	**Gender (Male)**	**Source of admission**	**Most common cause of death**	**Median LOS**	**Comorbid**	**Postoperative**
Australia (n=1036)	Moore (3) *2008*	2.6% (27)	30	-	ER 15% In-patient ward 33% OR 19% Another facility 26%	Respiratory failure (33%)	3.5 days	63% (17)	15%
United Kingdom (UK) (n=4034)	Sands (18) *2009*	5.1% (204)	37	58% (118)	ER 21% (43) In-patient ward 26% (54) OR 4% (8) Another facility 49% (99)	Infections 19.6% Injury/Poisonings 19.6%	2 days	-	-
Spain (n=6511)	Launes (16) *2011*	4.5% (311)	9	-	-	Respiratory failure	-	88%	-
Canada (n=68)	Fontana (10) *2013*	-	58	-	-	Congenital malformations 29%	-	58%	-

Location Total admissions	**Article *Year of publication***	**Mortality rate % (n)**	**Median age of death (months)**	**Gender (Male)**	**Source of admission**	**Most common cause of death**	**Median LOS**	**Comorbid**	**Postoperative**
USA (n=9516)	Burns (13) *2014*	2.4% (227)	25	55%	-	Multiorgan failure	5.7 days	63%	30% (16)
USA (n=10078)	Meert (35) *2015*	2.7% (275)	24	52%	-	Respiratory failure 29%	-	72% (199)	-
Japan (n=1894)	Suzuki (36) *2018*	3.3% (62)	24	52% (32)	-	Congenital heart disease 31%	8.5 days	-	18% (11)
Saudi Arabia (1254)	Thabet (37) *2018*	8.6% (108)	24	55.2%	-	Respiratory 34.2%	4 days	-	-
New Zealand and Australia (103 367)	Moynihan (22) *2019*	2.6% (2672)	15	56.8% (1517)	Another facility 39.3% (1051) In-patient ward 25% (667) ER 22.7% (606) OR 13% (348)	-	3.4 days	-	-

ER = Emergency room
LOS = Length of stay
OR = Operation room
PICU = Paediatric intensive care unit

PICU at RCWMCH

The population of children living in the Western Cape has increased by 21% (38) between 2002 and 2017. In 2014 Statistics South Africa reported that the Western Cape Province's population consisted of about 1.8 million children and approximately 930 000 of these children resided in the Cape Town Metropol (39).

Although the PICU in RCWMCH is located in an upper middle-income country with an estimated under-five mortality rate (U5MR) of 41-44 deaths per 1 000 live births, the U5MR for the Cape Town Metro district referring to RCWMCH was recently found to be 18 per 1 000 live births (26, 40). The mortality rate of the RCWMCH PICU declined from 9% in 2010 to 6% in 2015, which is much lower than the mortality rate for PICUs in the rest of Africa (17, 19, 28, 31). This is still significantly higher than some high-income countries, where mortality rates of 2.4-5.5% has been reported (1, 8, 18, 22, 35, 36). A more recent review of admission and mortality trends for a 10 year period at RCWMCH showed a 16% increase in PICU admissions, with an overall decrease in in-hospital mortality (30).

The PICU beds available for the Western Cape province include 22 beds at RCWMCH; 10-12 PICU beds in another tertiary facility in Cape Town and a few isolated PICU beds within the private health sector to serve the rapidly growing Western Cape paediatric population. In 2013, the RCWMCH PICU had a bed occupancy that was greater than 97%. High demand for PICU beds led to the development of a PICU admission protocol to optimize the utilization of the limited resources available in the Western Cape (17). With this high demand for PICU beds, long-stay patients can potentially limit resources available to children with more reversible conditions (20). This makes the limitation of specific interventions and withdrawal of LST in children with underlying lethal conditions and for those with potential poor outcome inevitable.

The Critical Care Society of Southern Africa published a consensus guideline in 2019 on ICU triage and rationing. This document aims to support and guide clinicians in the South African critical care context in making complex clinical and ethical patient decisions. It provides a triage policy to ensure that patients with a very high likelihood of benefitting from ICU are prioritised for admission, where resources are constrained. This document echoes the importance of having a triage system in place that is fair, consistent, efficient and maintains a high quality of intensive care with the best utilisation of available resources (41).

End-of-life decision making: Limitation of life-sustaining treatment

The decision on when and how to limit or withdraw certain treatments at RCWMCH is a complex process that does not follow a standardised protocol, owing to the recognition that all patients and their circumstances are different. We follow the Royal College of Paediatrics' guidelines (42), individualized to family needs, as appropriate to a culturally and spiritually diverse population. For the more complex cases where brain death is not the reason for withdrawal of LST, multi-disciplinary team members are involved in the discussions and decisions around how, where and when LST should be limited or withdrawn.

The Royal College of Paediatrics described three sets of circumstances where limitation of LST might be ethically permissible (42). They described situations where life-sustaining treatment may no longer be of overall benefit and to continue LST might not be in the best interest of the child. This document forms a solid framework of when withdrawal or limitation of LST should be considered.

1. When life is limited in quantity:
   - Brain stem death
   - Imminent death, where physiological deterioration is occurring irrespective of treatment
   - Inevitable death, where death is not immediately imminent but will follow and prolongation of life by LST confers no overall benefit
2. When life is limited in quality
   - Burdens of treatments, where treatments produce pain and suffering that outweigh any potential or actual benefits
   - Burdens of the child's underlying condition. The pain and distress from the child's underlying condition in itself overcome any potential or actual benefits in sustaining life
   - Lack of ability to benefit; the severity of the child's condition is such that it is difficult or impossible for them to benefit from continued life.
3. Informed competent refusal of treatment

   The older child with extensive experience of their illness may repeatedly and competently consent to the limitation of LST (41).

A Palliative Care team has become more active at RCWMCH over the last five years. Their involvement helps with end-of-life decision making for children with complex chronic conditions and life-limiting illnesses.

CONCLUSION AND MOTIVATION FOR THE STUDY

In a critical care unit where treatment is complex, high risk and expensive, it is paramount to review and understand the characteristics of patients who die in the unit in order to improve services and outcomes for critically ill children. It is important to recognise mortality patterns in order to set goals for future improvements and to inform optimal resource allocation. End-of-life treatment and planning is an integral part of paediatric intensive care medicine. These decisions in childhood are particularly complex and involve ethical and legal considerations. There are currently no published reports on the mode of death for children who die in South African PICUs, this study aimed to review the characteristics and modes of death of all patients dying in the paediatric intensive care unit at RCWMCH over a five-year period.

ETHICAL CONSIDERATIONS

Risks/benefits

As this was a retrospective review of patients who died during their stay in the PICU, this study could not change the care or outcomes of any of the children or families who formed part of this study. We hope that our findings can inform the future management of the dying child, by appropriate allocation of resources for the management of end of life treatment. Understanding the burden of specific diseases will help focus the limited resources to where children can benefit most. Reviewing the outcome of patients admitted to the PICU creates awareness among PICU staff and can potentially improve clinical practice. This review will help clinicians to give more accurate information to families on the potential outcome of their child.

Respect for persons

The need for written, informed consent was waived for this study, owing to its retrospective, non-interventional design, with associated minimal risk.

Confidentiality

Every patient received a study number. Information were sorted by this number and the patient remained anonymous. All electronic data collected are password protected and only the investigators have access to the data. No potentially identifiable information will be presented in any outputs arising from this study.

Conflicts of interest

There are no conflicts of interest to be declared.

Compliance and Independent review

Approval was obtained from the Departmental Research Committee; the Faculty of Health Sciences Human Research Ethics Committee (HREC) and from the Red Cross War Memorial Children's Hospital before starting this study. This study conformed to the principles stated in the Declaration of Helsinki (2013). [HREF REF 029/2018]

Limitations of study

The retrospective review was dependent on the quality of the death summaries and data entered, as part of standard care practice, on the Child PIP data set and PICU summary. Incomplete documentation may have affected the results of this study.

We only analysed data from the PICU data system and Child PIP database and individual folder reviews were not conducted.

This was a single-centre study, and results may not therefore be generalisable to other units in South Africa or beyond.

The lack of control group of children who survived PICU is a further limitation of this study, and therefore independent risk factors for death could not be determined. This warrants future investigation.

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Chapter 2: Publication-ready Manuscript:

Why, how and when do children die in a Paediatric Intensive Care Unit (PICU) in South Africa?

Investigators: Martie Wege[1,2]; Beyra Rossouw[1,2]; Andrew Argent[1,2]; Brenda Morrow[2]

1. *Paediatric Intensive Care Unit, Red Cross War Memorial Children's Hospital Cape Town, South Africa*
2. *Department of Paediatrics and Child Health, Faculty of Health Sciences, University of Cape Town, South Africa*

Correspondence:

Dr M Wege

Martie.wege@gmail.com

Paediatric Critical Care Specialist

Department of Paediatrics and Child Health

Red Cross War Memorial Children's Hospital

Klipfontein Road

7700

Cape Town

ABSTRACT

Objectives: To describe the characteristics of children who died and their modes of dying in a South African Paediatric Intensive Care Unit (PICU)

Design: Retrospective review of data extracted from the Child Healthcare Problem Identification Programme (Child PIP) and the PICU summary system (admission and death records) on children of any age who died in the PICU between 01 January 2013 and 31 December 2017.

Setting: Single-centre tertiary institution

Patients: All children who died during PICU admission were included.

Measurements and Main Results:

Four-hundred and fifty one (54% male; median (IQR) age 7 (1-30) months) patients died in PICU on median (IQR) 3 (1-7) days after PICU admission; 103 (22.8%) had a cardiac arrest prior to PICU admission.

Mode of death in 23.7% (n=107) was withdrawal of life sustaining therapies; 36.1% (n=163) died after limitation of life sustaining therapies; 22.0% (n=99) died after failed resuscitation and 17.3% (n=78) were diagnosed brain dead. Ultimately, 270 (60%) children died after the decision to limit or withdraw life sustaining therapies.

There was no difference in the number of deaths during office and after-hours periods (45.5% vs. 54%; p = 0.07).

Severe sepsis (21.9%) was the most common condition associated with death, followed by cardiac disease (18.6%).

Ninety-four (20.8%) patients were readmitted to the PICU within the same year; 278 (61.6%) had complex chronic disorders. During the last phase of life, 75.0% (n=342) were on inotropes, 95.9% (n=428) were ventilated, 12.0% (n=45) received inhaled nitric oxide and 10.8% (n=46) renal replacement therapy. Only 1.5% (n=7) of children became organ donors and post mortems were done in 47.2% (n=213) of the patients.

Conclusions: Most PICU deaths occurred after a decision to limit or withdraw life-sustaining therapy. Severe sepsis was the most common condition associated with death. Referral for organ donation was extremely rare.

Keywords: paediatric intensive care unit; death; end-of-life; mortality; mode of death

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Background

Modern medical therapies and technology have advanced rapidly over the last decade. These improvements have led to a decrease in childhood mortality in high income countries, despite an increase in the severity of illness of hospitalised children (1, 2). There is a concern that the declining mortality rate in children is accompanied by a rising disability rate and that children who previously would have died early because of treatment failure, may now die after a prolonged hospital admission (5, 6).

Although the Paediatric Intensive Care Unit (PICU) at Red Cross War Memorial Children's Hospital (RCWMCH), in Cape Town, South Africa, is located in an upper middle income country with an estimated under-five mortality rate (U5MR) of 41-44 deaths per 1 000 live births, the U5MR for the Cape Town Metro district referring to RCWMCH was recently found to be 18 per 1 0000 live births (26, 38). The mortality rate of the RCWMCH PICU declined from 9% in 2010 to 6% in 2015, which is much lower than the mortality rate for PICUs in other parts of Africa (17, 19) and only slightly higher than some high income countries, where a mortality rate of 2.4 -5.5% has been reported (1, 8, 18). A recent review of admission and mortality trends over a 10 year period at RCWMCH showed a 16% increase in PICU admissions, with an overall decrease in in-hospital mortality (30).

The main cause of death at RCWMCH was previously reported under the category of infectious diseases (25, 29, 30). This is different from high income countries where the most common cause of death is respiratory failure and underlying congenital malformations (1). The above analysis from RCWMCH was conducted in 2003, with a more recent review reporting the most common conditions associated with death to still be pneumonia and diarrhoea (30). A report from the *Child Healthcare Problem Identification Programme* (Child PIP) recorded deaths in South African (SA) hospitals for 2012/2013. This report confirmed that 19.4% of all deaths are attributed to pneumonia, followed by acute diarrhoea with hypovolaemic shock and sepsis (17.2%) (29). Unfortunately pneumonia and sepsis are not well defined, therefore many children with metabolic diseases, cardiac disease, poisoning etc may present with clinical features that overlap with those of respiratory distress, sepsis or circulatory failure, meaning that the actual cause of death may be missed.

