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Understanding children's deaths: learning from child death review in four high income countries

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Abstract

Despite pronounced reductions in child mortality in industrialised countries, variations exist within and between countries. Many child deaths are preventable, and much could be done to further reduce mortality. For the family, their community, and professionals caring for them, every child's death is a tragedy. Systematic review of all child deaths is grounded in respect for the rights of children and their families, and aimed towards the prevention of future child deaths. In a Series of three papers, we discuss child death in high-income countries in the context of evolving child death review processes. This paper outlines the background to and development of child death review in the USA, England, Australia, and New Zealand. We consider the purpose, process, and outputs of child death review, and discuss how these factors can contribute to a greater understanding of children's deaths and to knowledge for the prevention of future child deaths.

Key messages

- Child mortality rates in high-income countries are low compared with the rest of the world. However, international mortality rates vary substantially for different age groups, and modifiable factors can be identified in many deaths
- Although high-income countries have reliable death registration processes, concerns exist about the accuracy of cause of death data and the ability of such processes to inform health strategy to prevent future child deaths
- Processes for child death review have been developed in several countries to systematically gather comprehensive data for children's deaths, to identify potentially remediable factors, and to make recommendations for system improvement

Search strategy and selection criteria

We searched Medline for papers published in English from Jan 1, 1990, to Dec 5, 2012, using the following terms: (death* review*.mp or fatalit* review*.mp or perinatal mortalit* review*.mp or serious case* review*.mp or critical incident* review*.mp), limited to all child (0–18 years). We reviewed the titles and abstracts of 122 papers. We then retrieved the full text of 31 papers relevant to internally reported processes for child death review. Alongside this process, we searched LexisNexis with the terms “child mortality review”, “child death review”, “child welfare case

reviews”, “infant mortality review”, “fetal and infant mortality review”, “multidisciplinary child death reviews”, and “safeguarding children panels”. We retrieved relevant full texts on the basis of abstract review. We excluded state-level government reports from the USA. The combined searches provided an annotated bibliography of 81 papers about processes for child death review (appendix).

Introduction

In 2009, 66 000 children younger than 5 years died in high-income countries.(1) Although this figure accounts for only a small proportion of the global burden of childhood mortality (8%), up to a quarter of these deaths could be considered preventable (panel 1).(3) International data for child mortality are mainly from death certificates, which give little context to the complexity of contributory factors. Many high-income countries are introducing standardised processes for the review of child deaths that regard each death as a sentinel event from which knowledge can be derived. In this review, we consider how the child death review processes can contribute to a greater understanding of how and why children die.

With use of the international published work and our specific experience in four high-income countries (the USA, England, Australia, and New Zealand), we show the wide variation in international and national patterns of child death; examine the systems for recording and classification of child deaths and discuss their limitations; review the historical development of formal child death reviews and explain their framework in the USA, England, Australia, and New Zealand. The focus includes England, since child death review processes are established and data available; some death registration data are provided at aggregate UK or England and Wales levels and are reported here as such. We make recommendations for the standardisation of international child death review processes—their purpose, structure, process, and outputs, and how their effectiveness can be measured.

Panel 1: Definitions

Child

All children from birth to 17 years inclusive. We use the following age groups to explore mortality: younger than 1 year old (infant); 1–4 years, 5–9 years, 10–14 years, and 15–19 years. The group 15–19 years is used because most national data are presented in age bands of 5 years, allowing comparison with other bands even though this range extends beyond the usual definition of childhood.

Perinatal mortality

Stillbirths and deaths in the period from 24 weeks of gestation to 7 completed days after livebirths. Rates are calculated per 1000 total births.

Neonatal mortality

Death before the age of 28 completed days after livebirth. Rates are calculated per 1000 livebirths.

Infant mortality

Deaths of infants in the period from birth to less than 1 year of age. Rates are calculated per 1000 livebirths.

Postneonatal mortality

Deaths of infants from 28 days to 364 days old. Rates are calculated per 1000 livebirths.

Age-specific child mortality

Age bands are: younger than 1 year old (infant), 1–4 years, 5–9 years, 10–14 years, and 15–19 years. Rates are calculated per 100 000 population. Although widely used in developing countries, the concept of under-5 mortality is of less relevance in high-income countries because mortality in children aged 1–4 years is generally low. Therefore, we have separated infant mortality from 1–4 year mortality.

Preventable deaths

We use the definition of preventable child deaths from the Department for Education for England (2) as “those in which modifiable factors may have contributed to the death. These factors are defined as those which, by means of nationally or locally achievable interventions, could be modified to reduce the risk of future child deaths.”

