

Exploration of paediatric mortality

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Abstract

Aim

In Ireland, little data are readily available regarding causes of death in children after the age of one year. The aim of this study was to collate data on demographics and causes of paediatric mortality in the Mid-West region over a six-year period.

Methods

Data on children aged 0 to 18 who died between 01/01/2015 to 31/12/2020 were collated in Excel from a variety of different sources.

Results

A total of 152 children were identified as having died during the time-frame. Males accounted for n=87 (57%); post-neonatal deaths accounted for 95 cases. Mean age of the cohort who died in the post-neonatal period was 7.7 ± 6.7 years. Most prevalent cause of post-natal death was neurological/neuro-degenerative conditions n=27 (29%), followed by trauma, n=11 (12%), 'other' category n=10 (11%), SIDS n=9 (10%) and infectious diseases n=8 (8%). Congenital disorders, suicide, and oncological disease each comprised n=7 (4%). Deaths from cardiovascular causes accounted for n=6 (5%), with n=3 (3%) having no cause of death attributed at time of data collection.

Discussion

Gathering robust data regarding paediatric mortality is challenging. The collection of data needs resourcing and standardization to ensure trends in child mortality are identified, thereby assisting the development of intervention policies.

Introduction

The death of a child is a tragedy for the parents, extended family, community and the healthcare professionals involved in their care.¹ Globally, more than 5 million children died before turning 5 in 2021 alone, and tragically much of this loss of life is attributable to preventable causes.² The aim of this study was to collate data available on the demographics and causes of paediatric mortality in the Mid-West region of Ireland over a six-year period.

Although substantial progress has been made in reducing child mortality globally since 1990, many preventable child deaths still occur due to sub-optimal quality of care and adverse social and environmental circumstances.¹ It is important that we learn from child deaths in order to identify preventable causes which can inform targeted interventions from local through to national levels. An example of the benefit of a mortality register was seen with the SIDS registry based in Children's Health Ireland at Temple Street since 1992. It collected data on all sudden unexpected deaths in children under 2 years and conducted a population based case control study of risk factors for SIDS in the Irish Paediatric population.³ Successful interventions were formulated based on the evidence and successfully implemented nationally resulting in a substantial reduction in the number of SIDS deaths.³

In Ireland there is currently little data available on the circumstances and causes of death in children after the age of one year.³ Child death reporting is a statutory obligation in England and New Zealand¹ and while there is an existing National Paediatric Mortality Register (NPMR) in Ireland, death notification to the NPMR is currently on a voluntary basis. This potentially leads to an incomplete data-driven understanding of why children die in Ireland.³

Methods

Ethical approval was obtained from the Research Ethics Committee of the University Limerick Hospital Group and permission to proceed was obtained from the three coroners of the Mid-West region. Data on children aged 0 to 18 years old who had died between the 1st of January 2015 to the 31st of December 2020 were collated from multiple sources. Cases were identified from the regional mortuary records, records kept by the clinical nurse coordinator for children with life-limiting conditions (CNC-LLC), departmental morbidity and mortality meeting records, HIPE and the hospital chapel remembrance service records. Clinical details were obtained from hospital electronic systems such as iLab, NIMIS[®], Therefore[®] and medical records. Where post-mortem (PM) results were not available on the iLab system, data were obtained via the mortuary for PM results location - which were either with the office of the Coroner or with colleague Obstetricians, the latter in the case of diagnostic perinatal post-mortems. Data were analyzed using Excel and reference estimate of child mortality was acquired from the Central Statistics Office⁴. Results were analyzed, then divided into two main groups - neonatal and post-neonatal deaths, with a further classification of the post-neonatal group into 5 sub-divisions as per WHO publications²:

Neonatal – ages 0 to 28 days, Post-neonatal – ages 29 days to <1 year, ages 1 to 4 years, ages 5 to 9, ages 10 to 14 and ages 15 to 18.

Results

A total of 152 children were identified as having died during the six-year period between the 1st of January 2015 and the 31st of December 2020, as shown in table 1. Males accounted for 87 cases (57%). Neonatal deaths accounted for 57 cases (37%), and 95 deaths (63%) occurred outside the neonatal period. Mean age of the cohort who died in the post-neonatal period was 7.7±6.7 years, with 40 (42%) children dying at home, 31 (33%) in the emergency department, 18 (19%) in a

ward/ICU setting and 6 (6%) in 'other' location. Anticipated deaths comprised of 48 (31.5%) of the cohort, all with specialist involvement of our CNC-LLC. Post-mortem examinations were carried out in all but one neonatal death and in 47 (49%) of post-neonatal deaths. Cause of death by age group is shown in table 2. Overall, a cause of death was not available for 7 cases (4.6%), due to pending Coroner's inquests or post-mortem results. Aligning with international reporting norms and given live births in the MidWest for this time period totaled 26,342, we calculated the infant (aged <1 year) mortality rate at 2.4 per 1,000 live births and under-5 mortality at 3.8 per 1,000 live births (national reported rate 3.4 in 2018).⁵

Table 1: Characteristics of entire cohort categorised according to year of death.