End-of-life treatment in children is complex and involves ethical and legal considerations (10). Decisions have to be based on the best interest of the patient as well as considering the

families' interests and wishes. In the SA context, the ethical principle of distributive justice – doing the best for the most within resource constraints - comes into play. With limited available PICU resources, more specific attention and resource utilization may need to be focused on patients with better prognoses (2, 17, 18).

The mode of death and end-of-life decision-making process varies greatly between countries (3). The mode of death is defined as the manner or way of dying. Previous publications report the rate of PICU deaths after withdrawing or withholding life sustaining therapy to range between 15-75% (2, 8, 14, 16). There are currently no published reports on the mode of death for children who die in South African PICU's.

The aim of this study was to describe the mortality rates, characteristics, mode of death and epidemiology of children who died in the PICU at RCWMCH a five- year study period.

METHODS

Design and Setting

This study was a retrospective review of routinely collected data extracted from the Child PIP and the PICU summary system (admission and death records). The Hospital Information System was used to extract data on total hospital admissions and deaths and to identify any missed cases from the Child PIP or PICU summary system. The study was approved by the departmental scientific research committee, hospital management and the University of Cape Town's Faculty of Health Sciences Human Research Ethics Committee. [HREC REF NO: 029/2018]

The need for written, informed consent was waived for this study, owing to its retrospective, non-interventional design, with associated minimal risk.

Study population

The study population consisted of all children of any age who died in the PICU at RCWMCH over a five-year period between 01 January 2013 and 31 December 2017. Patients who were dead on arrival in the PICU were excluded.

Case definitions for mode of death

The mode of death is defined as the manner or way of dying, and was categorised as follows (13, 41):

Failed Cardiopulmonary resuscitation (CPR): Unsuccessful cardiopulmonary resuscitation.

Limitation/withholding of life-sustaining treatment (LLST): not initiating or increasing a life-sustaining intervention.

Withdrawal of life-sustaining treatment (WLST): the discontinuing of life-sustaining treatment in anticipation of death.

Brain death (BD): Formal determinations of brain death with brain stem testing and/or a brain perfusion scan.

Do-not-resuscitate (DNR) only: The decision to not resuscitate the patient in case of a cardiac arrest but to still continue with all other life-sustaining therapies.

Case definition for conditions associated with death

Conditions associated with death in SA are largely determined from death notification data reported by Statistics South Africa (Stats SA) or from in-hospital audit systems such as the Child PIP (26).

For the purposes of this study, conditions associated with death were first categorized using the World Health Organization's (WHO) International Classification of Diseases, tenth revision (ICD 10). The simple mortality list of 2014 was used. Conditions were listed according to the different chapters and were also coded for a more detailed diagnosis (Appendix 1).
Conditions associated with death according to the Child PIP database definitions, as well as the PICU summary system were also recorded separately (Appendix 2).

Case definition for underlying complex chronic conditions (CCC)

The definition developed by Feudtner et al for complex chronic conditions (CCC) was used: "Any medical condition that can be reasonably expected to last at least 12 months (unless death intervenes) and to involve either several different organ systems or one organ system severely enough to require specialty paediatric care and probably some period of hospitalization in a tertiary care center" (42).

Based on this definition, a comprehensive set of codes from the ICD-9 and ICD-10 system

were identified as being indicative of a CCC, and assigned to 11 categories to develop the CCCv2 classification (43). These were used to identify and categorize children with CCCs for this study (Appendix 3)

Child Healthcare Problem identification programme (Child PIP)

Child PIP is a mortality review process used in South Africa that allows assessment of the quality of care children received at specific health care facilities. At RCWMCH, for every PICU death the medical folder is reviewed by a critical care fellow who prepares a detailed analysis for presentation at the weekly mortality and morbidity meeting. (Appendix 4)

Patient Data

Data were collected on patient demographics and characteristics, including age at death; sex; ethnicity; admission risk of mortality, using the paediatric index of mortality score (PIM) (PIM2 from 2013-2015 and PIM3 for 2016-2017); admission diagnosis; and presence of any underlying complex chronic conditions at PICU admission. Other variables included HIV status, nutritional status, source of referral and the clinical service with primary responsibility for the admission (Medical, Cardiovascular surgery, General surgery, Neurosurgery, Trauma, other). Further data were collected on the length of PICU stay (LOS) in days, calculated as the difference between dates of death and PICU admission; mode of death and the type of life-sustaining treatment that was used prior to death, including the use of invasive or non-invasive ventilation, inotropes, nitric oxide and renal replacement therapy. Deaths were also categorized as occurring either after hours or during working hours, with working hours defined as 07:00 – 19:00 Monday to Friday and after hours including week nights, weekends and public holidays. Data were also collected on the cause of death; whether the patient was postoperative; elective or emergency admission; if a post-mortem was done; whether the patient was considered for organ donation and whether the death was considered avoidable or unavoidable from a PICU perspective.

Statistical analysis

Data were entered onto an Excel spreadsheet and then exported to Statistica version 13 (StatSoft Inc, Tulsa, USA) for statistical data analysis and management.

Demographic and patient characteristics were analysed and presented using descriptive

statistics appropriate to data distribution (normal or nonparametric), after testing for normality using the Shapiro-Wilks W test. Most data were expressed as percentages and absolute counts. Where continuous data were available they were summarized using median and interquartile ranges (25^{th}-75^{th} percentiles).

Independent variables for the categories of "mode of death" were compared using chi-square tests for categorical data and one-way ANOVA (analysis of variance) or Kruskall-Wallis tests for normal and nonparametric continuous variables respectively. A p value of <0.05 was considered statistically significant.

RESULTS

During the study period a total of 103 250 patients were admitted to RCWMCH with an overall hospital mortality of 1.23% (n=834). The PICU had 6 778 admissions (6.56% of hospital admissions) and a total of 470 deaths, with an overall PICU mortality of 6.93%. Of the 470 deaths, 19 were excluded because of incomplete information (n=17) or being diagnosed dead on arrival (n=2). Data were therefore analysed for 451 PICU deaths (Figure 1).

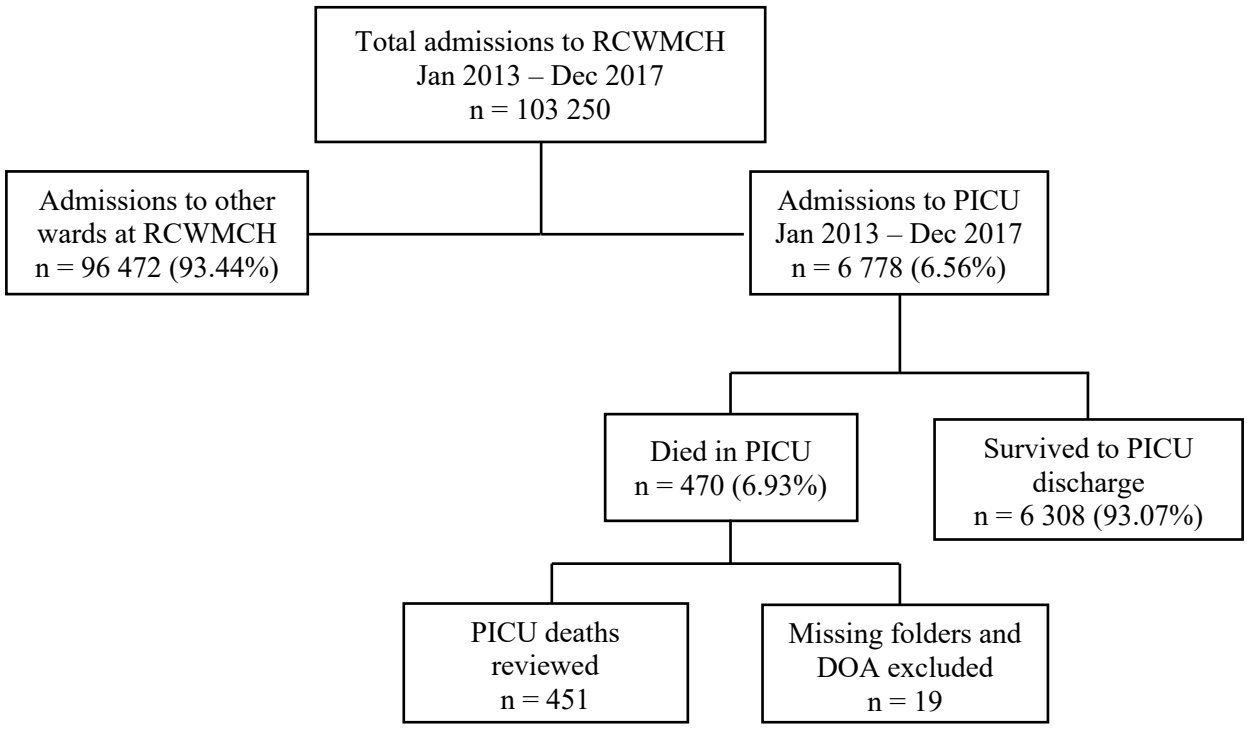

Figure 1. Selection and sampling flowchart

DOA = Dead on arrival

PICU = Paediatric intensive care unit

RCWMCH = Red Cross War Memorial Children's Hospital

Mortality data over the 5 year period

The overall hospital admissions trended downwards over the 5-year study period, but PICU admission numbers remained stable (Table 1). The average PICU mortality rate for the 5-year period was 7%. More than half (56%) of all hospital deaths occurred in the PICU.

Table 1. Admissions and overall mortality data

	2013	2014	2015	2016	2017
Hospital admissions (n)	21 785	21 308	20 173	19 596	20 388
Hospital deaths (Hospital mortality rate, %)	167 (0.77)	172 (0.81)	157 (0.78)	169 (0.86)	169 (0.82)
PICU admissions (PICU admission rate, %)	1 345 (6.17)	1 417 (6.65)	1 365 (6.77)	1 309 (6.68)	1 342 (6.58)
PICU deaths (n (% of hospital deaths))	93 (55.69)	100 (58.14)	81 (51.59)	87 (51.48)	97 (57.40)
PICU mortality rate (%)	6.91	7.06	5.93	6.64	7.23

Patient characteristics and clinical course

Characteristics of patients who died are presented in Table 2. The median (IQR) age of death was 7 (1-30) months, with 126 (27.94%) patients within the neonatal period. The median PICU LOS at the time of death was 3 (1-7) days. Approximately half (52.99%) the children had a normal weight for age and 6% of the patients who died were HIV infected.

The majority of children who died were categorized as medical admissions (46.12%; Table 2). More than half (54%) the patients died after hours ($p = 0.07$).

Of the patients who died, 61.64% had an underlying chronic condition. The presence of a complex chronic condition was significantly associated with PICU readmission ($chi^2 = 44.99$; $p < 0.0001$). Of the 94 readmissions, 86 (91.49%) had a CCC, compared to only 8 (8.51%) of the readmissions without CCD ($p < 0.0001$) (Table 3). The single patient with unknown CCC status in the readmission group was excluded from this analysis.

Most patients were intubated and ventilated (94.90%) and received vasoactive drugs (75.83%) in the 48-72 hours preceding their death. (Figure 2). Only 7 of the 451 patients (1.55%) became organ donors.

Almost half (n=213; 47.23%) the patients had a post mortem, of which 35.68% (n=76) were performed by the RCWMCH pathology service in cases where the cause of death was not yet confirmed, and 64.32% (n=137) were performed for medico-legal/forensic purposes where unnatural deaths were suspected.