Child deaths: the need for action

In the past century, child mortality in high-income countries has fallen to very low rates. Data from the UK, USA, Australia, and New Zealand show that rates vary by country, sex, and age groups (table 1, appendix).(4–8)

Analysis of data from European countries shows variation in child mortality (age 1–14 years) ranging from 13.4 to 14.3 deaths per 100 000 and postneonatal mortality from 0.9 to 1.6 deaths per 1000 livebirths.(9) Because of the small numbers in each age group, substantial year-on-year fluctuations can occur, particularly in countries with small populations. Mortality rates tend to be higher in boys than for girls. The highest rates are in infancy, particularly in the first month of life. Rates then decrease to very low amounts during middle childhood, before they rise to a second peak in adolescents, particularly in male adolescents.

Comparisons of data for England and Wales, the USA, Australia, and New Zealand show variations in cause of death across different age bands. Although the cause of deaths in infants might be broadly similar (perinatal complications, congenital abnormalities, chromosomal abnormalities, and sudden unexpected deaths), a different pattern is noted in causes of deaths in older children. For example, in comparison to the USA, New Zealand and Australia, a smaller proportion of child deaths in England and Wales are recorded to be due to external causes. One possible explanation for high rates of violent deaths in the USA is the role of firearms, which account for at least 80% of all youth homicides annually.(10) In Australia, a higher proportion of deaths in 15–19 years due to external causes are related to motor vehicle accidents and suicide, together with a higher death rate for Aboriginal and Torres Strait Islander youths than for other adolescents.(11) In New Zealand, unintentional injuries account for 48.1% of deaths and suicide for 26.3% of deaths in adolescents aged 15–19 years.(12)

Nationally, some categories of child deaths vary by region, ethnic origin, and socioeconomic status, particularly neonatal and infant deaths, sudden unexpected deaths in infancy, accidents and injuries, and maltreatment-related deaths.(3,8,13–20) For example, the 2006 UK confidential inquiry into deaths of children(3) showed substantial regional variations in frequency of death in adolescents aged 15–17 years, with higher mortality rates seen in those in the northeast of England and in Northern Ireland, than in the west midlands area. The same study showed significantly higher mortality rates in children of Pakistani and black African ethnic origin than in white children. In Australia, New Zealand, and the USA, excess child mortality exists in Indigenous populations.(5,6,12) For example, in New Zealand, the Māori postneonatal mortality was 3.2-times (3.6 per 1000 livebirths) that of non-Maori populations (1.1 per 1000 livebirths) in New Zealand in 2010. This excess mortality is also noted in other age groups (2.6-times higher in children aged 1–4 years; 2.3-times higher in children aged 5–9 years; 3.4 times higher in children aged 10–14 years; 2.1-times higher in children aged 15–19 years).¹² In the USA, mortality rates throughout childhood are higher in black or African American children than in those of other ethnic origin.(5)

Results of studies in high-income countries have consistently shown that factors can be identified in a substantial proportion of child deaths that could potentially be modified to reduce future child deaths.(21–24) In New Zealand, investigators have noted the preventability of many cases of sudden unexpected death in infancy,(25) drowning, unintentional injuries, and deaths from being hit at low-speed by motor vehicles.(8,26) The UK confidential inquiry identified avoidable factors in 31 (26%) deaths of 119 cases they reviewed, with potentially avoidable factors noted in a further 51 (43%) cases.(3) The study group identified specific failures in primary care services in 19 (23%) cases from a subgroup of 82 cases with direct primary care involvement. These instances included failures in preventive services, in recognition and appropriate response to acute illness, and in follow-up of at-risk children.

In England, of 4061 child death reviews that were completed in 2010–11, investigators noted that 800 (20%) had modifiable factors.(27) Modifiable factors were identified in a higher proportion of older children’s deaths (38% of deaths in those aged 15–17 years compared with 16% of deaths in those younger than 1 year) and in deaths from external unexplained causes (table 2). The existence of such variations in mortality data and the high prevalence of modifiable factors contributing to child deaths suggest that more could be done to prevent child mortality in all groups.

Systems to record and classify deaths

Accurate data for child deaths should underpin national and international strategies for child health and wellbeing. Although systems to record and classify child deaths provide national epidemiological data, several limitations affect their value as a public health strategy for the reduction of child mortality. These issues include inaccuracies in the process of death certification, restrictions imposed by reliance on single causes of death and by different systems for grouping cause of death, inability of systems to go beyond identification of what the child died from to consideration of how and why that child died, a lack of engagement and scrutiny at local or national levels, insufficient focus on learning of lessons or prevention of future child deaths, and little involvement of, or feedback to, families.

