

SHORT REPORT

Perinatal and infant autopsy

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Objectives: To measure perinatal and infant autopsy rate in Wales over a 10-year period and study factors influencing the decision to perform an autopsy.

Design: Retrospective cohort analysis of data from the All Wales Perinatal Survey.

Methods: Autopsy rates were calculated over a 10-year period (1994–2003), and reasons for not performing an autopsy were noted. Two time periods, 1994–1996 and 2001–2003 were compared, to study changing autopsy patterns.

Results: Over the 10-year period, there were 4393 perinatal and infant deaths, with data available for 4306 (98%) cases. Consent for autopsy was requested in 89% of cases and granted in 68%. When compared, the 3-year cumulative autopsy rate fell from 67.5% (95% confidence interval (CI) 65% to 69%) in 1994–1996, to 52.7% (CI 49% to 55%) in 2001–2003. The difference in the proportion of autopsies performed between the two time periods was 14.8% (CI 11% to 18%). Parental consent was granted in 76.2% (CI 73% to 78%) of cases in 1994–1996 and 60% (CI 57% to 63%) of cases in 2001–2003. The difference in proportion in consent for autopsy in the two time periods was 16% (CI 12% to 20%).

Conclusions: A decrease in perinatal and infant autopsy rates has been found in Wales over the past 10 years. Parental refusal has been the main cause of this decline.

An autopsy is an important audit tool that often discloses new information about the cause of death and sometimes finds evidence that the clinical diagnosis made before death was wrong.^{1–4} Even in cases where autopsy does not disclose additional information, the confirmation that clinical diagnoses were correct is reassuring to parents and clinicians. Moreover, perinatal autopsy may discover diseases that have implications for future pregnancies. However, autopsy rates have fallen in many countries.⁵ In Britain, this may have been hastened by public concern about organ retention after autopsies and the considerable debate about the requirement for information when obtaining parental consent. There have also been reports that clinicians are reluctant to seek consent for autopsy.⁶

The aim of this study was to examine the autopsy rate in Wales over a 10-year period, and to investigate whether there has been a change in the willingness of clinicians to seek, and parents to consent to, an autopsy.

METHODS

All stillbirths, spontaneous abortions, therapeutic abortions and infant deaths between 1 January 1994 and 31 December 2003 in Wales were identified using the All Wales Perinatal Survey, an ongoing population-based surveillance of mortality between 20 completed weeks of gestation and 1 year of age. Data were collected on the number of autopsies performed, and the reasons for not performing an autopsy were recorded as either “not requested” or “not permitted”.

The first 3 years (1994–1996) of the decade studied were compared with the last 3 years (2001–2003). Two time periods, 1994–1996 and 2001–2003, were compared, to study changing autopsy patterns. The use of 3-year cumulative data reduces the effect of random variation. We also calculated the proportion of autopsies performed in the two time periods by the type of infant death. This was performed to study if any change in autopsy rate could be explained by the change in autopsy rate in particular subgroups.

RESULTS

We found 4393 deaths in the period 1994–2003. No data regarding autopsy were available in 87 (2%) cases, and these were excluded from the analysis. In 482 of 4306 (11.2%) cases, permission for autopsy was not requested by clinicians. In 3824 of 4306 (88.8%) cases, consent for autopsy was requested and in 2608 (68.2%) cases, permission was granted. An autopsy was performed in 2604 of 4306 cases, an overall rate of 60.5%.

The autopsy rate declined over the 10-year period from 66.5% (95% confidence interval (CI) 62% to 70%) in 1994 to 47.9% (95% CI 42% to 53%) in 2003 (table 1). During the same period, the proportion of cases in which an autopsy was requested remained relatively static, but the rate at which consent was granted fell from 76.2% (95% CI 72% to 80%) in 1994 to 57.8% (95% CI 52% to 63%) in 2003.

When we compared the first 3 years (1994–1996) of the decade studied with the last 3 years (2001–2003), the cumulative autopsy rate fell from 67.5% (95% CI 65% to 69%) in 1994–1996 to 52.7% (95% CI 49% to 55%) in 2001–2003 (table 2). The difference in proportion of autopsies performed between the two time periods was 14.8% (95% CI 11% to 18%). Parental consent was granted in 76.2% (95% CI 73% to 78%) of cases in 1994–1996 and in 60% (95% CI 57% to 63%) of cases in 2001–2003. The difference in proportion in consent for autopsy in the two time periods was 16% (95% CI 12% to 20%). The rate of autopsy not requested by clinicians in the two time periods was 11% (95% CI 9% to 12%) in 1994–1996 and 12% (95% CI

Table 1 Proportion of request for consent, permission granted and overall autopsy for perinatal death according to year of death

