

ORIGINAL ARTICLE

Deaths from pertussis are underestimated in England

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Aims: To improve estimates of deaths from pertussis in England and to identify reasons for under ascertainment.

Methods: Comparison of deaths identified from enhanced laboratory pertussis surveillance, hospital episode statistics (HES), and Office for National Statistics (ONS) death registrations in England, 1994 to 1999.

Results: A total of 33 deaths were identified, 88% of infants less than 4 months old. There was overlap between all sources; 22 deaths were identified in the enhanced pertussis surveillance system, 18 in ONS mortality data, and nine in HES. Children who had died from pertussis without mention of pertussis on the death certificate were more likely to have been certified by coroners than those with mention of pertussis ($p = 0.0005$). Using capture–recapture analysis, the total number of deaths from pertussis in the five and a half year period is estimated to be 46 (95% CI 37 to 71), or around nine deaths per year.

Conclusions: National mortality statistics significantly under estimate deaths from pertussis in England and are inadequate for monitoring the national immunisation programme. The largest number of deaths is identified through enhanced laboratory surveillance. Death registration systems should take into account available microbiological information to ensure that cause of death is accurately assigned.

Mortality statistics are used to evaluate the impact of immunisation programmes and must be accurate for this purpose. A previous study identified 12 deaths from pertussis in England and Wales in 1995–97 through enhanced surveillance of laboratory confirmed cases, compared to only five in Office for National Statistics (ONS) mortality data from death registration.¹ This study examines death registrations in greater detail and compares these with deaths identified from enhanced laboratory surveillance and hospital episode statistics (HES) for the period 1994–99. The objectives were to improve the estimate of the number deaths caused by pertussis and to find out why pertussis had not been mentioned as the cause of death.

METHODS

Enhanced laboratory surveillance of pertussis has been carried out by the Public Health Laboratory Service (PHLS) since 1994. Culture confirmed cases of pertussis are identified through laboratories reporting to the PHLS Communicable Disease Surveillance Centre (CDSC) or sending isolates to the Pertussis Reference Laboratory. Cases are followed up by questionnaire. All fatal cases of pertussis held on the enhanced pertussis surveillance database at CDSC were extracted. Deaths with any mention of pertussis on the death certificate (ICD9 code 033) were identified from the ONS mortality data between 1 January 1994 and August 1999. Deaths which were likely to be the long term consequence of pertussis were excluded. Whether the death was certified by a doctor or coroner and whether the cause had been amended was noted. HES, which include ICD diagnostic code and outcome including death, are collected on all hospital admissions in England. All finished consultant episodes in the period 1 January 1994 to 31 March 1998 with any mention of pertussis and which ended with the patient's death were extracted from HES held at CDSC. The cases were matched on date of birth, sex, post code, and date of death.

The recorded cause of death in ONS data was identified for all pertussis deaths identified through HES or the enhanced

surveillance data without mention of pertussis on the death certificate. In order to examine the potential pool to which pertussis cases may be misclassified, all deaths mentioning these causes were identified. The proportion of deaths certified by coroners was then calculated for all these causes of death in children under 1 year of age.

A capture–recapture analysis was carried out to estimate the true number of deaths from pertussis, allowing for under-reporting in all three data sources.² Tests of two way interaction were carried out between the three as the sources are unlikely to be independent. These were included in different models to examine their impact on the estimates. Profile likelihood was used to estimate 95% confidence intervals.

RESULTS

Five deaths from delayed effects of pertussis were excluded. For four of the five individuals, all aged over 50 years, the final underlying cause of death was bronchiectasis.

In total, 33 deaths were detected from the three sources during the six years. There was overlap between all the sources (fig 1); 22 deaths were in the enhanced pertussis surveillance system, 18 in ONS data, and nine in HES. Hospital episodes for all but one of the infants missing from HES could be found, but they were not coded as having died during the admission. From the death certificates, all 33 infants died in an NHS hospital.

The median age at death was 1.7 months (range 2 weeks to 17 months). Twenty nine of the 33 deaths (88%) were of infants aged less than 4 months, too young to have been fully immunised.