Mortality statistics reported by international agencies such as UNICEF and WHO are broadly limited to those for infants and children aged younger than 5 years, and are sourced from records of death registrations, censuses, household surveys, and special studies. In developing countries, precise estimates are often subject to much uncertainty because the statistical and health information systems that underlie them are weak.^{28,29} By comparison, information systems in high-income countries are typically well developed and reliable, with complete or near-complete registration of all child deaths (panel 2). However, discrepancies and delays in the publication of data can occur, particularly when deaths are subject to coronial or police inquiries, and questions have been raised about the accuracy and consistency of death registration data.

Poor-quality death certification practice affects all mortality analysis. In a study of 179 neonatal deaths in a 7 year period in a neonatal unit in Australia, investigators reported concordance between the perinatal death certificate and a clinicopathological summary in only 58% of cases.³² The main reasons for this discordance were the incorrect transposition of the categories for main and other causes of death, and the recording of a non-pathological disorder as the main cause of death. If these factors were addressed, then the accuracy of the perinatal death certificate would improve from 58% to 91%.³² In a study in Arizona, child fatality review teams examined 4806 deaths and reported basic errors in demographics in 3% of death certificates and errors in the cause of death in 13%.²² In the UK confidential inquiry, the reviewing panels identified inaccuracies in the medical certificate of the cause of death in 33 (35%) of 95 cases.³ In two-thirds (22) of these cases, an additional diagnosis should have been included on the death certificate, in 14 of which, the missing diagnosis was considered a major, direct, or overwhelming cause of death. Panel members were

most consistent in recording deaths due to malignancy, trauma, and sudden infant death, and least consistent in recording deaths reviewed as congenital or chronic medical conditions.(31)

Other investigators have studied the accuracy of death certificates in specific disorders. Some researchers have suggested that some of the decline in reported sudden infant death syndrome deaths in the USA from 1999 to 2001 was related to changes in the way that these deaths were investigated, reported, and classified.(33,34) Death certificates have also been shown to be inaccurate in child maltreatment deaths.(35–37) Results of one surveillance study of three US states showed that the death certificate was the least reliable source of data for the identification of maltreatment, and that child death review reports, child protective service data, and, in one state, hospital records, were more reliable.(38)

Finally, although many studies have shown errors in death certification, few have considered the accuracy of the official cause of death that is registered by national agencies in charge of mortality statistics. Assessment of only the death certificates might not result in a correct estimate of the overall quality of international mortality statistics.(39) International comparisons of mortality patterns are further complicated by countries continuing to publish data using slightly different cause of death groupings, age bands, and time periods. Most international mortality statistics are based on a single underlying cause of death as defined in the International Classification of Diseases. However, the process of ranking the leading causes of death by international organisations is directly affected by the intended use of the list.(40) For example, groupings used to plan and deliver health services would be different from those used to formulate public health measures for the prevention and control of diseases. Ranking lists used by WHO split deaths from cancer and deaths from accidents into further subcategories. The largest causes of death in children aged 1–14 years depend specifically on this method of ranking. In England and Wales, when categories for cancers and accidents are both split, congenital malformations are the largest cause of death for both boys and girls. However, when cancers and accidents are grouped, they become the first and second cause of death, respectively. Such variations in practice emphasise the difficulties in comparison of international mortality data.

Table 1 – Infant, Child and adolescent Death rates per 1,000 live births / per 100,000 population: 2009-10 by country, age and sex⁴⁻⁸

2009	<i>UK</i>		<i>USA</i>		<i>Australia</i>		<i>New Zealand</i>	
	Male	Female	Male	Female	Male	Female	Male	Female
Infant	4.9	4.1	7.0	5.7	4.8	3.7	5.4	4.5
1-4 y	18	18	29	24	23	18	35	33
5-9 y	10	9	13	11	11	9	9	14
10-14 y	12	11	18	13	12	10	18	17
15-19 y	43	19	74	32	49	22	78	31

2010	<i>UK</i>		<i>USA</i>		<i>Australia</i>		<i>New Zealand</i>	
	Male	Female	Male	Female	Male	Female	Male	Female
Infant	4.6	3.9	6.7	5.6	4.8	3.4	6.1	4.2
1-4 y	18	16	30	23	22	17	31	27
5-9 y	10	8	13	10	12	9	8	5
10-14 y	9	8	16	12	12	8	15	14
15-19 y	34	20	70	28	49	21	67	31