Year	No of deaths	Consent requested (%)	Consent granted (%)	Autopsies performed (%)
1994	492	429 (87.2)	327 (76.2)	327 (66.5)
1995	463	401 (86.6)	313 (78.0)	312 (67.4)
1996	453	420 (92.7)	313 (74.5)	312 (68.9)
1997	485	427 (88.0)	289 (67.7)	288 (59.4)
1998	465	429 (92.3)	297 (69.2)	297 (63.9)
1999	421	385 (91.4)	266 (69.1)	266 (63.2)
2000	390	340 (87.2)	204 (60.0)	203 (52.0)
2001	390	361 (92.6)	222 (61.5)	222 (56.9)
2002	384	331 (86.2)	203 (61.3)	203 (52.9)
2003	363	301 (82.9)	174 (57.8)	174 (47.9)
Total	4306	3824 (88.8)	2608 (68.2)	2604 (60.5)

Table 2 Proportion of autopsies performed, with 95% CI and difference in proportions between 1994–1996 and 2001–2003 by type of death

	1994–1996 proportion (95% CI)	2001–2003 proportion (95% CI)	Difference in proportion (95% CI)
Therapeutic abortion	87 (80 to 92)]	70 (62 to 77)	17 (06 to 26)
Spontaneous abortion	75 (68 to 80)	54 (46 to 61)	21 (11 to 30)
Stillbirth	70 (66 to 74)	52 (47 to 56)	18 (12 to 24)]
Neonatal death	50 (45 to 55)	33 (27 to 39)	17 (09 to 25)
Post-neonatal death	69 (63 to 75)	73 (64 to 80)	–3(–13 to 06)
Total	67 (65 to 69)	52 (49 to 55)	15 (11 to 18)

10% to 14%) in 2001–2003. The difference in the proportion of autopsies not requested by clinicians in the two time periods was 1% (95% CI –1% to 4%).

When we compared the proportion of autopsies performed in the two time periods by type of death, there was a fall in autopsy performed in four of the five subgroups (table 2). The only group in which there was no fall in proportion of autopsy performed was the post-neonatal group.

DISCUSSION

We found that autopsy rates in Wales have declined in the past 10 years, but the main decline has been since 2000. The cause of this is uncertain, but there are probably several factors. During the mid-1990s, a publication from Wales showed that the quality of perinatal autopsy improved when performed by a perinatal pathologist, and this stimulated a regionalisation of perinatal pathology services.^{1–7} Although this improved the quality of the examination, another effect was that some autopsies were performed at a centre 150 miles away from the hospital in which the death occurred. This is likely to have inhibited parents from consenting to an autopsy.

Perhaps more important is the controversy surrounding the public revelation that organs were often retained after an autopsy without the explicit consent of the parents. This became public knowledge at the end of 1999 and coincided with the marked decline in autopsy rates since 2000.⁸ Notably, the fall occurred because parents were refusing to give permission rather than because of a decline in the proportion of cases in which clinicians sought permission. In addition, the finding that the proportion of autopsies performed in most subgroups (therapeutic abortion, spontaneous abortion, stillbirth and neonatal death) has declined suggests that the reason for the fall is more general. The only group that did not see a decline is the post-neonatal group, in which most autopsies are performed by the coroners, and there is no parental choice.

Our data suggest that the confidence of doctors in the value of an autopsy has not altered. There is also no evidence that the recently introduced more complex and thorough consenting procedures have inhibited clinicians from seeking consent for an autopsy. However, we cannot be certain that clinicians

themselves have not lost confidence in the value of an autopsy, particularly in cases where they feel that the cause of death is known. This might reflect the way in which they counsel parents, leading to refusal in consenting to an autopsy.⁶ Our data also suggest that the declining rates are due to parents withholding consent. This may be due to many factors, including a lack of confidence in the examination or its value, but it may also reflect a rejection of the examination in light of a more thorough explanation of the procedure when consent is sought. An individual unit in Scotland, where the clinicians, midwives and neonatal nursing staff were motivated, and a perinatal pathology service, which was located on the same site, have managed to reverse the decline in neonatal autopsy rates.⁹

CONCLUSION

Our findings suggest that the main reason for the decline in perinatal and infant autopsy rates is due to parental refusal. The retention of organs after autopsies, centralisation of perinatal pathology services and the new detailed consenting procedure may all have contributed.

Perinatal and infant autopsy is an important tool in clinical care, audit, research and teaching. Hence, there is a need for obstetricians and paediatricians to review counselling practice in their units and for the Royal College of Paediatrics, Royal College of Obstetrics and Gynaecology, and Royal College of Pathologists to jointly develop a strategy to deal with declining perinatal and infant autopsy rates.

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