Table 2. Characteristics of patients who died in PICU (n=451)

Baseline variable		**Data (n (%))**
Age (median (IQR) months		7 (1-30)
Gender	Male	247 (54.67)
	Female	204 (45.33)
Nutritional status	Normal	239 (52.99)
	Severe UWFA	88 (19.51)
	Moderate UWFA	91 (20.18)
	Severe malnutrition	22 (4.88)
	OWFA	6 (1.33)
	Unknown	5 (1.11)
HIV status	Negative	315 (69.84)
	Exposed, but negative	78 (17.29)
	Infected on treatment	15 (3.33)
	Infected, not on treatment	13 (2.88)
	Unknown	30 (6.65)
Complex chronic condition	Total CCC	278 (61.64)
(ICD-10) classification	Premature and neonatal conditions	83 (29.86)
	Cardiovascular	58 (20.86)
	Congenital or genetic defects	41 (14.74)
	Hematologic or immunologic	30 (10.79)
	Gastrointestinal	18 (6.47)
	Malignancy	15 (5.36)
	Neurological or neuromuscular	13 (4.68)
	Metabolic	8 (2.88)
	Renal/Urologic	5 (1.80)
	Devices	3 (1.08)
	Respiratory	3 (1.08)

	Transplantation	1 (0.36)
Diagnostic category	Medical	208 (46.12)
	Cardiac	85 (18.85)
	General surgery	67 (14.86)
	Trauma	58 (12.86)
	Neurosurgery	18 (3.99)
	Haematology-Oncology	14 (3.10)
	Ear nose and Throat surgery	1 (0.22)
Cardiac arrest prior to PICU admission	Yes	103 (22.84)
	No	346 (76.72)
	Unknown	2 (0.44)
Readmission to PICU	Yes	94 (20.84)
	No	357 (79.16)
Postoperative during PICU stay	Yes	167 (37.03)
	No	284 (62.97)
Elective vs emergency admissions to PICU	Elective	40 (8.8)
	Emergency	410 (90.91)
	Unknown	1 (0.22)
Source of admission	**Other facilities** Another government hospital Clinics Private hospital	146 (32.37) 112 (76.71) 17 (11.64) 17 (11.64)
	RCWMCH medical or surgical ward Medical emergencies Theatre Trauma unit	130 (28.82) 92 (20.40) 50 (11.09) 33 (7.32)

Categorical data are presented as n (%) throughout

CCD: Complex chronic conditions,

HIV: Human immunodeficiency virus,

OWFA: Overweight for age,

PICU: Paediatric intensive care unit,

RCWMCH: Red Cross War Memorial Children's Hospital,

UWFA: Under-weight for age

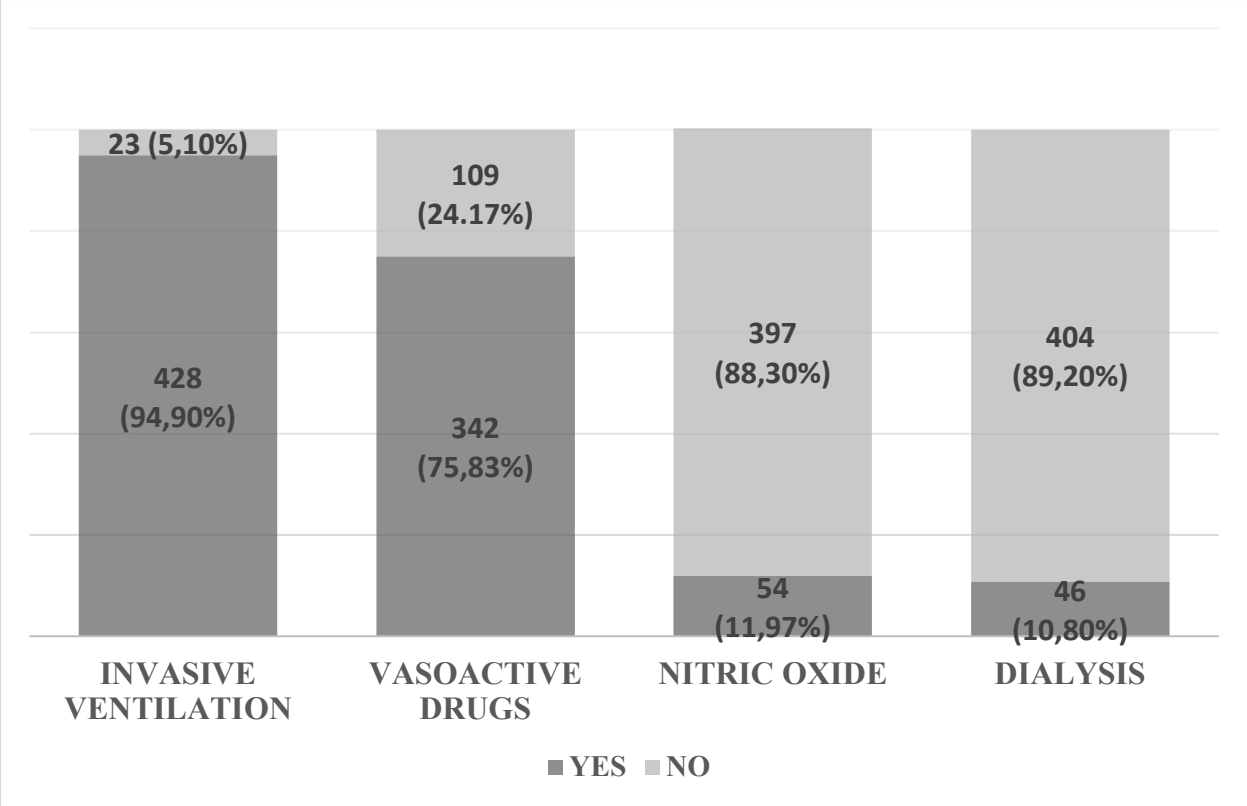

Figure 2. Interventions received during the 48-72 hours preceding death. Data are presented as n (%).

Conditions associated with death

The main conditions associated with death, according to Child PIP, were infections (n=136; 30.16%), followed by circulatory (n=84; 18.64 %), digestive system (including all abdominal surgical cases; n=61; 13.53%), respiratory (n=57; 12.64%) and nervous system (n=39; 8.65%) conditions.

ICD-10 data also showed infections to be the main condition associated with death (n=114 ; 25.28%); followed by external causes (n=61; 13.53%); congenital/chromosomal, including congenital cardiac abnormalities (n=60; 13.30%); nervous system, including meningitis (n=60; 13.30%) and respiratory system (n=55; 12.20%).

The PICU summary system reported the most common conditions associated with death to be sepsis (n=99 ; 21.95%) followed by cardiac disease (n=83; 18.4 %), pneumonia (n=54; 11.8 %), accident-related (n=51; 11.31%) and bowel-related surgical cases (n=45; 9.98%). Accidents included all road-related, drownings and burns deaths.

Mode of death

Mode of death could not be established in four cases (0.89%) owing to missing data. Active WLST was the most common mode of death (n=107; 23.73%) followed by failed resuscitation (n=99; 22%) and death after a DNR order (n=95; 21.06%); 17.29% (n=78) were diagnosed brain dead and 15.08% (n=68) died after limiting other LST (Table 3).

Mode of death varied over time (Figure 3) but there was no clear directional trend ($chi^2 = 32.34$; $p = 0.009$). There was no difference on *posthoc* analysis in the relative proportions of failed CPR compare to LLST over time ($chi^2 = 7.04$; $p = 0.13$).

There was no difference in the proportions of modes of death between patients with CCC, readmissions and post-operative patients ($chi^2 = 14.94$; $p = 0.13$). Ultimately, 60% (n=270) of children died after the decision was made to limit or withdraw LST. Children who died because of brain death or failed CPR had a significantly shorter LOS compared to the children who died after a decision to limit or withdraw life-sustaining therapies (Figure 4).

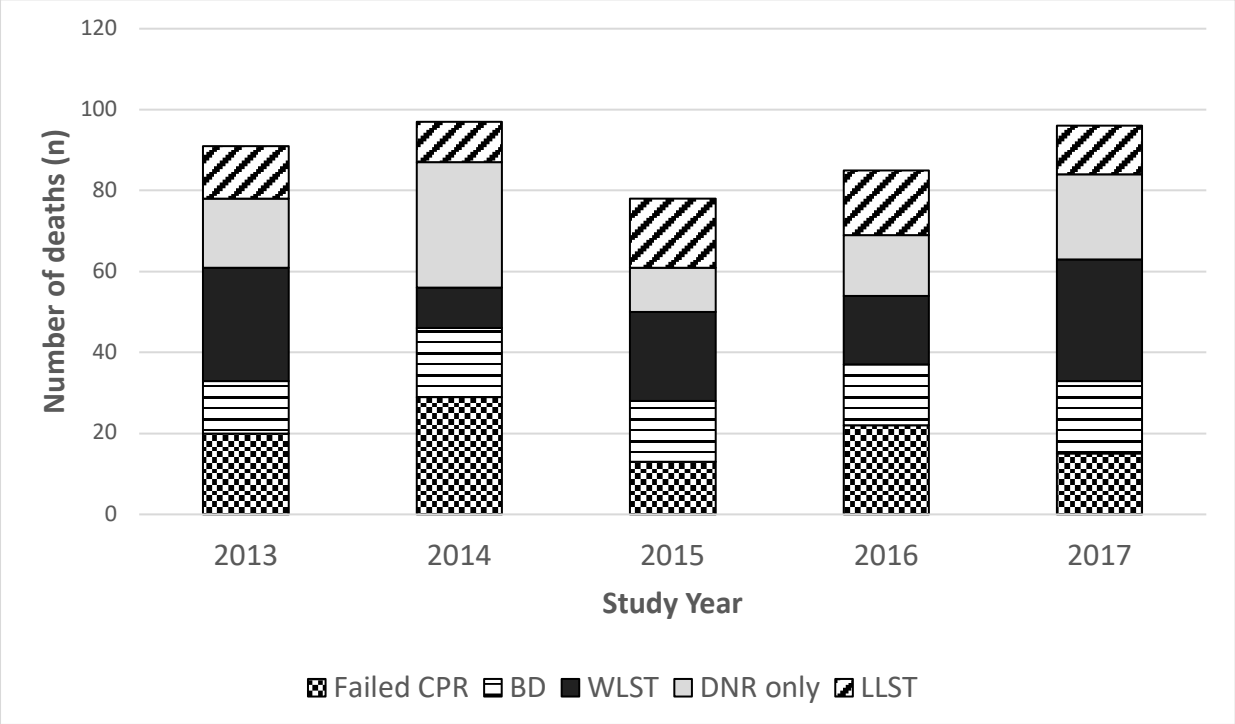

Figure 3. Mode of death over study period

BD = Brain death

CPR = Cardiopulmonary resuscitation

DNR = Do-not-resuscitate

LLST = Limitation of life sustaining treatments

WLST = Withdrawal of life sustaining treatment

Table 3. Association between patients with complex chronic conditions, those readmitted to the PICU, postoperative patients and mode of death (n=447).

	n (%)	BD	Failed CPR	DNR only	WLST	LLST
All patients	447 (100)*	78 (17.29)	99 (21.95)	95 (21.06)	107 (23.73)	68 (15.08)
CCC	278 (61.64)	20 (7.19)	60 (21.58)	63 (22.66)	76 (27.34)	56 (20.14)
Postoperative	167 (37.02)	24 (14.37)	38 (22.75)	30 (17.96)	50 (29.94)	23 (13.77)
Readmission	94 (20.84)	5 (5.32)	21 (22.34)	24 (25.53)	21 (22.34)	23 (24.47)

*Four patients excluded owing to missing data. Data presented as n (%) throughout.