Table 2 Preventable deaths in children < 18 yrs in England, 2010-11²⁷

Category of Death	Number of deaths reviewed (% of all deaths in this category)	Number (%) with modifiable factors identified
Trauma and other external factors	225 (6%)	152 (68%)
Suicide or deliberate, self-inflicted harm	70 (2%)	44 (63%)
Deliberately inflicted injury, abuse or neglect	47 (1%)	29 (62%)
Sudden, unexpected, unexplained death	299 (7%)	179 (60%)
Infection	251 (6%)	72 (29%)
Acute medical or surgical condition	218 (5%)	61 (28%)
Chronic medical condition	237 (6%)	34 (14%)
Perinatal/neonatal event ¹	1,449 (36%)	148 (10%)
Chromosomal, genetic and congenital abnormalities	968 (24%)	70 (7%)
Malignancy	251 (6%)	11 (4%)

Unknown	3 (0%)	0 (0%)
Total	4,018 (100%)	800 (20%)

¹ All deaths of children aged 0-18 years are reviewed in the English system. Fetal deaths and stillbirths are excluded. The category of perinatal/neonatal event relates to deaths where the event/sequence of events leading to the death originated in the perinatal or neonatal period.

Panel 2: Source and quality of mortality data

Death certification processes are similar in England, the USA, Australia, and New Zealand. Typically, the attending doctor certifies death due to natural causes through the completion of a medical certificate of cause of death. Either coroners or medical examiners (dependent on the jurisdiction) routinely investigate and certify specific categories of deaths such as accidents, homicides, and suicides. Coroners are usually selected or appointed officials and are not required to be medically trained, whereas medical examiners are physicians. In New Zealand, coroners have to have a practising certificate as a barrister or solicitor. In England and Wales about 80% of all deaths are certified by a doctor and 20% by a coroner.³⁰ For infant deaths, linkage of birth and death registration data allows information about social and biological factors of the parents to be obtained. Registrars of births, deaths, and marriages are responsible for the registration of births and deaths. The underlying cause of death is chosen from the medical certificate of cause of death or the coroner's certificate. Coding systems have been established in each country to assign the most appropriate cause of death from the medical certificate of cause of death using the International Classification of Diseases (ICD-10) and on the basis of WHO rules and guidelines for mortality and morbidity coding. Data on all registered deaths are then centrally collated, analysed, and published annually by the Office for National Statistics in England and Wales, the National Center for Health Statistics in the USA, the Australian Bureau of Statistics in Australia, and the Ministry of Health and Child and Youth Mortality Review Committee in New Zealand.

Child death review processes

Routine death registration does not capture all factors that might contribute to a child's death. The purposes of a child death review are to systematically gather comprehensive data for child deaths, to identify notable and potentially remediable factors, and to make recommendations for system improvements to prevent future child deaths and improve child health and welfare. To be effective, child death review needs to be multidisciplinary and not limited to health. Although the review is typically a confidential process, consideration should be given to how to keep the family at the centre of the process, treated with care and respect, and provided with opportunities to be involved in and informed about all aspects of the review process.

Processes for child death review have evolved in many ways in different countries, but commonly have two interrelated stages: a prospective rapid-response investigation of some deaths and a retrospective review of all or some child deaths (panel 3).^(42,62) In England, multiagency

rapid-response teams investigate all unexpected deaths of children aged 0–18 years; in New Zealand, sudden unexpected deaths in infancy are investigated in this way; elsewhere, only suspicious deaths might undergo rapid response review. The purposes of the rapid response are to investigate unexpected child deaths, gather relevant clinical and contextual information to understand the causes and contributory factors, to learn from the death, and to provide support to the family.⁽⁶²⁾ The main purposes of retrospective reviews are to learn lessons and prevent future child deaths. Similar to the rapid-response model, the precise format and remit of the retrospective review might vary. In some areas, all deaths are reviewed; in others, reviews only occur for some causes or age groups.

To identify current knowledge and practice in relation to child death review, we did a literature review incorporating peer-reviewed and other reports, and drew on direct knowledge of the processes in all four countries. In particular, three areas of practice were scrutinised: the child death review process itself, national government reports on child death reviews, and published work using child death review data to better classify, describe, and prevent deaths (appendix). Table 3 shows the major differences between the national child death review processes in the USA, England, Australia, and New Zealand: legislation, rapid response, and retrospective multiprofessional review (organisation, scope, data sources, participants, analytical framework, family engagement, and output).

