

ORIGINAL ARTICLE

The quality and value of sudden infant death necropsy reporting in Ireland

K M Sheehan, M McDonnell, E M Doyle, T Matthews, D M Devaney

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Background: Infant necropsies are important for identifying cause of death. Recently issued guidelines have recommended investigations to be performed following sudden unexpected death in infants.

Aims: To evaluate the quality and value of infant postmortem reporting.

Methods: Postmortem reports from 1994–1996 and 1998–2000 in Ireland were evaluated using the National Sudden Infant Death Register. Scoring was by a modification of the Rushton system based on the extent of the postmortem data. The finding of additional pathological information was also assessed.

Results: Of the 274 cases registered during the selection period, reports were available for 245. Overall quality of necropsy reporting was below the minimum accepted standard in 55.5%; 47% of the necropsies were performed in regional paediatric pathology centres. The quality of necropsies performed in regional centres was significantly higher than those performed elsewhere. Although 86% of the cases were defined as sudden infant death syndrome (SIDS; no cause of death found), the finding of additional pathological information was significantly related to the extent of the necropsy. There was a significant improvement in the quality of necropsies after the postmortem guidelines were issued.

Conclusions: The overall quality of sudden unexpected infant death necropsies in Ireland is less than adequate. A minimum accepted standard of necropsy is required before a diagnosis of SIDS can be made. Although standards have improved recently, this study highlights the need to adhere to published guidelines and the importance of auditing the effect of introducing practice guidelines on clinical practice to complete the audit loop.

See end of article for authors' affiliations

Correspondence to:
Dr D Devaney, Department of Pathology, The Children's University Hospital, Temple Street, Dublin 1, Ireland; deirdre.devaney@tsc.h.ie

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The necropsy has been widely recognised as a valuable tool in assessing the cause of death and is a vital part of medical education and quality assurance.¹ Despite this, the rate of consented "hospital" necropsies has been declining in both adults and infants over the past three decades, and this decline has been accelerated by the negative publicity that has arisen from the recent organ retention controversy in some countries.² Necropsies required by law have a more secure future, because of the dependence on the findings for death certification in cases of sudden or unexpected deaths. Thus, the importance of a high quality necropsy is evident, not only in achieving accurate death certification, but in ensuring high medical standards and counteracting the negative public image.

The infant necropsy requires a more meticulous examination with a different protocol and diverse range of questions to be answered. The cause of death is frequently elusive and in contrast to the adult necropsy, additional investigations are required to exclude disease. Furthermore, the information obtained is viewed as a useful and necessary tool in helping parents come to terms with the death of their child and provide information for future pregnancies.³

During the 1990s, there were several critical reviews in the UK evaluating the standard of necropsy practice and the relevance of some necropsy findings. Overall, studies showed that approximately 46% of all infant necropsies failed to reach the accepted standard.^{4,6} If "sudden and unexpected infant deaths" (SUIDS) are analysed separately, the failure rate rises dramatically.^{4,5} After the issue of guidelines for paediatric necropsies with emphasis on high quality investigations, it has been shown that the standards in necropsy reporting improve.⁷ With regard to the value of the necropsy, in both neonatal and postneonatal cases, new information is obtained in 17–44% of cases.^{5,7,8}

"The infant necropsy requires a more meticulous examination with a different protocol and diverse range of questions to be answered"

The Royal College of Pathologists in the UK and the Faculty of Pathology of the Royal College of Physicians of Ireland issued guidelines, in 1993 and 1996, respectively, recommending investigations that should be performed following the sudden unexpected death of an infant.^{9,10} These guidelines give a detailed description of all investigations that are advised after the death of an infant. The recommendations issued by the Confidential Inquiry into Stillbirths and Deaths in Infancy Consortium in the UK also incorporate the Royal College's guidelines.¹¹ There are currently no data in Ireland regarding the quality of necropsies being performed during this period.

Furthermore, in Ireland, most SUIDS in infants under 1 year are classified as sudden infant death syndrome (SIDS) and the rate of SIDS has been declining.¹² Given that the diagnosis of SIDS requires a negative clinical history with exclusion of suspicious causes of death, in addition to a negative full post-mortem examination,¹³ the purpose of our present study was to determine the quality of necropsy reporting in Ireland in SUIDS and to assess the value of the investigation.