BD = Brain death
Failed CPR = Failed cardiopulmonary resuscitation
DNR = Do not resuscitate
WLST = Withdrawal of life sustaining therapies
LLST = Limitation of life sustaining therapies
CCC = Complex chronic conditions

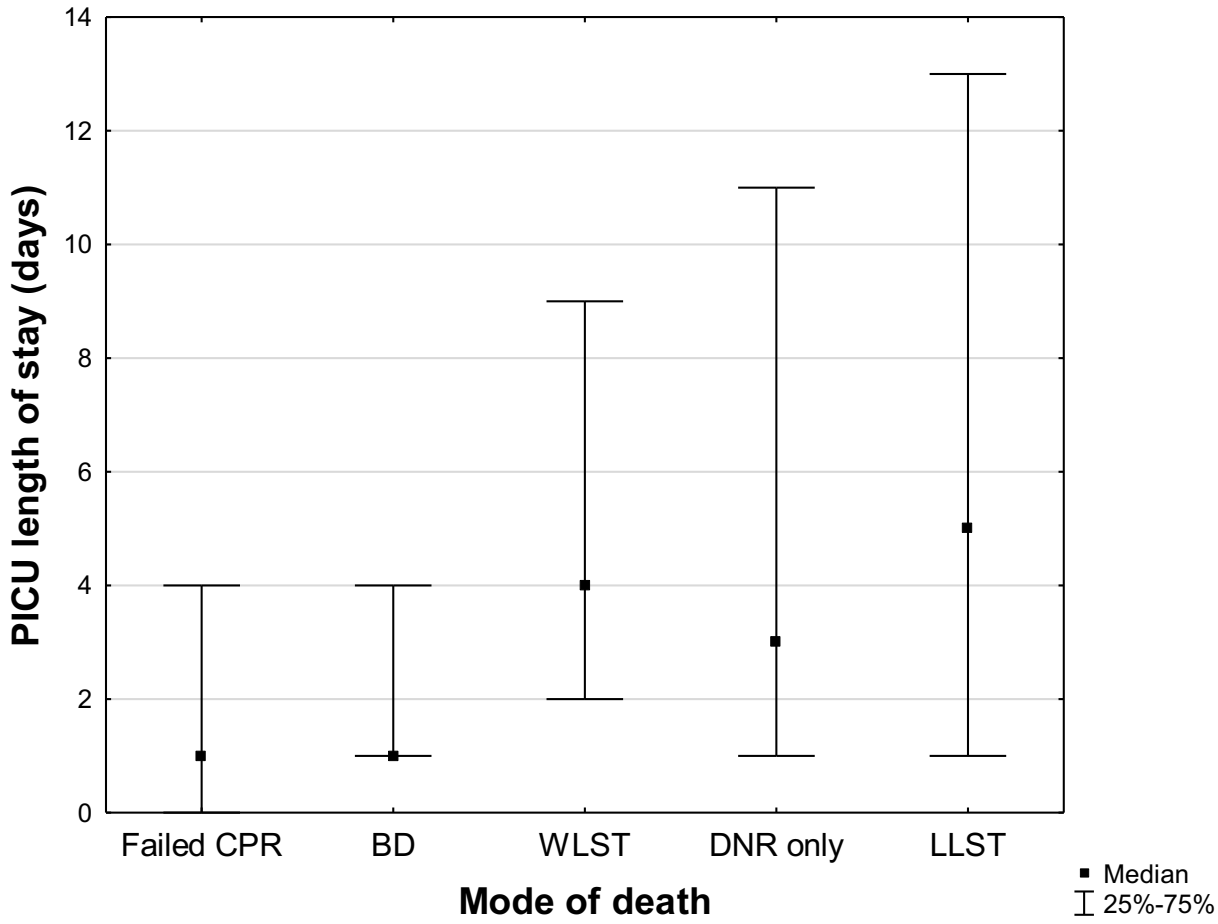

Figure 4. PICU length of stay (LOS) and mode of death using using Kruskal Wallis Anova and median test (p < 0.0001)

DISCUSSION

This is the first report on the mode of PICU death in sub-Saharan Africa. Death after withdrawal or withholding of life-sustaining therapy was found to be the most common mode of death in our unit (60%), followed by failed CPR and brain death, which is similar to international reports (3, 10, 13, 18, 22, 24). The CPR failure rate of 22% is higher than the 6-14% rates reported from well-resourced countries such as the United Kingdom, United States and Canada (10, 13, 18), but similar to the failed CPR rate reported from Australia, New Zealand (21%) and Pakistan (28.2%) (4, 24) and substantially lower than some of the South American countries, where most patients (73.5%) have been reported to die after failed CPR (7). The reasons for this finding cannot be determined from the results of this study, but may relate to severity of illness and quality of CPR. This warrants further research. Most previous reports grouped withdrawal and limitation of LST together (3, 4, 7-15). Some reports had an additional category for DNR (3, 4, 7, 8, 11, 12, 14-16). For our study purpose we added DNR

as a separate mode of death category because in clinical practice a number of children have a DNR decision whilst still receiving maximal interventive therapies. This group is different from those where a decision has been made to with-hold or withdraw life sustaining therapies in addition to a DNR. With the increased involvement of a dedicated paediatric palliative care team at RCWMCH over recent years, we expected to demonstrate a trend to fewer children dying after failed CPR and more dying after LLST over recent years. Although the proportions of different modes of death changed over the study period, there was no difference in the relative proportion of failed cardiac arrests compared to LLST over time. It is, however, possible that more children are now dying at home and in the general hospital wards after LLST/WLST .

The overall mortality rate of our unit is comparable to reports from South American and some European countries (7, 9, 37). In 2015 we saw a very encouraging decrease in mortality, reaching <6%. Unfortunately, mortality subsequently increased again peaking at just over 7% in 2017. The cause for this increase in mortality is not clear but may relate to the opening of an additional two district hospitals in the Western Cape in 2016 and 2017. The availability of these new facilities may have led to more children being resuscitated in hospital before transfer, whereas previously they would likely have died in the community (26). The Western Cape is also experiencing an influx of people from other provinces like the Eastern Cape and this adds to the demands on the health care system (45).

Even with the slight increase in mortality over the 2016-2017 period, our overall mortality rate of 7% is an improvement from the 11.4% reported 10 years ago (17, 19) and is comparable with other reports from high and middle income countries (7, 11, 18, 37). Unfortunately, we were not able to obtain standardized mortality rates in a consistent manner for the entire study period, which limits direct comparison amongst different PICUs. However it can be noted that our mortality rate was substantially lower than the 16.2% reported from another PICU in South Africa (19) and the rest of Africa, where mortality rates up to 40% have been reported (28, 32, 35).

More than half (56%) of all hospital deaths occurred in the PICU. With the increased involvement of our palliative care team, more children are now planned for home deaths where this was previously not considered. Previous work done at RCWMCH in the early 2000's in the midst of the HIV epidemic showed that 37% of hospital deaths occurred in the PICU and

36% in the medical wards (25). The proportional increase in PICU deaths may reflect earlier PICU referral, end-of-life planning in PICU and overall improvement in the medical care of children in the wards. Over the last decade the wards outside the PICU at RCWCH implemented the use of non-invasive ventilation in the form of high flow nasal cannula (HFNC) and continuous positive airway pressure (CPAP). Only those children who failed the trial of NIV in the wards would be admitted to PICU in respiratory failure, with a resulting high risk of mortality.

The proportion of hospitalized children who died in our PICU correlates with previous reports from Toronto (11), but is far lower than Great Ormond Street, where up to 90% of hospital deaths occurred in the PICU setting (1). Something of great concern for the Metro health district in Cape Town is that more children still die out-of-hospital (55%) than in-hospital (26). The main cause for out-of-hospital deaths were from potentially treatable conditions such as pneumonia and gastroenteritis. With an in-hospital mortality rate at RCWMCH of 1.25%, the very high rate of out-of-hospital deaths in an urban area highlights concerns about access to health care facilities (26, 38).

More than half (54%) the patients in this study died out of normal working hours (19h00 – 07h00 on weekdays or weekends and public holidays), however this mortality rate was not significantly different to that occurring during work hours. It would seem intuitive that withdrawals of life-sustaining therapy are more likely to occur during working hours, owing to staff availability, however families are more likely to be present after hours, which may partly explain the high proportion of deaths occurring during this time.

We did not collect data on the actual precipitating cause of death (e.g. respiratory, renal or circulatory failure), as this was inconsistently reported in the medical notes. The three different coding systems used to classify conditions associated with death all identified infections as the primary condition associated with mortality. Our findings differ from most high income countries, where most of the large centres found respiratory disease to be the main condition associated with death (3, 7, 10, 16, 31). Similar to our findings using ICD-10 coding, Sands et al found the most common condition associated with death in the UK over a 10-year period to be infections and injury/poisoning- related (18). The PICU summary system and CHIP systems both identified cardiac disease as the second most common associative condition. We found a major difference in how the Child PIP and ICD-10 systems grouped patients. Child PIP

separates accidents, burns, abuse, homicide and poisoning whilst ICD-10 coding groups these together as external/unnatural deaths. This lead to an undercount of unnatural deaths using the Child PIP system. Similarly, ICD-10 categorizes congenital heart disease as a congenital abnormality whereas Child PIP classifies this as a circulatory death. From the results of this study, one cannot appreciate the high prevalence of neonates who die as a consequence of necrotising enterocolitis, as in Child PIP this is classified broadly under "digestive system", whilst ICD-10 categorizes these deaths as "perinatal deaths". This reflects the immense difficulty we have in SA with death reporting and it is therefore strongly recommended that a standardised method of reporting be developed and implemented.
Children with complex chronic disorders are surviving longer and more of them have access to the PICU, whereas previously these children may have been denied PICU admission (17). In this study, 61% of children who died had an underlying chronic condition, which is comparable to reports of between 45-81% in well-resourced countries (3, 7, 10, 13, 16, 31); however it is higher than expected for a middle income country (4) with limited resources. There are no previous reports available on the prevalence of complex chronic conditions in children dying in South African PICUs, however one report from Ethiopia reported that children with comorbid conditions were ten times more likely to die (28).

Children with a CCC were more likely to have been readmitted to the PICU than those without a CCC. It is therefore important to identify children with CCCs, as they appear to have a worse prognosis than children without a complex comorbidity. However, the lack of a control group who survived PICU admission limits this recommendation, and further controlled studies are recommended to identify those at greater risk of PICU mortality. Kalzen et al (47) demonstrated that multiple admissions to a PICU were associated with a significant decrease in survival over time, and the presence of a CCC further impaired survival over time.

Although most neonatal services occur in other secondary and tertiary centres in the Metropole, the majority of neonates, including preterm neonates, with surgical problems are managed at RCWMCH. It is therefore striking that a quarter (27%) of all deaths in this study occurred during the neonatal period and almost a fifth of all PICU deaths were premature or ex-premature babies.

It is concerning that over the 5 year study period, only seven (1.5%) of the 451 analysed deaths became organ donors; with brain death being the mode of death in all seven. This low rate of

referral for organ donation may relate to the high incidence of associated infections, multiorgan involvement, and young age and also different cultural and religious beliefs. This requires further investigation, as there is currently a long waiting list of children urgently requiring solid organ transplants.

The study was limited by being from a single site (limiting external validity) and by the retrospective study design along with the inherent challenges in completing death certification. Another major limitation of this study is that we recorded conditions associated with death as they were reported by other clinicians, and there was no standardisation of diagnosis. It is recommended that further research be conducted, using the standardized mortality rate, to ascertain whether the increased mortality rate was due to sicker children being admitted to the unit. Unfortunately, in 2016 we changed the severity of illness scoring system from PIM 2 to PIM 3, and whilst PIM 2 has been validated for use in our context (46), PIM 3 has not. We therefore were not able to derive standard mortality rates. The lack of control group of children who survived PICU is a further limitation of this study, and therefore independent risk factors for death could not be determined. This warrants future investigation.

This study only investigated mortality, and we cannot comment on morbidity outcomes of PICU admission. A multi-site study of eight PICUs reported the prevalence of a new morbidity after PICU admission to be twice the mortality rate, occurring in all types of patient (48). It is recommended that this be prospectively investigated in the South African context.

In a critical care unit where treatment is complex, high risk and expensive, it is paramount to review and understand the characteristics of patients who die in the unit in order to improve services and outcomes for critically ill children. This is the first report on mode of death in children from a South African intensive care unit. Ideally, this needs to be repeated in a few years' time to identify change in mortality and mode of death over years. It will be interesting to compare the mode of death and different end-of-life practices between PICUs in South Africa with similar resources and ethical, cultural and religious considerations. Understanding the burden of specific diseases help to focus the limited resources to where children can benefit most.

CONCLUSION

The majority of hospital deaths occurred in the PICU, with most of these deaths following a decision to limit or withdraw life sustaining therapies. The majority of children who died had a comorbid complex chronic condition. PICU LOS before death was shorter in those whose cause of death was brain death or failed CPR compared to those following LLST/WLST. The most common conditions associated with death in a South African PICU were septicaemia, cardiac disease, pneumonia, accident- related and bowel- related surgical deaths.

Conflicts of interest

There are no conflicts of interest to be declared.