National legislation underpins child death review in England and New Zealand, and state-based legislation in the USA (table 3). The advantages of a statutory framework are that all aspects of the review processes are standardised—eg, in England, the prospective rapid-response investigation of all unexpected deaths ensures that tests, scene of death examination, and final overview occur systematically, to better inform the coroner’s conclusion of cause of death. The USA, England, Australia, and New Zealand have multi-agency mortality overview panels whose remit is broadly similar: undertake a comprehensive systematic review to make recommendations to prevent future deaths. In England and New Zealand, all child deaths are scrutinised, whereas in the USA and Australia only some deaths are reviewed. Such formal reporting and the automatic making of recommendations to constituent agencies (local safeguarding children boards, state, and national legislators), informs policy in a more pragmatic way than is possible through an annual review of national statistics. In the USA and New Zealand, national internet-based data-collation systems provide high-quality information about child deaths through scrutiny of aggregate data from many

deaths. Such comprehensive review is not possible with existing national death registration processes and national statistical agencies.

This US national database is now used as the core source for a multistate case registry for sudden unexpected death in infancy at the US Centers for Disease Control and Prevention (CDC). In New Zealand, the National Child and Youth Mortality Review Committee (CYMRC) database is used for annual reporting of an overview of deaths and as a source of data for detailed review of specific causes of death. Both processes can contribute to more accurate data for cause of death than was available through historical certification processes, and an improvement in knowledge and systems.

Panel 3: History of CDR

Formalised child death reviews began in Los Angeles, CA, USA, in the 1970s, and focused on suspicious deaths, with a process based on a local hospital's adult mortality review.(41–44) Two parallel processes, child death review and fetal–infant mortality review emerged and gained momentum in the late 1980s. The initial focus of child death review was to improve the investigation of suspicious deaths; the focus of fetal–infant mortality review was to improve systems of care for women and infants.(45) In 1995, the US advisory board on child abuse and neglect recommended creation of a national system of child death review teams at state and local levels to understand and reduce child abuse and deaths from neglect,(46) which eventually led to a national child death review resource centre to support child death review as a public health effort and promote the reviews of all potentially preventable child deaths up to age 18 years. By 2006, 49 of 50 states had some form of child death review. The US Government recognises the importance of child death review in the national health objectives for 2020.(47)

In the UK, formal child death review procedures began later than in the USA.(41) England and Wales have a long history of the review of all deaths related to maltreatment through multiagency serious case reviews.(48) These in-depth reviews are required when a child dies and abuse or neglect is known or suspected to be a factor in the death.(2) Data from all English serious case reviews are collated and analysed every 2 years.(49–52) During the 1990s, paediatricians and police officers began to develop multiagency protocols for investigating sudden unexpected infant deaths and supporting affected families.(53) They recognised that the strength of joint agency working was that it used the skills and particular responsibilities of each professional group. This work coincided with several high-profile cases involving infant homicide convictions that raised concerns about miscarriages of justice. Baroness Helena Kennedy, a human rights lawyer, chaired an intercollegiate working group that produced national recommendations for investigation of infant deaths.(54) The Children Act (2004) provided legislation requiring all local authorities put in place procedures both to respond rapidly to unexpected child deaths and to review all childhood deaths systematically. National guidelines were developed, drawing on the experience of the small number of newly started child death review teams.(2,55–57)

In Australia, establishment of processes for child death review resulted from several different reports of particular child deaths in various jurisdictions, reviews of child protection services, or examinations of child death data.(58–60) Formal review processes for child deaths were recommended to achieve quality assurance and accountability in child

protection systems. Between 1985 and 2009, Victoria, New South Wales, Western Australia, Queensland, South Australia, and the Northern Territory established processes for review; additionally, in the Australian Capital Territory, reviews are done of deaths of children who are known to both care and protection services and ACT health.(58,59) In Australia, there is no process for child death review in a standardised framework that is supported by national legislation and guidance. As a consequence, processes in Australia vary considerably, with little consistent planning, communication, and policy development at a national level.(60)

In response to New Zealand's high postneonatal mortality rate, a postneonatal mortality review committee was established in Auckland in 1984.(25,61) Likewise, other regions established committees. These committees gradually disappeared, mainly because of concerns about the confidentiality of the information and lack of protection of participants. The child and youth mortality review committee (CYMRC) was established in 2001 to collect and analyse data for all deaths in young people aged between 28 days and 24 years. The New Zealand Public Health and Disability Act 2000 provides strict guidance on the production, disclosure, and recording of information. Until 2010, this committee was accountable and made recommendations directly to the Minister of Health. The committee now reports to the health quality and safety commission. The child and youth mortality review committee scrutinises data from a network of local child and youth mortality review groups in every district health board. A centrally held national database allows individuals to both directly contribute and use relevant information. Separate national mortality committees examine perinatal, maternal, and perioperative deaths, and those from family violence.