METHODS

The register

All SUIDS in the Republic of Ireland are notified to the coroner and then registered with the National Sudden Infant Death

Abbreviations: CSO, Central Statistics Office; MAS, minimum accepted score; NSIDR, National Sudden Infant Death Register; SIDS, sudden infant death syndrome; SUIDS, sudden and unexpected infant deaths

Table 1 Modification of the Rushton scoring system

Factor category	Total score	Factor breakdown	Score
Weights and measures*	80*	Body weight	20
		Crown rump	20
		Crown heel	20
		Head circumference	20
Main organ weights*	40*	Heart	8
		Lungs	8
		Liver	8
		Kidney	8
		Brain	8
Minor organ weights	15	Spleen	5
		Adrenals	5
		Thymus	5
Normal values	20	Heart, lungs, liver, kidney, brain	4 each
Histology main organ*	50*	Heart	10
		Lungs	10
		Liver	10
		Kidney	10
		Brain	10
Histology minor organ	30	Spleen	10
		Adrenals	10
		Thymus	10
Radiology	100		100
Microbiology	50	Swabs	20
		Blood culture	10
		PCR	10
		CSF	10
Biochemistry	20		20
Toxicology*	35*		35
Virology	10		10
Metabolic investigations†	50		50
Total maximum score	500		500
Minimum accepted score	205		205

The maximum score was 500.

*Items included in the minimum accepted score; †a score of 50 was given for any of the following metabolic tests: frozen tissue, acyl carnitine screen, organic acid screen, skin fibroblast culture, or basic metabolic screen. CSF, cerebrospinal fluid; PCR, polymerase chain reaction.

Register (NSIDR). Each quarter, the Central Statistics Office (CSO) issues to the register details of deaths in children from birth to 2 years. For each death, a medical certificate of the cause of death and CSO form 102 are provided. The NSIDR compiles these data in accordance with the Data Protection Act. In addition, a system of notification ensures that the appropriate professionals report all suspected cases of SUDS to the NSIDR within 48 hours and the register then obtains information regarding birth details, necropsy report, medical certificate as to cause of death, CSO form 102, medical history, and medical report from the general practitioner. Parents are also invited to participate in home interviews at which a comprehensive questionnaire is completed. The information collected by the NSIDR provides comprehensive data on all sudden, unexpected deaths among the infant population in the Republic of Ireland.

Subjects

Cases were selected from the NSIDR where a full necropsy report was available. The necropsy report is obtained from the coroner in whose jurisdiction the child has died. In this study, reports were collected from 48 coroner districts in the Republic of Ireland.

Data analysis

Necropsy reports from the years 1994–1996 and 1998–2000 were evaluated. The quality of the reports were scored by a pathologist using a modification of the system described by Rushton,⁶ which includes factors that are identified by the Royal College of Pathologists as being an essential part of the necropsy in an infant who dies suddenly and unexpectedly.^{9, 10} The parameters that were scored included: (1) body weights and measurements, (2) organ weights, (3) quoting normal

values, (4) histology of main organs (heart, liver, lungs, kidneys, and brain), (5) histology of other organs (thymus, spleen, and adrenals), (6) radiology, (7) microbiology, (8) biochemistry, (9) toxicology, and (10) special tests (such as metabolic test and virology). Table 1 provides a detailed breakdown of parameters and scores assigned. The total maximum obtainable score was 500 and the minimum accepted score (MAS) was set at 205, based on previous similar studies.^{5–7}

The study also set out to assess the value of performing the necropsy and to determine whether any additional information was obtained from detailed postmortem investigations and whether they were contributory to the cause of death. This was assessed by examining the final clinicopathological conclusion in the reports and categorising the data as: (1) new diagnostic information obtained that contributed to the cause of death, (2) additional information obtained but non-contributory to cause of death, and (3) no new information obtained. The data were analysed using the Student's *t* test.

RESULTS

According to the CSO, there were 307 993 live births registered during the years 1994–1996 and 1998–2000. During this period, 274 cases of sudden and unexpected infant death were registered with the NSIDR, and the necropsy reports were available for assessment in 245 cases. The mean age of the child at death was 18.2 weeks. The male to female ratio was 1.4:1. The necropsies were performed in 36 different hospitals in 48 coroner's districts around the Republic of Ireland.