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Standard Web Site/Electronic Format: Marion DW, Domeier R, Dunham CM, et al: Practice management guidelines for identifying cervical spine injuries following trauma. Available at: http://www.east.org. Accessed July 1, 2000

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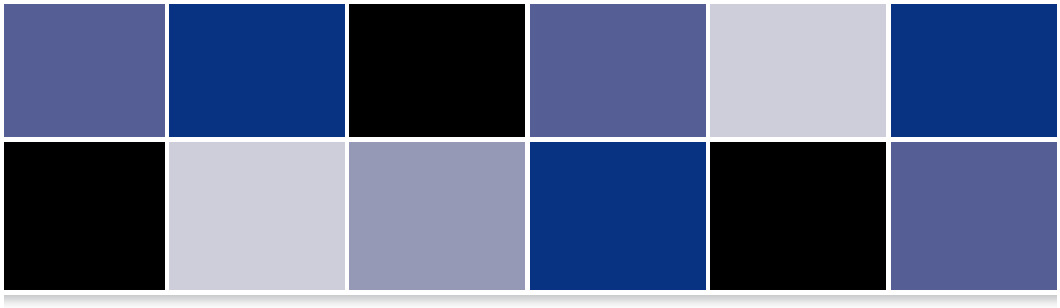
Appendix 1 WHO ICD-10 cause of death collection



WHO Application of ICD-10 for low-resource settings initial cause of death collection

The Startup Mortality List (ICD-10-SMoL)

V2.0

World Health Organization

Reference to ICD-10 chapter	Code	Cause of death	Optional subcategory	Coding hints
ICD-10 chapter 1		**Certain infectious and parasitic diseases**		**excludes** respiratory infections not listed here
	5-1	Cholera		
	5-2	Typhoid and paratyphoid		
	5-3	Other and unspecified diarrhoeal diseases		**includes** gastroenteritis, other foodborne infections
	5-4	Tuberculosis		**excludes** HIV disease, with tuberculosis
	5-4.1		Respiratory tuberculosis, confirmed bacteriologically or histologically	
	5-4.9		Other tuberculosis	
	5-5	Plague		
	5-6	Leprosy		
	5-7	Tetanus		
	5-8	Diphtheria		
	5-9	Whooping cough		
	5-10	Meningococcal infection		**includes** meningococcal meningitis, **excludes** unspecified meningitis (see nervous section)
	5-11	Septicaemia		
	5-12	Infections with a predominantly sexual mode of transmission		
	5-12.1		Syphilis	
	5-12.9		Other and unspecified infections with a predominantly sexual mode of transmission	
	5-13	Acute poliomyelitis		
	5-14	Rabies		

Reference to ICD-10 chapter	Code	Cause of death	Optional subcategory	Coding hints
	5-15	Dengue		
	5-16	Yellow fever		
	5-17	Other viral haemorrhagic fevers		
	5-18	Measles		
	5-19	Viral hepatitis		
	5-19.1		Hepatitis B	
	5-19.8		Other viral hepatitis	
	5-19.9		Unspecified viral hepatitis	
	5-20	Human immunodeficiency virus [HIV] disease		
	5-20.1		HIV disease with tuberculosis	
	5-20.2		Other and unspecified HIV disease	
	5-21	Malaria		
	5-21.1		Malaria, parasitologically confirmed	
	5-21.9		other and unspecified malaria	
	5-22	Leishmaniasis		
	5-23	Trypanosomiasis		
	5-24	Schistosomiasis		
	5-25	Other and unspecified infectious diseases		
ICD-10 chapter 2		**Neoplasms**		**includes** all neoplasms of all organ systems, including cancer
	5-26	Malignant neoplasm of lip, oral cavity and pharynx		
	5-27	Malignant neoplasm of Oesophagus		
	5-28	Malignant neoplasm of stomach		
	5-29	Malignant neoplasm of colon, rectum and anus		
	5-30	Malignant neoplasm of liver and intrahepatic bile ducts		
	5-31	Malignant neoplasm of pancreas		
	5-32	Malignant neoplasm of larynx		
	5-33	Malignant neoplasm of trachea, bronchus and lung		
	5-34	Malignant melanoma of skin		
	5-35	Malignant neoplasm of breast		
	5-36	Malignant neoplasm of cervix		

Reference to ICD-10 chapter	Code	Cause of death	Optional subcategory	Coding hints
		uteri		
	5-37	Malignant neoplasm of other and unspecified parts of uterus		
	5-38	Malignant neoplasm of ovary		
	5-39	Malignant neoplasm of prostate		
	5-40	Malignant neoplasm of bladder		
	5-41	Malignant neoplasm of meninges, brain and other parts of central nervous system		
	5-42	Non-Hodgkin lymphoma		
	5-43	Multiple myeloma and malignant plasma cell neoplasms		
	5-44	Leukaemia		
	5-45	Other and unspecified malignant neoplasms		
	5-46	Benign neoplasms		
ICD-10 chapter 3		**Diseases of the blood and blood-forming organs and certain disorders involving the immune mechanism**		**excludes** neoplasms and cancers
	5-47	Anaemias		
	5-48	Other diseases of the blood and blood-forming organs and certain disorders involving the immune mechanism		
ICD-10 chapter 4		**Endocrine, nutritional and metabolic diseases**		**excludes** neoplasms and cancers
	5-49	Diabetes mellitus		
	5-50	Protein-energy malnutrition		
	5-51	Other and unspecified endocrine, nutritional and metabolic diseases		
ICD-10 chapter 5		**Mental and behavioural disorders**		
	5-52	Alcohol use disorders		
	5-53	Drug use disorders		
	5-54	Other mental and behavioural disorders		

Reference to ICD-10 chapter	Code	Cause of death	Optional subcategory	Coding hints
ICD-10 chapter 6		**Diseases of the nervous system**		**excludes** neoplasms and cancers
	5-55	Meningitis		
	5-56	Alzheimer's disease, dementias		
	5-57	Other diseases of the nervous system		
ICD-10 chapter 7	**5-58**	**Diseases of the eye and adnexa**		**excludes** neoplasms and cancers
ICD-10 chapter 8	**5-59**	**Diseases of the ear and mastoid process**		**excludes** neoplasms and cancers
ICD-10 chapter 9		**Diseases of the circulatory system**		**excludes** neoplasms, cancers and cardiac arrest (I46)
	5-60	Acute rheumatic fever and chronic rheumatic heart diseases		
	5-61	Hypertensive heart diseases		
	5-62	Ischaemic heart diseases		**includes** myocardial infarction
	5-63	Other heart diseases		
	5-64	Cerebrovascular diseases		
	5-65	Other and unspecified diseases of the circulatory system		
ICD-10 chapter 10		**Diseases of the respiratory system**		**excludes** neoplasms and cancers
	5-66	Influenza		
	5-67	Pneumonia		
	5-68	Other acute lower respiratory infections		**excludes** infections specified in the infectious disease section
	5-69	Chronic lower respiratory diseases		**includes** chronic obstructive lung disease, asthma
	5-70	Other and unspecified diseases of the respiratory system		

Reference to ICD-10 chapter	Code	Cause of death	Optional subcategory	Coding hints
ICD-10 chapter 11		**Diseases of the digestive system**		**excludes** neoplasms and cancers
	5-71	Gastric and duodenal ulcer		
	5-72	Appendicitis		
	5-73	Liver cirrhosis		
	5-74	Other diseases of the digestive system		
ICD-10 chapter 12	**5-75**	**Diseases of the skin and subcutaneous tissue**		**excludes** neoplasms and cancers, melanoma of skin
ICD-10 chapter 13	**5-76**	**Diseases of the musculoskeletal system and connective tissue**		**excludes** neoplasms and cancers
ICD-10 chapter 14		**Diseases of the genitourinary system**		**excludes** neoplasms and cancers
	5-77	Glomerular and renal tubulo-interstitial diseases		**includes** pyelonephritis
	5-78	Other and unspecified diseases of the genitourinary system		**includes** urinary tract infection, **excludes** pyelonephritis
ICD-10 chapter 15		**Pregnancy, childbirth and the puerperium**		**excludes** tetanus, external causes
	5-79	Pregnancy with abortive outcome		
	5-80	Maternal hypertensive disorders		
	5-81	Obstructed labour		
	5-82	Maternal haemorrhage		
	5-83	Maternal sepsis		
	5-84	Other direct obstetric deaths		**excludes** tetanus
	5-85	Indirect obstetric deaths		

Reference to ICD-10 chapter	Code	Cause of death	Optional subcategory	Coding hints
ICD-10 chapter 16		**Certain conditions originating in the perinatal period**		**excludes** tetanus, external causes, malformations, neoplasms, cancers, endocrine diseases (e.g. diabetes mellitus)
	5-86	Fetus and newborn affected by maternal factors and by complications of pregnancy, labour and delivery		
	5-87	Disorders relating to length of gestation and fetal growth		
	5-87.1		Prematurity	
	5-87.2		Low birth weight	
	5-87.9		Other and unspecified disorders relating to length of gestation and fetal growth	
	5-88	Birth trauma		
	5-89	Intrauterine hypoxia and birth asphyxia		
	5-90	Other and unspecified perinatal conditions		
ICD-10 chapter 17		**Congenital malformations, deformations and chromosomal abnormalities**		
	5-91	Congenital hydrocephalus and spina bifida		
	5-92	Congenital malformations of the heart		
	5-93	Down syndrome and other chromosomal abnormalities		
	5-94	Other and unspecified congenital malformations		
ICD-10 chapter 18	**5-95**	**Symptoms, signs and abnormal clinical and laboratory findings, not elsewhere classified**		**includes** cause of death not specified, or when only 'respiratory arrest' or 'cardiac arrest' is reported

Reference to ICD-10 chapter	Code	Cause of death	Optional subcategory	Coding hints
ICD-10 chapter 20		**External causes of morbidity and mortality**		
	5-96	Road traffic accidents		
	5-97	other transport accidents		
	5-98	Falls		
	5-99	Accidental drowning and submersion		
	5-100	Exposure to smoke, fire and flames		
	5-101	Exposure to forces of nature		**includes** earthquake, tsunami, storm and flood
	5-102	Accidental poisoning by and exposure to noxious substances		**includes** noxious substances eaten as food **excludes** foodborne infections (see infectious diseases)
	5-102.1		Alcohol poisoning	
	5-102.2		Drug poisoning	
	5-102.9		Other and unspecified poisoning	
	5-103	Intentional self-harm		
	5-104	Assault		
	5-105	Conflict and war		
	5-106	Other and unspecified external causes		

Appendix 2 Child Healthcare Problem identification programme: Causes of Death

Child Healthcare Problem Identification Programme

Causes of Death

ChIP v2.0

Please note: The **nutritional** categories and the clinical and laboratory classifications concerning **HIV** do not appear here. They have to be captured in the relevant fields on the data sheet.

Category	Causes of Death	Code
Infections and Parasitic Diseases	Acute diarrhoea, hypovolaemic shock	101
	Chronic diarrhoea	102
	Dysentery	103
	TB: Pulmonary	110
	TB: Meningitis	111
	TB: Miliary, other extra-pulmonary	112
	Septicaemia, possible serious bacterial infection	120
	Congenital Infections (not HIV)	130
	Meningitis: bacterial	140
	Meningitis: viral (meningo-encephalitis)	141
	Other inflammatory disease of CNS (e.g. abscess)	142
	Measles	150
	Other possible serious infection (specify)	151
	Malaria	170
	Hospital-acquired infection	180
Oncology, Haematology	Tumours	201
	Leukaemias	204
	Anaemia	202
	Other Oncology / Haematology (specify)	203
Endocrine, Nutritional, Metabolic	IDDM, DKA	301
	Hypoglycaemia	304
	Other Endocrine, Nutritional, Metabolic (specify)	305
Nervous System	Status epilepticus	401
	Other Nervous System (specify)	402
Circulatory System	RHD, Rheumatic fever	501
	Heart failure, Pulmonary oedema	502
	Myocarditis	503
	Cardiomyopathy	507
	Congenital Heart Disease	504
	Endocarditis	505
	Other Circulatory System (specify)	506
Respiratory System	Croup	601
	Pneumonia, LRTI (ARI)	602
	PCP (suspected)	603
	PCP (confirmed)	608
	Pneumothorax, Pyothorax, Pleural effusion	604
	Asthma	605
	Congenital malformations of the respiratory system	606
	Other Respiratory System (specify)	607

Category	Causes of Death	Code
Digestive System	Cirrhosis, Portal Hypertension, Liver Failure, Hepatitis	701
	Surgical (appendix, hernia, intestines, peritoneum)	702
	Other Digestive System (specify)	703
Genito-urinary System	Acute nephritis	801
	Acute renal failure	802
	Chronic renal disease	803
	Other Genito-urinary System (specify)	804
Ill-defined / Unknown Cause	Ill-defined / Unknown causes of mortality	900
Other Diagnosis	Other diagnosis (specify)	901
Burns	Burns	1000
Poisoning	Paraffin	1101
	Corrosives	1102
	Other Poisoning (specify)	1103
Bites and Stings, Toxic plants	Bites and stings, Toxic plants	1200
Inhalation / Aspiration	Inhalation of foreign body or gastric contents	1300
Accidents	Transport-related accidents	1400
	Other accidents (incl. Drowning; specify)	1500
Non-accidental injury, Abuse	Non-accidental injury, Abuse-related, Neglect	1600
Homicide	Homicide	1700
Suicide	Suicide	1800

Underlying Conditions	Code
Cerebral palsy	1
Hydrocephalus	2
Birth defect (preconception = chromosomal/genetic, or post conception e.g. foetal alcohol syndrome)	3
Ex-low birthweight / preterm infant	4
Twin / Multiple pregnancy	5
Other Underlying Condition (specify)	10