Table 3: Comparison between child death review processes in USA, England, Australia and New Zealand

Country	USA³¹		England			Australia	New Zealand
Type of Review	Child Death Review / Child Fatality Review	Fetal and Infant Mortality Review	Child Death Overview	Serious Case Review	Perinatal Mortality Review	Child Death Review	Child and Youth Mortality Review Committee
Legislation	Federal law encourages reviews of child abuse deaths; 43 states have legislation mandating or enabling CDR	No federal legislation. Few states have legislation, and most programs operate under state public health research authorizations	Local Safeguarding Children Boards Regulations 2006 Children Act 2004, Working Together to Safeguard Children (HM Government 2004, 2006)	Local Safeguarding Children Boards Regulations 2006	Commissioned by National Patient Safety Agency; no legislative framework	No national legislation or guidance. Each state contain different legislative, operational frameworks, and reporting laws	Public Health and Disability Act 2000 and Amendment 2010
Prospective Rapid - Response	Variable by local jurisdiction. May involve sub-committee of retrospectives review team	Not conducted	Mandatory for all unexpected deaths. Joint agency process involving health, social care and police	All child maltreatment deaths are managed prospectively under the joint agency investigation	Not conducted	No standardised process	No standardised process, except for SUDI

Retrospective Panel Review - organisation	State laws dictate structure: 49/50 states have State Advisory Panel, 37/50 states additionally have local review teams. Majority managed by public health or social service agencies.	Conducted at city or county level. Little state oversight; managed by hospitals or health departments	Standardised Child Death Overview Panel reviews covering Local Government Authority area (typical population 500,000)	Multi-agency review along strict time-line. Local Government Authority area (typical population 500,000)	Local hospital maternity unit	No standardised process. No national system. CDR teams established in 7/8 states. State level review although variable criteria for case selection	21 local CYMRC in 20 District Health Boards and National Committee
Retrospective Panel Review - purpose	To conduct a comprehensive, multidisciplinary review of child deaths, to better understand how and why children die, and use the findings to take action that can prevent other deaths and improve the health and safety of children	To improve services and resources for women, infants, and families with the long-term goal of contributing to infant mortality reduction	To analyse information on each death and to identify (i) any case giving rise to a Serious Case Review (ii) any matter of concern affecting the welfare of children in area of the authority; (iii) any wider public health/safety concern arising from a particular death or pattern of deaths	To learn lessons to improve the way in which individuals and agencies work to safeguard and promote the welfare of children	To provide information on perinatal deaths at local, regional and national level for health care providers, commissioners and policy makers	To examine systemic problems to promote future prevention efforts and appropriate actions	(1) To identify national trends and patterns of illness, incidents and accidents leading to death which may indicate where health, education, social or environmental systems are not functioning to protect children and young people. (2) To develop policies and initiatives that can keep children and young people safe

							and healthy.
Retrospective Panel Review - scope	Scope of cases varies: all states review to age 18yrs; most review some SUIDs, accidents, homicides, suicides and preventable natural deaths. One state only reviews child abuse deaths.	Fetal and infant deaths selected by team but not usually all deaths. Differs from CDR in that FIMR are usually anonymous.	All child deaths 0-18 years; all causes; data made anonymous	All child deaths where abuse or neglect is known or suspected to be a factor; Scope for reviewing non-fatal cases abuse/neglect	All stillbirths and neonatal deaths	Very variable between state (mainly child abuse only, some include serious injury).	All deaths from 28 days through to the 25 th birthday. Deaths <28 days are reviewed by the Perinatal and Maternal Mortality review Committee
Retrospective Panel Review - participants	Multiagency membership involving public health, health professionals (especially family physicians and paediatricians),	Varies; similar to CDR but with inclusion of perinatal health providers. Second tier team of community members to	Multiagency, fixed core membership as in U.S., plus co-opted specialists	Multiagency, independent chair	Health professionals as per CDR but with inclusion perinatal health providers	Multiagency; varies between states	Multiagency and multi-sectorial