Total scores for the quality of the necropsy reports ranged from 0 to 500. The median score was 184. The overall quality of the necropsy report was below the MAS of 205 in 55.5% (136

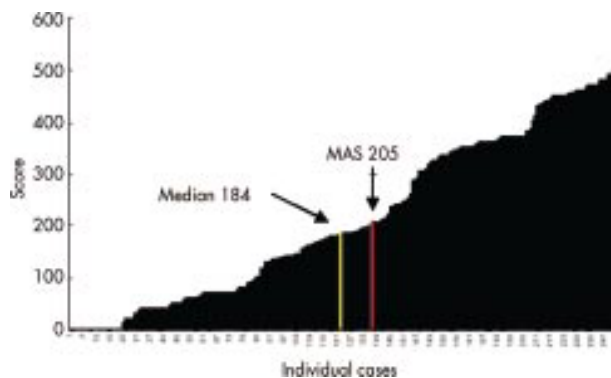


Figure 1 Overall quality of necropsy scores, 1994–2000. Total scores for the quality of the necropsy reports ranged from 0 to 500. The median score was 184. The overall quality of the necropsy report was below the minimum accepted standard (MAS) of 205 in 55.5% (136 of 245) of all cases. Twenty four reports scored 0 and one report scored 500.

of 245) of all cases (fig 1). Twenty four reports scored 0 and one report scored 500. One hundred and fifteen of the necropsies (47%) were performed in a regional paediatric pathology centre by specialist consultant paediatric pathologists. Four necropsies were performed by consultant forensic pathologists and the remainder by general consultant histopathologists. The quality of the necropsies performed in regional centres was significantly higher than those performed in non-regional centres ($p < 0.001$). The mean score for necropsies performed in a regional centre was 320.7 compared with 111.4 for necropsies performed in non-regional centres. The quality score for the necropsy performed in a regional centre failed to achieve a MAS in 21% of cases compared with 84% for those done in non-regional centres. There was no relation identified between the quality of the necropsy performed and the age of the infant at death.

The total quality score was then analysed according to the individual parameters that were assessed. This revealed that histology, body weights and measurements, and organ weights had the highest scores (fig 2), whereas radiology, microbiology, and biochemistry had the lowest scores.

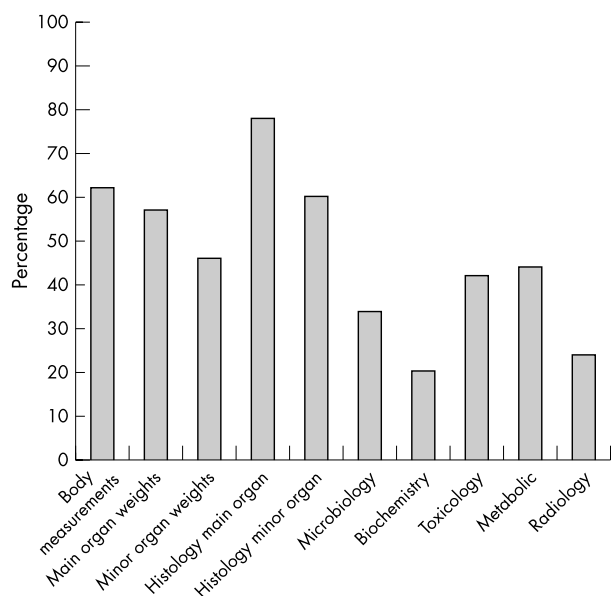


Figure 2 Summary scoring of individual necropsy parameters. The data are expressed as the mean score as a percentage of the maximum obtainable score for each parameter.

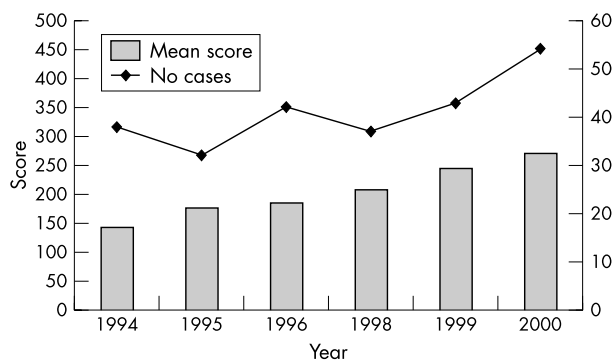


Figure 3 Mean quality of necropsy score by year. In comparing the years before (1994–1996) and after (1998–2000) the issue of the guidelines in Ireland, there was a significant improvement in the quality of the necropsy performed (mean score, 166 v 245; $p < 0.01$).