Appendix 3: Categories of Complex chronic conditions ICD-10 Diagnosis

Categories	Subcategories	ICD-10
Neurologic and Neuromuscular	Brain and spinal cord malformations	Q00-Q07, G90.1
	Mental retardation	F71-F73
	CNS degeneration and diseases	E75.0, E75.1, E75.2, E75.4, F84.2, G11.1-G11.4, G11.8, G11.9, G12.0- G12.2, G12.8, G12.9, G31.01, G31.09, G31.8, G31.89, G32.89, G93.8, G93.9, G94, G91.1, G31.9, G25.3, G95.19, G95.89, G90.9, Q85.1
	Infantile cerebral palsy	G80
	Epilepsy	G40.311, G40.301, G40.211, G40.219, G40.411, G40.419, G40.111, G40.119, G40.804, G40.911, G40.919
	Other disorders of CNS	G37.1, G37.2, G37.8, G81.90, G82.90, G82.50-G82.54, G83.5, G83.9, G93.1, G93.5, R40.3, 0016070, 0016071, 0016072, 0016073, 0016074, 0016075, 0016076, 0016077, 0016078, 001607B, 0016370, 0016371, 0016372, 0016373, 0016374, 0016375, 0016376, 0016377, 0016378, 001637B, 001U074, 001U076, 001U077, 001U079, 001U374, 001U376, 001U377, 001U379, 00B70ZZ, 00B73ZZ, 00B74ZZ, 00T70ZZ, 00T73ZZ, 00T74ZZ
	Occlusion of cerebral arteries	I63.30, I63.50
	Muscular dystrophies and myopathies	G71, G72
	Movement diseases	G10, G20, G21.0, G21.11, G21.19, G21.8, G23.0-G23.2, G23.8, G24.02, G24.8, G25.3-G25.5, G25.81-G25.83, G25.89, G25.9, G80.3
	Devices	T85.09XA, T85.190A, T85.192A, T85.199A, T85.79XA, Z98.2, Z45.41, Z45.42, 00160J0, 00160J1, 00160J2, 00160J3, 00160J4, 00160J5, 00160J6, 00160J7, 00160J8, 00160JB, 00160K0, 00160K1, 00160K2, 00160K3, 00160K4, 00160K5, 00160K6, 00160K7, 00160K8, 00160KB, 00163J0, 00163J1, 00163J2, 00163J3, 00163J4, 00163J5, 00163J6, 00163J7, 00163J8, 00163JB, 00163K0, 00163K1, 00163K2, 00163K3, 00163K4, 00163K5, 00163K6, 00163K7, 00163K8, 00163KB, 001U0J4, 001U0J6, 001U0J7, 001U0J9, 001U0K4, 001U0K6, 001U0K7, 001U0K9, 001U3J4, 001U3J6, 001U3J7, 001U3J9, 001U3K4, 001U3K6, 001U3K7, 001U3K9, 009600Z, 009630Z, 009640Z, 00H00MZ, 00H03MZ, 00H04MZ, 00H60MZ, 00H63MZ, 00H64MZ, 00HE0MZ, 00HE3MZ, 00HE4MZ, 00HU0MZ, 00HU3MZ, 00HU4MZ, 00HV0MZ, 00HV3MZ, 00HV4MZ, 00W60JZ, 00W63JZ, 00W64JZ, 00WU0JZ, 00WU3JZ, 00WU4JZ, 01HY0MZ, 01HY3MZ, 01HY4MZ, 0DH60MZ, 0DH63MZ, 0DH64MZ, 0W110J9, 0W110JB, 0W110JG, 0W110JJ, 3E1Q38X, 3E1Q38Z
	Transplantation	N/A
Cardiovascular	Heart and great vessel malformations	Q20, Q21.2-Q24, Q25.1-Q26, Q28.2, Q28.3, Q28.9, 02170ZP, 02170ZQ, 02170ZR, 02BK0ZZ, 02LR0ZT, 02LS0ZZ, 02LT0ZZ, 02NH0ZZ, 02RK0JZ, 02RL0JZ, 02RM0JZ, 02RP0JZ, 02RQ07Z, 02RQ0JZ, 02RR07Z, 02RR0JZ, 02SP0ZZ, 02SW0ZZ, 02U70JZ, 02UA0JZ, 02UA3JZ, 02UA4JZ, 02VR0ZT, 02WA0JZ
	Endocardium diseases	I34.0, I34.8, I36.0, I36.8, I37.0, I37.8
	Cardiomyopathies	I42, I43, I51.5
	Conduction disorder	I44, I45, I47, I48, I49.0
	Dysrhythmias	I49.1-I49.5, I49.8, I49.9, R00.1
	Other	I27.0, I27.1, I27.2, I27.81, I27.89, I27.9, I50.9, I51.7, I51.81, I63.139, I63.239, Z95.1
	Devices	T82.519A, T82.529A, T82.539A, T82.599A, T82.110A, T82.111A, T82.120A, T82.121A, T82.190A, T82.191A, T82.01XA, T82.02XA, T82.03XA, T82.09XA, T82.211A,

		T82.212A, T82.213A, T82.218A, T82.221A, T82.222A, T82.223A, T82.228A, T82.518A, T82.528A, T82.538A, T82.598A, T82.6XXA, T82.7XXA, Z95.0, Z95.2, Z95.3, Z95.810-Z95.812, Z95.818, Z45.010, Z45.018, Z45.02, Z45.09, Z95.9, 02H40JZ, 02H40KZ, 02H43JZ, 02H44JZ, 02H44KZ, 02H60JZ, 02H60KZ, 02H63JZ, 02H63KZ, 02H63MZ, 02H64JZ, 02H64KZ, 02H70KZ, 02H73JZ, 02H73KZ, 02H73MZ, 02H74KZ, 02HA0QZ, 02HA0RS, 02HA0RZ, 02HA3QZ, 02HA3RS, 02HA4QZ, 02HA4RS, 02HK0JZ, 02HK0KZ, 02HK3JZ, 02HK3KZ, 02HK3MZ, 02HK4JZ, 02HK4KZ, 02HL0JZ, 02HL0KZ, 02HL0MZ, 02HL3JZ, 02HL3KZ, 02HL3MZ, 02HL4JZ, 02HL4KZ, 02HL4MZ, 02HN0JZ, 02HN0KZ, 02HN0MZ, 02HN3JZ, 02HN3KZ, 02HN3MZ, 02HN4JZ, 02HN4KZ, 02HN4MZ, 02WA0QZ, 02WA0RZ, 02WA3QZ, 02WA3RZ, 02WA4QZ, 02WA4RZ, 03HK0MZ, 03HK3MZ, 03HK4MZ, 03HL0MZ, 03HL3MZ, 03HL4MZ, 03WY0MZ, 03WY3MZ, 03WY4MZ, 0JH600Z, 0JH605Z, 0JH606Z, 0JH607Z, 0JH608Z, 0JH609Z, 0JH60AZ, 0JH60MZ, 0JH60PZ, 0JH630Z, 0JH635Z, 0JH636Z, 0JH637Z, 0JH638Z, 0JH639Z, 0JH63AZ, 0JH63MZ, 0JH63PZ, 0JH70MZ, 0JH73MZ, 0JH800Z, 0JH805Z, 0JH806Z, 0JH807Z, 0JH808Z, 0JH809Z, 0JH80AZ, 0JH80MZ, 0JH80PZ, 0JH830Z, 0JH835Z, 0JH836Z, 0JH837Z, 0JH838Z, 0JH839Z, 0JH83AZ, 0JH83MZ, 0JH83PZ, 0JWT0MZ, 0JWT0PZ, 0JWT3MZ, 0JWT3PZ, 0JWTXMZ, 4B02XSZ, 4B02XTZ, 5A02110, 5A02116, 5A0211D, 5A02210, 5A02216, 5A0221D
	Transplantation	T86.20-T86.22, Z94.1, 02YA0Z0, 02YA0Z1, 02YA0Z2
Respiratory	Respiratory malformations	Q30-Q34, P280
	Chronic respiratory diseases	G47.35, I27.82, I43, J84.112, J96.20, Z90.2
	Cystic fibrosis	E84
	Other	0B110Z4, 0B113Z4, 0B114Z4, 0BTC0ZZ, 0BTC4ZZ, 0BTD0ZZ, 0BTD4ZZ, 0BTF0ZZ, 0BTF4ZZ, 0BTG0ZZ, 0BTG4ZZ, 0BTJ0ZZ, 0BTJ4ZZ, 0BTK0ZZ, 0BTK4ZZ, 0BTL0ZZ, 0BTL4ZZ, 0BTM0ZZ, 0BTM4ZZ, 0CTS0ZZ, 0CTS4ZZ, 0CTS7ZZ, 0CTS8ZZ
	Devices	J95.00-J95.04, J95.09, Z43.0, Z93.0, Z99.0, J95.850, Z99.11, Z99.12, 0B110F4, 0B113F4, 0B114F4, 0B21XFZ, 0BHR0MZ, 0BHR3MZ, 0BHR4MZ, 0BHS0MZ, 0BHS3MZ, 0BHS4MZ, 0BW10FZ, 0BW13FZ, 0BW14FZ, 0JH604Z, 0JH634Z, 0JH804Z, 0JH834Z, 0WQ6XZ2, 3E1F78Z
	Transplantation	T86.810, T86.811, T86.819, Z94.2, 0BYC0Z0, 0BYC0Z1, 0BYC0Z2, 0BYD0Z0, 0BYD0Z1, 0BYD0Z2, 0BYF0Z0, 0BYF0Z1, 0BYF0Z2, 0BYG0Z0, 0BYG0Z1, 0BYG0Z2, 0BYH0Z0, 0BYH0Z1, 0BYH0Z2, 0BYJ0Z0, 0BYJ0Z1, 0BYJ0Z2, 0BYK0Z0, 0BYK0Z1, 0BYK0Z2, 0BYL0Z0, 0BYL0Z1, 0BYL0Z2, 0BYM0Z0, 0BYM0Z1, 0BYM0Z2
Renal and Urologic	Congenital anomalies	Q60-Q64
	Chronic renal failure	N18
	Other	Z90.5, Z90.6, 0T160Z8, 0T160ZA, 0T164Z8, 0T164ZA, 0T170Z8, 0T170ZA, 0T174Z8, 0T174ZA, 0T180Z8, 0T180ZA, 0T184Z8, 0T184ZA, 0TB60ZZ, 0TB63ZZ, 0TB64ZZ, 0TB67ZZ, 0TB68ZZ, 0TB70ZZ, 0TB73ZZ, 0TB74ZZ, 0TB77ZZ, 0TB78ZZ, 0TT00ZZ, 0TT04ZZ, 0TT10ZZ, 0TT14ZZ, 0TT20ZZ, 0TT24ZZ, 0TT60ZZ, 0TT64ZZ, 0TT67ZZ, 0TT68ZZ, 0TT70ZZ, 0TT74ZZ, 0TT77ZZ, 0TT78ZZ, 0TTB0ZZ, 0TTB4ZZ, 0TTB7ZZ, 0TTB8ZZ, 0TTD0ZZ, 0TTD4ZZ, 0TTD7ZZ, 0TTD8ZZ
	Chronic bladder diseases	G83.4, N31.2, N31.9
	Devices	T85.71XA, Z93.50-Z93.52, Z93.59, Z93.6, Z91.15, Z99.2, Z43.5, Z43.6, Z46.6, 031209D, 031209F, 03120AD, 03120AF, 03120JD, 03120JF, 03120KD, 03120KF, 03120ZD, 03120ZF, 031309D, 031309F, 03130AD, 03130AF, 03130JD, 03130JF, 03130KD, 03130KF, 03130ZD, 03130ZF, 031409D, 031409F, 03140AD, 03140AF, 03140JD, 03140JF, 03140KD, 03140KF, 03140ZD, 03140ZF, 031509D, 031509F, 03150AD, 03150AF, 03150JD, 03150JF, 03150KD, 03150KF, 03150ZD, 03150ZF, 031609D, 031609F, 03160AD, 03160AF, 03160JD, 03160JF, 03160KD, 03160KF, 03160ZD, 03160ZF, 031709D, 031709F, 03170AD, 03170AF, 03170JD, 03170JF, 03170KD, 03170KF, 03170ZD, 03170ZF, 031809D, 031809F, 03180AD, 03180AF,