Year	2015	2016	2017	2018	2019	2020	Total
Number of deaths	23	35	15	28	31	20	152
Sex							
Male	17	15	7	14	18	16	87
Female	6	20	8	14	13	4	65
Mean age(yrs)	2.02	6.01	7.59	5.91	4.33	3.27	-
Place of death							
Hospital	12	21	11	23	23	14	104
Elsewhere	11	13	4	5	8	6	47
Not specified	0	1	0	0	0	0	1
Post-mortem							
Yes	15	23	11	19	23	12	103
No	8	12	4	9	8	8	49

Place of death definition; Hospital (Emergency department, ward or ICU), Elsewhere (Home or Other location).

Neonatal causes of death.

Of the 57 cases within the neonatal period as seen in figure 1, the most prevalent cause of death identified within the six years was stillbirths inclusive of intrauterine deaths, n=21 (37%), followed by congenital or genetic causes, n=16 (28%), perinatal events, n=6 (10%), prematurity, n=5 (9%), infectious diseases, n=4 (7%), and one case of SIDS (2%). Cause of death was unavailable in 4 cases (7%) at time of data collection and tagged as Not Available, or 'N/A'.

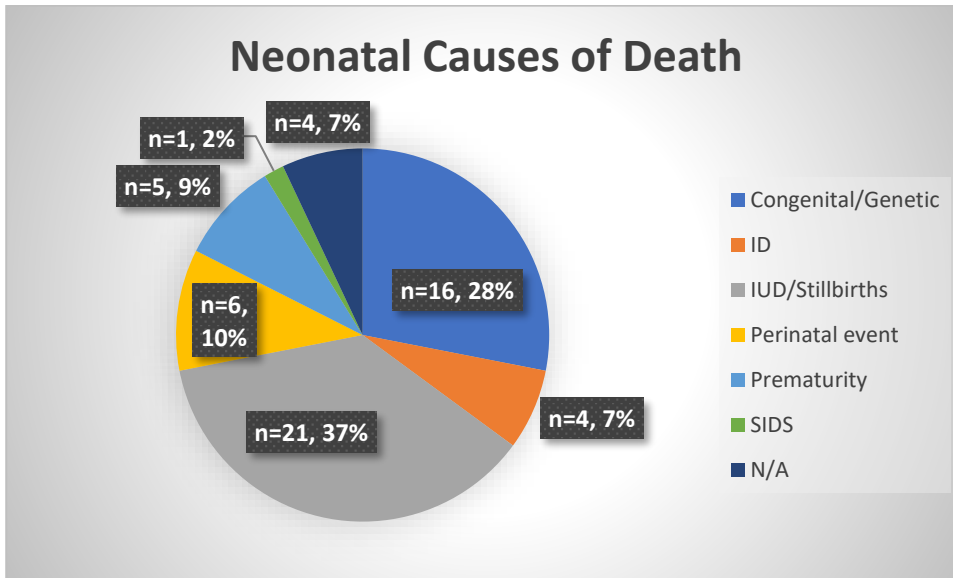


Figure 1: Causes of death in the neonatal group.

Post-neonatal causes of death.

Outside of the neonatal period as demonstrated in figure 2, the most prevalent cause of death was neurological and neuro-degenerative conditions, n=27 (29%), followed by trauma, n=11 (12%), and other category, n=10 (11%), SIDS, n=9 (10%), infectious diseases, n=8 (8%), congenital disorders, suicide, and oncological disease, n=7 (4%) for each of the three categories. Deaths from cardiovascular causes accounted for 6 cases (5%) and cause of death was unavailable in 3 cases (3%) at time of data collection and are tagged as Not Available, or 'N/A'.

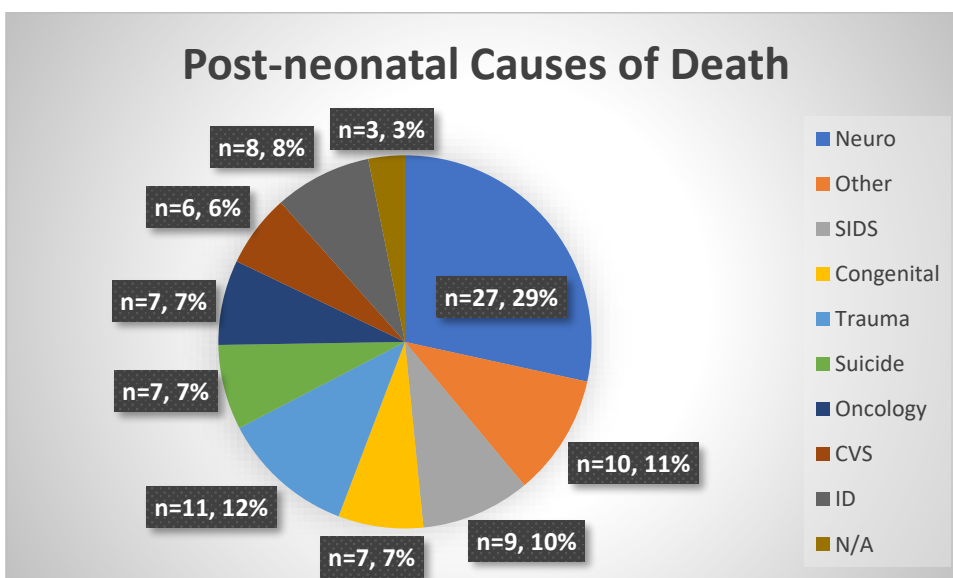


Figure 2. Post-neonatal causes of death. Other – Metabolic, Respiratory, Surgical, Toxins, Undetermined.