	social services, medical examiners/coroners, law enforcement, prosecutors, emergency response, education and mental health	develop recommendations .					
Retrospective Panel Review - data sources	Case records from all participating agencies as available; some abstracts prepared ahead of meetings.	Birth and death certificates; medical records; maternal interview	Submitted proformas from all professionals with knowledge of the child and family; data taken from case records	Individual agency reports compiled from records and interviews with key informants	Data proformas submitted by local health professionals in each maternity unit	Document and case record review. Interviews with key informants in some states.	Information comes from multiple sources, including Births Deaths and Marriages, Ministry of Health, Child Youth and Family, Coronial Services, Water Safety, Ministry of Transport and the local CYMRC
Retrospective panel review - analytic framework	Ecological framework analysis; public health and injury prevention analysis of risk factors	Ecological framework analysis; determination of level of contribution of different factors	Ecological framework analysis; determination of level of contribution of different factors	No set analytic framework Systems analysis approach recommended in recent Munro review ²⁹	No set analytic framework	No set analytic framework	Local CYMRC: Systems analysis approach National CYMRC: descriptive reports with analysis of risk factors
Retrospective	No family	Maternal	Family engage in	Requirement to	No family	No family	No family

panel review - Family involvement	involvement, but this is under development using the UK model	interview	CDR process; no direct family attendance at panel review	consider how family members should be involved	involvement	involvement, except Victoria	involvement
Retrospective panel review - Outputs	Recommendations to governor, state legislators, state and local agencies and public for policy and practice improvements. 42 states issue annual reports. National web-based data collation.	Some have state level report of findings. No national data collation. Most programs use one of two reporting tools: Basinette or National FIMR system.	Recommendations to Local Safeguarding Children Board and constituent agencies; annual report. Limited collation and analysis of data at national level.	Overview Report and executive summary published. All overview reports submitted to national government; biennial analyses of all Serious Case Reviews	Local unit audit; proformas submitted nationally. Local, regional and national collation of data; annual national report on perinatal mortality	No national collation but State level reports of findings.	Overview of deaths annually. Reports on specific classes of death or population groups.

Effect of child death review

The USA is starting to achieve the potential of a formal child death review process with comprehensive data reporting. In June, 2011, 39 states were enrolled in the US national child death review case reporting system; this number has since increased to 41 states, with a further five scheduled to enrol. The states using the system represent more than 95% of the US population and have more than 95% of all deaths. This internet-based system allows users to enter comprehensive information about the child, caretakers, supervisors, and perpetrators of violent acts; the incident, death investigation, manner, and cause of death; specific risk factors; services needed; prevention recommendations and actions; and factors affecting the case review process. Most states using this system generate comprehensive annual reports on their findings from child death review. The national programme can create reports of de-identified aggregated data. National data or reports are provided to federal agencies and researchers on request through a data dissemination policy. Data for violent deaths are also being matched with data from the CDC's national violent death reporting system to ascertain completeness of data in both systems. Many initiatives at state level have been developed as the result of child death review. Many fall into the classic injury prevention framework of education, enforcement, and environmental modification.

Washington State's child death review has published evidence of actions taken as a result of a review of deaths from drowning, showing changes in legislation, public awareness, and safety measures.(64) After these measures were implemented, no drowning deaths were noted for 10 years in one particular stretch of public water where several deaths of young people had previously occurred. In England, lessons from standardised processes for child death review are still to be translated into large-scale policy initiatives. Outcomes from the child death review process can be quantified at a local, regional, and national level. Locally, a formal approach to individual child deaths has resulted in better diagnostic ability and identification of modifiable factors. A study of early starter child death overview panels in England showed that local actions had been taken in response to death reviews.(55)

In Australia, outcomes from child death review processes still mainly indicate its close interface with child protection. Better assessment by child protection practitioners has resulted in more systematic information collection, improved multiagency working, and a particular focus on the practice environment. However, some states now produce comprehensive child death review annual reports

that make specific recommendations on public health directly to local government and suggest how to improve the accuracy of medical certificate of cause of death information. The Australian and New Zealand child death review and prevention group initiative aims to share information about issues in the reporting of child deaths in agencies across jurisdictions, to analyse data from agencies with child death review functions, and to work towards consistency in national reporting.(65) The New Zealand CYMRC provides a detailed annual overview of regional and national trends.(8) Additionally, the committee has published focused reports on issues such as sudden unexpected death in infancy,(12) youth suicide,(12) low-speed run over deaths,(26) alcohol-related harm,(66) poisoning,(67) and suffocation and strangulation.(68)

Future challenges

Although many prevention initiatives have been established as a result of child death reviews, whether the review processes themselves have resulted in a reduction in national child death rates has not been assessed. Our search identified only one published study reporting a significant decline in child protection system issues associated with a decline in child deaths after government action on review-finding recommendations.(69) To our knowledge, no data have been published for the cost and cost-effectiveness of these processes. Continued assessment of the process and outcomes is therefore needed to justify the resources invested in them, and before the potential benefit of review is achieved.