		03180JD, 03180JF, 03180KD, 03180KF, 03180ZD, 03180ZF, 031909F, 03190AF, 03190JF, 03190KF, 03190ZF, 031A09F, 031A0AF, 031A0JF, 031A0KF, 031A0ZF, 031B09F, 031B0AF, 031B0JF, 031B0KF, 031B0ZF, 031C09F, 031C0AF, 031C0JF, 031C0KF, 031C0ZF, 03WY0JZ, 03WY3JZ, 03WY4JZ, 03WYXJZ, 05HY33Z, 06HY33Z, 0JH60WZ, 0JH60XZ, 0JH63WZ, 0JH63XZ, 0JH80WZ, 0JH80XZ, 0JH83WZ, 0JH83XZ, 0JHD0WZ, 0JHD0XZ, 0JHD3WZ, 0JHD3XZ, 0JHF0WZ, 0JHF0XZ, 0JHF3WZ, 0JHF3XZ, 0JHL0WZ, 0JHL0XZ, 0JHL3WZ, 0JHL3XZ, 0JHM0WZ, 0JHM0XZ, 0JHM3WZ, 0JHM3XZ, 0T130ZB, 0T134ZB, 0T140ZB, 0T144ZB, 0T16079, 0T1607C, 0T1607D, 0T160J9, 0T160JC, 0T160JD, 0T160K9, 0T160KC, 0T160KD, 0T160Z9, 0T160ZC, 0T160ZD, 0T163JD, 0T16479, 0T1647C, 0T1647D, 0T164J9, 0T164JC, 0T164JD, 0T164K9, 0T164KC, 0T164KD, 0T164Z9, 0T164ZC, 0T164ZD, 0T17079, 0T1707C, 0T1707D, 0T170J9, 0T170JC, 0T170JD, 0T170K9, 0T170KC, 0T170KD, 0T170Z9, 0T170ZC, 0T170ZD, 0T173JD, 0T17479, 0T1747C, 0T1747D, 0T174J9, 0T174JC, 0T174JD, 0T174K9, 0T174KC, 0T174KD, 0T174Z9, 0T174ZC, 0T174ZD, 0T18079, 0T1807C, 0T1807D, 0T180J9, 0T180JC, 0T180JD, 0T180K9, 0T180KC, 0T180KD, 0T180Z9, 0T180ZC, 0T180ZD, 0T183JD, 0T18479, 0T1847C, 0T1847D, 0T184J9, 0T184JC, 0T184JD, 0T184K9, 0T184KC, 0T184KD, 0T184Z9, 0T184ZC, 0T184ZD, 0T1B0ZD, 0T1B4ZD, 0T25X0Z, 0T29X0Z, 0T29XYZ, 0T2BX0Z, 0T9000Z, 0T9030Z, 0T9040Z, 0T9070Z, 0T9080Z, 0T9100Z, 0T9130Z, 0T9140Z, 0T9170Z, 0T9180Z, 0T9370Z, 0T9380Z, 0T9470Z, 0T9480Z, 0TQ67ZZ, 0TQ77ZZ, 3E1K38Z, 3E1M39Z, 5A1D60Z
	Transplantation	T86.10-T86.12, Z94.0, 0TY00Z0, 0TY00Z1, 0TY00Z2, 0TY10Z0, 0TY10Z1, 0TY10Z2
Gastrointestinal	Congenital anomalies	Q39.0-Q39.4, Q41-Q45
	Chronic liver disease and cirrhosis	K73, K74, K75.4, K760-K763, K765, K768
	Inflammatory bowel diseases	K50, K51
	Other	I82.0, K55.1, K56.2, K59.3, Z98.0, Z90.3, Z90.49, 0CT70ZZ, 0CT7XZZ, 0D13079, 0D1307A, 0D1307B, 0D1607A, 0D160ZA, 0DT50ZZ, 0DT54ZZ, 0DT57ZZ, 0DT58ZZ, 0DT60ZZ, 0DT64ZZ, 0DT67ZZ, 0DT68ZZ, 0DT80ZZ, 0DT84ZZ, 0DT87ZZ, 0DT88ZZ, 0DT90ZZ, 0DT94ZZ, 0DT97ZZ, 0DT98ZZ, 0DTE0ZZ, 0DTE4ZZ, 0DTE7ZZ, 0DTE8ZZ, 0FT00ZZ, 0FT04ZZ, 0FTG0ZZ, 0FTG4ZZ
	Devices	K94.20, K94.22, K94.23, K94.29, Z93.1-Z93.4, Z43.1-Z43.4, Z46.51, Z46.59, 0D11074, 0D110J4, 0D110K4, 0D110Z4, 0D113J4, 0D11474, 0D114J4, 0D114K4, 0D114Z4, 0D15074, 0D150J4, 0D150K4, 0D150Z4, 0D153J4, 0D15474, 0D154J4, 0D154K4, 0D154Z4, 0D16074, 0D160J4, 0D160J9, 0D160JA, 0D160K4, 0D160K9, 0D160KA, 0D160Z4, 0D163J4, 0D16474, 0D164J4, 0D164J9, 0D164JA, 0D164K4, 0D164K9, 0D164KA, 0D164Z4, 0D16874, 0D168J4, 0D168J9, 0D168JA, 0D168K4, 0D168K9, 0D168KA, 0D168Z4, 0D1B0Z4, 0D1B4Z4, 0D1B8Z4, 0D1H0Z4, 0D1H4Z4, 0D1H8Z4, 0D1K0Z4, 0D1K4Z4, 0D1K8Z4, 0D1L0Z4, 0D1L4Z4, 0D1L8Z4, 0D1N0Z4, 0D1N4Z4, 0D1N8Z4, 0D20X0Z, 0D20XUZ, 0D20XYZ, 0D787ZZ, 0D7E7ZZ, 0DBB7ZZ, 0DH50DZ, 0DH50UZ, 0DH53DZ, 0DH53UZ, 0DH54DZ, 0DH54UZ, 0DH57DZ, 0DH57UZ, 0DH58DZ, 0DH58UZ, 0DH63UZ, 0DH64UZ, 0DHA3UZ, 0DHA4UZ, 0DHA8UZ, 0DN87ZZ, 0DNE7ZZ, 0DW04UZ, 0DW08UZ, 0WQFXZ2, 3E1G78Z, 3E1H78Z
	Transplantation	T86.40-T86.42, T86.890, T86.891, T86.899, T86.850, T86.851, T86.859, Z94.4, Z94.82, Z94.83, 0DY80Z0, 0DY80Z1, 0DY80Z2, 0DYE0Z0, 0DYE0Z1, 0DYE0Z2, 0FY00Z0, 0FY00Z1, 0FY00Z2, 0FYG0Z0, 0FYG0Z1, 0FYG0Z2, 3E030U0, 3E030U1, 3E033U0, 3E033U1, 3E0J3U0, 3E0J3U1, 3E0J7U0, 3E0J7U1, 3E0J8U0, 3E0J8U1
Hematologic or immunologic	Hereditary anemias	D55-D58
	Aplastic anemias	D60-D61, D71
	Hereditary immunodeficiency	D80-D89, D72.0, M30.3, M35.9

	Coagulation/hemorrhagic	D66, D68.2, D69.41, D69.42, D69.49
	Leukopenia	D70.0, D70.4
	Hemophagocytic Syndromes	D76.1-D76.3
	Sarcoidosis	D86.9
	Acquired immunodeficiency	B20-B24
	Polyarteritis nodosa and related conditions	M30.0, M31.0, M31.1, M31.30, M31.4, M31.6
	Diffuse diseases of connective tissue	M32.10, M33.90, M34.0, M34.1, M34.9
	Other	07TP0ZZ, 07TP4ZZ
	Devices	N/A
	Transplantation	07YP0Z0, 07YP0Z1, 07YP0Z2, 30230AZ, 30230G0, 30230G1, 30230X0, 30230X1, 30230Y0, 30230Y1, 30233AZ, 30233G0, 30233G1, 30233X0, 30233X1, 30233Y0, 30233Y1, 30240AZ, 30240G0, 30240G1, 30240X0, 30240X1, 30240Y0, 30240Y1, 30243AZ, 30243G0, 30243G1, 30243X0, 30243X1, 30243Y0, 30243Y1, 30250G0, 30250G1, 30250X0, 30250X1, 30250Y0, 30250Y1, 30253G0, 30253G1, 30253X0, 30253X1, 30253Y0, 30253Y1, 30260G0, 30260G1, 30260X0, 30260X1, 30260Y0, 30260Y1, 30263G0, 30263G1, 30263X0, 30263X1, 30263Y0, 30263Y1
Metabolic	Amino acid metabolism	E70.0, E70.2, E70.3, E70.4, E70.8, E71.0-E71.5, E72.0-E72.4, E72.8, E72.9
	Carbohydrate metabolism	E74.0-E74.4, E74.8, E74.9
	Lipid metabolism	E75, E77.0, E77.1, E78.0-E78.4, E78.5-E78.9, E88.1, E88.8
	Storage disorder	E76.0-E76.3, E85
	Other metabolic disorders	277.4, E79.1, E79.8, E80.4-E80.7, E83.0, E83.1, E83.3, E83.4, D84.1, E88, H49.8
	Endocrine disorders	E00.9, E23.0, E23.2, E22.2, E23.3, E23.7, E24.0, E24.2, E24.3, E24.8, E24.9, E26.81, E25.0, E25.8, E25.9, 0GT00ZZ, 0GT04ZZ, 0GT40ZZ, 0GT44ZZ, 0GTK0ZZ, 0GTK4ZZ, 0GTR0ZZ, 0GTR4ZZ, 0UT20ZZ, 0UT24ZZ, 0UT27ZZ, 0UT28ZZ, 0UT2FZZ, 0UT40ZZ, 0UT44ZZ, 0UT47ZZ, 0UT48ZZ, 0UT70ZZ, 0UT74ZZ, 0UT90ZZ, 0UT94ZZ, 0UT97ZZ, 0UT98ZZ, 0UT9FZZ, 0UTC0ZZ, 0UTC7ZZ, 0UTC8ZZ, 0VTC0ZZ, 0VTC4ZZ, 0W4M070, 0W4M0J0, 0W4M0K0, 0W4M0Z0, 0W4N071, 0W4N0J1, 0W4N0K1, 0W4N0Z1
	Devices	Z46.81, Z96.41, 0JH60VZ, 0JH63VZ, 0JH70VZ, 0JH73VZ, 0JH80VZ, 0JH83VZ, 0JHD0VZ, 0JHD3VZ, 0JHF0VZ, 0JHF3VZ, 0JHG0VZ, 0JHG3VZ, 0JHH0VZ, 0JHH3VZ, 0JHL0VZ, 0JHL3VZ, 0JHM0VZ, 0JHM3VZ, 0JHN0VZ, 0JHN3VZ, 0JHP0VZ, 0JHP3VZ, 0JHT0VZ, 0JHT3VZ
	Transplantation	N/A
Other Congenital or Genetic Defect	Chromosomal anomalies	Q90.9, Q91.3, Q91.4, Q91.7, Q92.8, Q93, Q95.0, Q96.9, Q97, Q98, Q99.8, Q99.9
	Bone and join anomalies	E34.3, M41.0, M41.2, M41.30, M41.8, M41.9, M43.30, M96.5, Q72.2, Q75.0, Q75.2, Q75.9, Q76.0-Q76.2, Q76.4-Q76.7, Q77, Q78.0-Q78.4, Q78.8, Q78.9
	Diaphragm and abdominal wall	K44.9, Q79.0-Q79.5, Q79.9, Q79.59
	Other congenital anomalies	Q81, Q87.1-Q87.3, Q87.40, Q87.81, Q87.89, Q89.7, Q89.9, Q99.2
Malignancy	Neoplasms	C00-C96, D01-D09, D3A.0, D37-D49, Q85.0, 3E00X05, 3E01305, 3E02305, 3E03005, 3E03305, 3E04005, 3E04305, 3E05005, 3E05305, 3E06005, 3E06305, 3E0A305, 3E0F305, 3E0F705, 3E0F805, 3E0G305, 3E0G705, 3E0G805, 3E0H305, 3E0H705, 3E0H805, 3E0J305, 3E0J705, 3E0J805, 3E0K305, 3E0K705, 3E0K805, 3E0L305, 3E0L705, 3E0M305, 3E0M705, 3E0N305, 3E0N705, 3E0N805, 3E0P305, 3E0P705, 3E0P805, 3E0Q305, 3E0Q705, 3E0R305, 3E0S305, 3E0V305, 3E0W305, 3E0Y305, 3E0Y705
	Devices	N/A
	Transplantation	T86.00-T86.02, T86.09, Z94.81, Z94.84
Premature and Neonatal	Fetal malnutrition	P05.01, P05.11, P05.02, P05.12, P05.2, P05.9
	Extreme immaturity	P07.01, P07.02, P07.21-P07.25