Although toxicology and metabolic tests are difficult to perform and not widely available, they had higher scores than microbiology and biochemistry. Performing histology yielded more information than any other test performed, whether in cases where a cause of death was found or as additional information in SIDS.

The necropsy scores were then analysed in the six individual years evaluated. The mean quality score in the year 1994 was 147, compared with a mean score of 260 in 2000, with a gradual improvement in quality with time (fig 3). When comparing the years before (1994–1996) and after (1998–2000) the issue of the guidelines in Ireland, there was a significant improvement in the quality of the necropsies performed (mean score 166 v 245; $p < 0.01$).

The second aim of the study was to determine the value of the necropsy and to assess the relevance of the additional pathological information obtained. In 13.4% ($n = 33$) of cases, a cause of death was found after necropsy. The remaining 86% ($n = 212$) of cases were classified as SIDS, in which no cause of death was found. In 18% ($n = 45$) of the SIDS group, additional information was found at necropsy, which was non-contributory to the cause of death. There was no significant difference in the quality of the necropsy performed if a cause of death was identified at necropsy. Assessment of the overall quality scores showed a mean score of 205 where a cause of death was found and a score of 210 where no cause of death was found ($p = 0.7$). However, in the SIDS group, the finding of additional pathological information was significantly related to the extent of the necropsy. The mean quality score was 341.6 when additional information was obtained and 175.2 in the absence of additional findings ($p < 0.001$).

DISCUSSION

The overall infant mortality rate in the Republic of Ireland has declined from a rate of 8/1000 live births in 1991 to 6/1000 live births in 2000. This mortality rate remains one of the lowest among developed countries, and results, in part, from the decline in neonatal mortality and SIDS. Whereas the rate of SIDS has been declining, the proportion of SIDS as a percentage of SUDS remains constant.¹² In contrast to previous studies,^{4,5} we only evaluated those infants who died suddenly and unexpectedly, so that perinatal deaths, spontaneous abortions, stillbirths, and expected infant deaths were excluded. Our study was made possible by the fact that all SUDS in Ireland require a coroner's necropsy, so that necropsy reports were made available to the NSIDR.

Fifty five per cent of the SUDS necropsy reports were below the accepted standard. In two comparable reviews of SUDS necropsy reports in the UK, substandard rates of 68% and 91% have been reported.^{4,5} When all infant deaths are included,

failure rates are approximately 46%.^{4,6} When analysing the individual parameters assessed, in keeping with previous studies,⁶ body weights and measurements were well recorded, with special techniques such as radiology and microbiology scoring < 25% of their potential maximum score. However, although most of the reports included body weights and measurements, < 12% compared them with the normal expected values, questioning the purpose of performing this procedure. Moreover, five reports did not include the age of the child at death, so that in those cases, body weights and measurements were meaningless. It must be emphasised that radiology was not included in the MAS, although ideally it should be part of a standard necropsy because, in its absence, non-accidental injury cannot be excluded. Similarly, metabolic tests were not considered part of the MAS, yet if not included, there is the risk, albeit small, of an inherited metabolic disorder being overlooked.

“We feel there should be no minimum accepted standard”

The fact that necropsies performed in regional centres produced a higher quality score than non-regional necropsies supports the concept that infant necropsies should be performed in a regional paediatric centre. This finding was also reported by Vujanic *et al*,⁵ who found that there was an increase in paediatric necropsy referrals to specialist centres after the revision of guidelines.⁷ In a follow up study, where 46% of all cases were below the accepted standard, only 4.9% of those were performed by paediatric pathologists.⁴ In Ireland, in recent years, there also has been a tendency to move towards this practice; however, with only a handful of paediatric pathologists, this is not always feasible. In addition, if a child dies in a remote district, it is not always geographically possible to perform the necropsy in a specialist centre, particularly when trying to achieve a balanced sensitivity towards family predicaments.