Although we have reviewed their development in four countries, processes for child death review are being developed elsewhere.(41) Other countries could learn from established processes, but the approach might need to be adapted to local needs and contexts, including to relevant national legislation. In the USA, England, Australia and New Zealand, child death review aims to provide a comprehensive analysis of child deaths to better understand how children die and to inform national mortality statistics and policies to prevent future child deaths. National legislation would further standardise processes in countries, and international collaboration would assist in the comparison of child mortality data in high-income countries across age bands. Locally, a systematic approach to inquiry can lead to better understanding of how and why a child died—eg, more rigorous approaches to investigation have been linked to the identification of infections, congenital malformations, intentional and unintentional injuries, and metabolic disorders as causes of sudden unexpected deaths in infants.(70–73) A diagnosis is invaluable to a bereaved parent and might allow them to

undergo counselling for future pregnancies. However, at a state and national level, child death review teams need to show an increased ability to move from case review to effective action.

Flexibility in a team's approach to child death review can help to improve effectiveness—eg, teams might combine reviews of similar cases so that recommendations can be based on several child deaths or use a two-tier process consisting of a technical team that reviews cases and a prevention team to create recommendations and promote action. A US national study of the fetal–infant mortality review programmes (over half of which were combined with child death review teams) showed that two-tier systems were more likely to report implementation of recommendations than were those with one-tier systems.⁽⁷⁴⁾ Clear lines of accountability between child death review teams and legislative and commissioning bodies will enable review teams to be more effective. National leadership is important for the development of national databases with the academic support to analyse data and publish reports, such as that provided by the New Zealand CYMRC. In the USA, national leadership supports the process, but there is still no federal mandate or dedicated funding to states.

Prospective systematic inquiry could be extended to child deaths in hospital. This process already occurs in some parts of England and the USA, and allows standardised identification of modifiable factors related to treatment, equipment, protocols, teamwork, knowledge, and socioeconomic circumstances. The USA has specific guidance to help teams to review deaths from asthma, or sudden cardiac or perinatal causes, but such teams need a more specialised membership to ensure the quality of these reviews. In New Zealand, all deaths are reviewed. Information from clinically focused reviews are used by CYMRC, along with extra information from the community, to consider what lessons can be learnt about family support and hospital processes.

The role of the family and the community in the child death review process should be clearly defined. In England, the rapid response is regarded as a family-centred approach. Family members are given the opportunity to contribute to individual case reviews, and follow-up is formally addressed. However, the extent to which this approach is being followed, and family perspectives of the process have yet to be assessed. The US fetal–infant mortality review model also strives to have information from a maternal interview as a key component of the case file. However, review teams in the USA and Australia have been slow to engage families in the process perhaps because child death review was originally established as a response to maltreatment. Families and the community can be

important allies for development and implementation of prevention recommendations; however, the potential for this approach has yet to be fully achieved and assessed.

Summary

Until the early 20th century, child deaths were not routinely investigated in a separate manner from adult deaths. International child mortality data are limited to information from the death certification process. Detailed comparison of child mortality patterns across high-income countries is a challenge since national departments of statistics present data in many ways—eg, age cohorts and diagnostic details vary in description, and other data such as socioeconomic status and location of death might not be presented at all. A standardised approach across national boundaries would allow better comparisons of health-care outcomes.

Child death review began in the USA, has become a statutory requirement in England and New Zealand, and is gaining prominence in Australia. Canada and Wales have also developed national death review processes.⁽⁴¹⁾ Processes for child death review could greatly increase understanding of how and why children die, and provide a framework for the detailed investigation of unexpected deaths. They could contribute to better accuracy in coding of cause of death, and help to increase precision in the classification of specific situations in which diagnostic drift is a particular issue (eg, sudden infant death syndrome). Child death review also provides a methodological framework for the formal assessment of modifiable factors that contribute to child death including those intrinsic to the child, to the family and environment, and to health-care services. Although considerable challenges remain before the full potential of child death initiatives can be achieved, formal child death review marks a departure from how child deaths have been previously investigated.

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