	Cerebral hemorrhage at birth	P10.0, P10.1, P10.4, P52.4, P52.8
	Spinal cord injury at birth	P11.5
	Birth asphyxia	P21.0, P21.9, P84
	Respiratory diseases	P25.0-P25.3, P25.8, P27.0, P27.1, P27.8
	Hypoxic-ischemic encephalopathy	P91.6
	Other	P35.0, P35.1, P25.21, P25.22, P56.0, P57.0, P57.8, P61.3, P61.4, P77.3, P83.2, P91.2
Miscellaneous, Not Elsewhere Classified	Devices	T84.019A, T84.029A, T84.039A, T84.049A, T84.059A, T84.069A, T84.099A, T84.498A, T84.119A, T84.129A, T84.199A, T84.498A, T84.50XA, T84.60XA, , T84.7XXA, T86.90-T86.92, T86.99, T86.10-T86.12, T86.40-T86.42, T86.20-T86.22, T86.810, T86.811, T86.819, T86.00-T86.02, T86.09, T86.890, T86.891, T86.899, T86.850, T86.851, T86.859, T86.5, T86.890, T86.891, T86.899, T87.0X9, T87.1X9, T87.2, Y83.1, Y83.3, Z99.81, 0RG00J0, 0RG00J1, 0RG00JJ, 0RG00K0, 0RG00K1, 0RG00KJ, 0RG00Z0, 0RG00Z1, 0RG00ZJ, 0RG03J0, 0RG03J1, 0RG03JJ, 0RG03K0, 0RG03K1, 0RG03KJ, 0RG03Z0, 0RG03Z1, 0RG03ZJ, 0RG04J0, 0RG04J1, 0RG04JJ, 0RG04K0, 0RG04K1, 0RG04KJ, 0RG04Z0, 0RG04Z1, 0RG04ZJ, 0RG10J0, 0RG10J1, 0RG10JJ, 0RG10K0, 0RG10K1, 0RG10KJ, 0RG10Z0, 0RG10Z1, 0RG10ZJ, 0RG13J0, 0RG13J1, 0RG13JJ, 0RG13K0, 0RG13K1, 0RG13KJ, 0RG13Z0, 0RG13Z1, 0RG13ZJ, 0RG14J0, 0RG14J1, 0RG14JJ, 0RG14K0, 0RG14K1, 0RG14KJ, 0RG14Z0, 0RG14Z1, 0RG14ZJ, 0RG40J0, 0RG40J1, 0RG40JJ, 0RG40K0, 0RG40K1, 0RG40KJ, 0RG40Z0, 0RG40Z1, 0RG40ZJ, 0RG43J0, 0RG43J1, 0RG43JJ, 0RG43K0, 0RG43K1, 0RG43KJ, 0RG43Z0, 0RG43Z1, 0RG43ZJ, 0RG44J0, 0RG44J1, 0RG44JJ, 0RG44K0, 0RG44K1, 0RG44KJ, 0RG44Z0, 0RG44Z1, 0RG44ZJ, 0RG60J0, 0RG60J1, 0RG60JJ, 0RG60K0, 0RG60K1, 0RG60KJ, 0RG60Z0, 0RG60Z1, 0RG60ZJ, 0RG63J0, 0RG63J1, 0RG63JJ, 0RG63K0, 0RG63K1, 0RG63KJ, 0RG63Z0, 0RG63Z1, 0RG63ZJ, 0RG64J0, 0RG64J1, 0RG64JJ, 0RG64K0, 0RG64K1, 0RG64KJ, 0RG64Z0, 0RG64Z1, 0RG64ZJ, 0RGA0J0, 0RGA0J1, 0RGA0JJ, 0RGA0K0, 0RGA0K1, 0RGA0KJ, 0RGA0Z0, 0RGA0Z1, 0RGA0ZJ, 0RGA3J0, 0RGA3J1, 0RGA3JJ, 0RGA3K0, 0RGA3K1, 0RGA3KJ, 0RGA3Z0, 0RGA3Z1, 0RGA3ZJ, 0RGA4J0, 0RGA4J1, 0RGA4JJ, 0RGA4K0, 0RGA4K1, 0RGA4KJ, 0RGA4Z0, 0RGA4Z1, 0RGA4ZJ, 0SG00J0, 0SG00J1, 0SG00JJ, 0SG00K0, 0SG00K1, 0SG00KJ, 0SG00Z0, 0SG00Z1, 0SG00ZJ, 0SG03J0, 0SG03J1, 0SG03JJ, 0SG03K0, 0SG03K1, 0SG03KJ, 0SG03Z0, 0SG03Z1, 0SG03ZJ, 0SG04J0, 0SG04J1, 0SG04JJ, 0SG04K0, 0SG04K1, 0SG04KJ, 0SG04Z0, 0SG04Z1, 0SG04ZJ
	Transplantation	T86.5, T86.90-T86.92, T86.99, T86.890, T86.891, T86.899

Appendix 4: Child Health Identification Programme Mortality review process

Child Healthcare Problem Identification Programme

THE CHILD PIP MORTALITY REVIEW PROCESS

Saving lives through death auditing

It is the structured clinical audit of all children dying in hospital (including in casualty/outpatients, and those who are 'dead on arrival') that enables a thorough assessment of the quality of care that children receive in the health system.

For a clinical audit / mortality review to be successfully implemented there are two vital requirements:

1) Dedicated individuals willing to spend time and effort to make the process happen
2) A carefully structured system where roles and responsibilities are well-defined

Thus, the mortality review process in a paediatric/children's ward consists of two main activities:

1) The data collection process
2) The actual mortality review process

Data collection

To conduct a mortality review, 2 data sources are needed:

1) The ward admissions, discharges and deaths register
2) The individual clinical records of the children who die

Keep a separate register of children who die for tracing their medical records. Admission and deaths counts should be captured on **monthly tally sheets**. Detailed information on each death should be captured on the **death data capture sheet**.

To organise and keep track of the data it is helpful to compile a lever arch file, clearly labelled ChIP. It is helpful to order the contents in each section as follows:

1) Laminated copies of code lists (Cause of death and Modifiable factors), and growth charts
2) Monthly dividers for each month followed by a Monthly Tally Sheet for that month as well as a Death Data Capture Sheet completed for each death that occurred during that month
3) Spare data capture forms

The review process

Follow the four components of the mortality review process in your hospital:

Component	When	Who	Purpose
1. 24 hour review	Each death should be reviewed and summarised within 24 hours	The attending doctor or nurse at the time of the death	• Ensure all necessary information is captured at a time when information is available
2. Preparatory meeting	Before the Mortality Review Meeting	The doctor and nurse in charge of the ward/unit	• A detailed analysis of **all** deaths, with **case selection** for presentation at the Mortality Review Meeting • Compilation of monthly statistics for presentation at the meeting
3. Mortality review/ChIP meeting (see below)	Weekly to monthly depending on load	Whole paediatric department (doctors and nurses) as well as clinic staff	• Presentation of statistics, case discussions and task reviews • Assign new **tasks** based on each meeting's discussion • Ensure all data capture sheets have been **completely completed**
4. Epidemiology & Analysis	6 monthly/annually	Managers and clinical personnel	• Broader problem identification with trend assessment, and with proposed solutions/recommendations

The 24 hour review

Every single death occurring in your hospital should be summarised using the ChIP Death Data Capture sheet at the time of death. The person best placed to do this is either the on-duty doctor or by way of handover, the daytime team responsible for the long-term care of the child. The death summary should be regarded as no more burdensome, and no less important, than the discharge summary for other children leaving the ward/unit.

It is still best to have a single person in the ward/unit making sure that this process happens.
This can be a doctor or a nurse.

The preparatory meeting

This meeting is crucial. All data capture sheets must be **completely completed,** to the stage of readiness for entry onto the computer. This means that all fields must be filled in, and **codes** must be entered where required. This makes data entry onto the computer efficient and accurate, and allows for any category of employee to enter data.

Careful selection of cases for presentation will enhance learning opportunities, and facilitate problem identification, and task definition and allocation.

> The preparatory meeting is the responsibility of the most senior doctor and most senior nurse in the ward/unit.

The mortality review meeting

Mortality meetings must be well organised and managed by the nurse and doctor responsible for the paediatric/children's ward.

1) Meetings should be held weekly to monthly depending on the number of deaths.
2) A suitable time and venue is needed.
3) All staff involved with child care should be invited (doctors, nurses, allied healthworkers and administrators). Staff must understand that mortality meetings are very important. It is especially helpful to invite staff from clinics referring to the hospital.
4) Case presentations should be concise and professional. Discussion is encouraged if the presenter does not provide the cause of death and modifiable factors. This is best done by the group.
5) The meeting should by consensus establish the main cause of death and then look carefully for modifiable factors. The meeting must never become a "witch hunt", and should be confidential. The meeting should NOT be dominated by senior doctors. The thoughts and insights of **all** participants make the meeting worthwhile.
6) All decisions (causes and modifiable factors) made must be recorded on the mortality sheets (death data capture sheets) for entry later onto a computer.
7) **Problems with the process of caring for children in the hospital, the referring clinics and in communities must be identified and prioritised, and plans should be made and documented for addressing each problem.**
8) Tasks arising out of discussions around cases should be assigned to team members, and minuted. Progress with the tasks should be reviewed at the start of the next meeting.

The meeting agenda

A typical mortality review agenda is a follows:

1) Welcome and introductions, and identification of a minute taker
2) Review of tasks set at last meeting
3) Summary of last meeting's statistics
4) Summary of this meeting's statistics
5) Case presentations
6) **Task identification and allocation**
7) Closure and date of next meeting

Epidemiology and Analysis

The power of ChIP lies in its ability to provide instant feedback on child death and quality of care information to ward/unit staff. Simply by initiating this systematic review process, change will happen.

It is however important both for the identification of broader system problems and for monitoring change that 6 monthly or annual reviews are performed.

These reviews should be compiled into reports, which document both findings and recommendations arising out of the review. This is the point at which the power of ChIP can be used for communicating problems to managers. Once the process of mortality review is established in your site, the report will also look at success of implementation of, and response to, previous recommendations.

You can use the ChIP Report Proforma for guiding your report writing.

Making change happen

When making recommendations, it is important to link each recommendation clearly to specific information arising out of your ChIP review process. It is then useful to clearly define its requirements for implementation at each of the following levels:

1) Policy
2) Administration
3) Clinical practice
4) Education

Finally, responsibility for implementation at each level should be assigned, so that at the next review, implementation (or lack thereof) can be accounted for (for an example of this see "Saving Children 2005").

> By conducting mortality reviews in this systematic way, we will both save lives, and improve quality of care, through death auditing.

(Adapted from Philpott and Voos: "4 Key Components of a Successful Perinatal Audit Process", Kwilekwaz #29, 2001)

Appendix 5 Human research ethics committee HREC REF: 029/2018

UNIVERSITY OF CAPE TOWN
Faculty of Health Sciences
Human Research Ethics Committee

Room E53-46 Old Main Building
Groote Schuur Hospital
Observatory 7925
Telephone [021] 406 6492
Email: sumayah.ariefdien@uct.ac.za
Website: www.health.uct.ac.za/fhs/research/humanethics/forms

15 January 2018

HREC REF: 029/2018

Prof B Morrow
Division of Paediatrics & Child Health
5th Floor-ICH Building
Red Cross Children's Hospital
Rondebosch

Dear Prof Morrow

PROJECT TITLE: WHY, HOW AND WHEN DO CHILDREN DIE IN A PAEDIATRIC INTENSIVE CARE UNIT (PICU) IN SOUTH AFRICA? (MPHIL CANDIDATE - DR M WEGE)

Thank you for submitting your study to the Faculty of Health Sciences Human Research Ethics Committee (HREC) for review.

It is a pleasure to inform you that the HREC has **formally approved** the above-mentioned study.

Approval is granted for one year until the 30 January 2019.

Please submit a progress form, using the standardised Annual Report Form if the study continues beyond the approval period. Please submit a Standard Closure form if the study is completed within the approval period.
(Forms can be found on our website: www.health.uct.ac.za/fhs/research/humanethics/forms)

We acknowledge that the student: Dr M Wege will also be involved in this study.

Please quote the HREC REF in all your correspondence.

Please note that the ongoing ethical conduct of the study remains the responsibility of the principal investigator.

Please note that for all studies approved by the HREC, the principal investigator **must** obtain appropriate institutional approval, where necessary, before the research may occur.

Yours sincerely

Signature Removed

PROFESSOR M BLOCKMAN
CHAIRPERSON, FHS HUMAN RESEARCH ETHICS COMMITTEE

Federal Wide Assurance Number: FWA00001637.
Institutional Review Board (IRB) number: IRB00001938

HREC:029/2018