There are limitations to our study. The scoring system involved an arbitrary score given to each parameter, which is clearly easy to apply to each case, but it does not give us insight into the expertise of the pathologist performing the necropsy, the facilities available, and the ability to interpret the information gathered. For example, in one case, a diagnosis of aspiration pneumonia was given in the absence of pulmonary histology. A recurring problem in evaluating reports was in reviewing histology, it was often impossible to ascertain which organs were examined, because a blank statement “histology was normal” was given. Furthermore, in our study, a “minimum accepted standard” was outlined which, in practice, could be easily achieved. In reality, this standard would not be accepted in a specialist centre. Nevertheless, any hospital that has the facilities for a pathologist to do a necropsy must have a weighing scales, a measuring tape, and techniques for histology—a few simple items which alone would achieve the MAS score. However, it must be stressed that we feel there should be no minimum accepted standard. Indeed, the professional guidelines do not include or support a “minimum practice”.

Interestingly, although toxicology and metabolic tests are somewhat difficult to perform and are not widely available, they had higher scores than microbiology and biochemistry, which are available in every hospital. The reason for this is unclear, but we speculate that this may be related to the ease of taking the samples for these tests and the time available: toxicology involves taking blood/urine only, and general histopathologists would be very familiar with performing this test for adult necropsies. In contrast, microbiology requires having sterile swabs and collection utensils close to hand, and these would be infrequently used for necropsies. In addition, biochemistry is best performed on vitreous humour, and most

Take home messages

- The overall quality of necropsy reporting was below the minimum accepted standard in 55.5% of cases
- The quality of necropsies performed in regional centres was significantly higher than those performed elsewhere
- The finding of additional pathological information in the sudden infant death syndrome was significantly related to the extent of the necropsy
- Although there has recently been a significant improvement in the quality of necropsies, this study emphasises the need to adhere to published guidelines and the importance of auditing the effect of introducing standard practice procedures

general pathologists would not routinely perform this test. Metabolic tests may have earned higher mean scores because any one metabolic test was required to achieve the maximum score for that parameter (table 1).

It is interesting to note that where a cause of death was found, the quality of the necropsy did not appear different to that when no cause was found. This is possibly because if a cause of death was found at necropsy, the pathologist then limited the number of additional ancillary investigations (such as metabolic tests and virology) because they were no longer indicated. In the SIDS group, the finding of additional pathological information was significantly related to a high quality necropsy score. Although these findings were non-contributory to death, they have potential value. Parents may feel guilty if a necropsy finds “nothing”. The finding of a minor pathological abnormality indicates that a detailed examination was performed.³ Furthermore, it may explain some of the non-specific illnesses that these children often have before death—for example, oesophagitis.

It is conceivable that the organ retention controversy may have had an impact on the quality of sampling by pathologists in Ireland. However, the controversy came to light in 2000, and would therefore not have had a significant impact on our study, which evaluated reports from 1994–96 and 1998–2000. In addition, all of the cases in our study were coroner’s necropsies, so that the issue of consent for organ retention did not occur. Nevertheless, a policy was endorsed at the end of our study whereby parents and next of kin were actively informed if an organ was retained.

One of the positive findings of our study was the improvement in necropsy scores after the issue of the Faculty of Pathology guidelines in Ireland in 1996. However, during the years before and after the issue of the guidelines, there was not a significant increase in referrals to specialist centres: 48% v 46%, respectively. This is encouraging and suggests that the non-regional centres are improving their practice in an attempt to achieve the high standard already present in regional centres. Although the improvement was predominantly in the regional centres (score 307 to 432), the non-regional centres also had better scores (70 to 138).

In summary, the overall quality of SUDS necropsies in Ireland is less than adequate. Although the standard of necropsy reporting has improved in recent years, this study emphasises the greater need for pathologists to continue to adhere to the published guidelines. In addition, it highlights the importance of auditing the effect of introducing practice guidelines on clinical practice to complete the audit loop.

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Authors’ affiliations

K M Sheehan, E M Doyle, D M Devaney, Department of Pathology, The Children’s University Hospital, Temple Street, Dublin 1, Ireland
T Matthews, Department of Paediatrics, The Children’s University Hospital
M McDonnell, The National Sudden Infant Death Register of the Irish Sudden Infant Death Association, the Children’s University Hospital

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