Table 2. Causes of death by age group

<i>Age group</i>	<i>Neuro</i>	<i>Trauma</i>	<i>SIDS</i>	<i>Congenital</i>	<i>Suicide</i>	<i>Oncology</i>	<i>CVS</i>	<i>ID</i>	<i>IUD</i>	<i>Prematurity</i>	<i>Perinatal event</i>	<i>Other</i>	<i>N/A</i>
<i>Neonatal</i>	-	-	1	16	-	-	-	4	21	5	6	-	4
<i>Post-neonatal</i>	7	1	9	5	-	-	1	1	-	-	-	1	1
<i>1 - 4 years</i>	5	3	-	2	-	3	1	2	-	-	-	-	1
<i>5 - 9 years</i>	4	-	-	-	-	3	1	1	-	-	-	3	-
<i>10 - 14 years</i>	5	2	-	-	1	-	1	1	-	-	-	3	1
<i>15-18 years</i>	6	5	-	-	6	1	2	3	-	-	-	3	-

Table 2. Definitions: Neonatal (0-28 days); Post-neonatal (28 days to less than 1 year); Neuro - Neurological/Neurodegenerative condition; SIDS – Sudden Infant Death Syndrome; CVS – Cardiovascular; ID – Infectious Diseases; IUD – Intrauterine death, including stillbirths; Other – Respiratory, Surgical, Metabolic, Toxins, Undetermined; N/A – Cause of death not available at time of data collection.

Discussion

Our study reports child mortality causes and demographics for the MidWest region of Ireland from 2015 to 2020. Overall, excluding stillbirths from the cohort, there were 131 deaths in the population aged <18 years old. The region encompasses Clare, Limerick and North Tipperary and census data from 2016 shows a total population (albeit aged <19 years old) of 114,856 giving a crude mortality rate of 11.4 per 10,000 population⁴. The Infant mortality rate for the region at 2.4/1,000 is lower than the OECD average and slightly lower than the Irish overall reported rate of 3.0/1,000 in 2020⁶. It must be acknowledged that during this time period some infants could possibly have died in paediatric intensive care units in Dublin and these cases could thereby have potentially been omitted from our study. The under 5 mortality rate is regarded as an indicator of child health as well as the overall development and well-being of a population⁷. The calculated rate in our regional population of 3.8/1,000 live births is close to our national recorded rate and lower than the OECD average of 4.5/1,000 in 2020⁷, albeit with the same caveat as discussed above.

Of the post-natal group, almost 20% of deaths were from either suicide or trauma, representing potentially modifiable causes of mortality in this population. Although numbers in our study are small relative to the larger national population, Ireland has the fourth highest adolescent suicide rate in the EU/OECD [UNICEF, 2017]. The incidence of preventable causes of death could be decreased by targeted public awareness campaigns, particularly regarding water and road safety, as well as suicide intervention programmes. This would need to involve the collaboration of inter-governmental agencies to ensure the implementation of effective strategies, particularly using media accessed by the adolescent population. Consideration should also be given to establishing a system of multidisciplinary child death review, to further explore preventable factors and recurrent patterns which may be identified from individual cases of unanticipated child death. This is used effectively in other countries such as Canada and the USA⁸.

Our results also highlight the importance of multidisciplinary and specialized approach to the care of children with life limiting conditions. Of the 48 'anticipated' deaths within the study period, 29 (60%) died at home or in hospice care, with involvement of the CNC-LLC. The role of a CNC-LLC commenced in the region in 2012, with plans to expand this role from one to two CNC-LLC's imminently.

Our study is limited by the potential for omission of cases who may have died outside of the region e.g. abroad, in road traffic accidents outside of the jurisdiction, or very unwell children who had been transferred for tertiary paediatric care. Multiple broad sources were explored in attempts to mitigate case omission, a time-consuming process which highlights the need for a more streamlined national source for case identification and to negate case duplication.

In order to learn from child deaths, there needs to be a standardized method of reporting these deaths to a national paediatric mortality database to enable establishment of trends in order to introduce and implement measures that mitigate preventable causes of death in the Irish paediatric

population. One such example is seen in the National Child Mortality Database of England which is the first of its kind anywhere in the world,⁹ which has served as a platform for promoting research in Paediatrics in areas of child mortality and the COVID-19 pandemic^{10,11}.

Declaration of Conflict of Interest:

Dr Orla Neylon is a member of the National Paediatric Mortality Register (NPMR), under National Office of Clinical Audit (NOCA).

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