None of the three possible two-way interactions were significant, but in view of the likelihood of interaction, that between ONS and HES which was close to significance

Abbreviations: CDSC, Communicable Disease Surveillance Centre; HES, hospital episode statistics; ONS, Office for National Statistics; PHLS, Public Health Laboratory Service

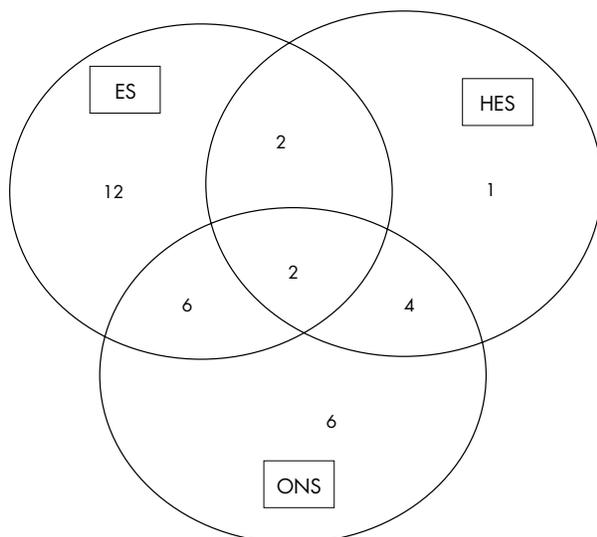


Figure 1 Overlap between deaths in enhanced pertussis surveillance system (ES), ONS mortality database (ONS), and hospital episode statistics (HES).

($p = 0.08$) was included in the model. This yielded an estimate of 13 deaths missing from the combined data (95% CI 4 to 38). Thus, the total deaths from pertussis in the five and a half year period is estimated at 46 (95% CI 37 to 71), or around nine deaths per year.

For 15/33 deaths (45%) the medical certificate of cause of death did not mention pertussis. This occurred for 13 deaths identified through enhanced surveillance, one death in the HES, and one death of an infant who was identified in both. Of these 15 infants, eight (53%) had been certified by coroners. In contrast, all of the 18 infants with a mention of pertussis on the death certificate had been certified by doctors (Fisher's exact test, $p = 0.0005$). In four (22%) of these 18, the cause of death had been amended to pertussis after the original death registration. Table 1 shows the causes of death on the death certificates of the 15 infants for whom there is no mention of pertussis. This includes the 14 from whom *Bordetella pertussis* had been cultured, of whom seven were certified by coroners. None of the deaths certified by coroners had indicated that bacteriology might be available later and none had been amended.

In the period 1993–99, certificates which included any mention of the causes in table 1 gave it as the underlying cause of death for 273/834 (33%) infants less than 28 days old and 549/625 (88%) infants aged 28 days to 1 year old (table 2). Coroners were more likely to assign cause of death to pneumonia, organism unspecified (ICD9 486), given in 68% of deaths certified by coroners for infants less than 28 days old compared with 24% by doctors ($p < 0.0005$), and in 39% of deaths certified by coroners in infants 28 days to 1 year old compared with 21% by doctors ($p < 0.0005$). Doctors were more likely than coroners to ascribe the cause of death to primary pulmonary hypertension (60% versus 11% in neonates, and 13% versus 7% in infants 28 days to 1 year, $p < 0.0005$). In infants 28 days to 1 year old, doctors were more likely to assign cause of death to infantile cerebral palsy (17% versus 7%,

Table 1 Final cause of death in infants who were identified as having pertussis in other data sources, but certified without mention of pertussis

Final underlying cause of death (ICD9)	Cause of death	Number of deaths certified by coroner	Number of deaths certified by doctor	Total
420	Acute pericarditis		1	1
343.9	Infantile cerebral palsy		1	1
481	Pneumococcal pneumonia (lobar pneumonia, organism unspecified)	1		1
416.0	Primary pulmonary hypertension		1	1
425.4	Other primary cardiomyopathies	1	1	2
427.5	Cardiac arrest		1	1
466.1	Acute bronchiolitis	1	2	3
482.3	Pneumonia due to streptococcus	1		1
486.0	Pneumonia, organism unspecified	3		3
747.0	Patent ductus arteriosus	1		1
Total		8	7	15

Table 2 Number of deaths in 1993–99 in infants where one of the causes of death in table 1 was given as the final underlying cause of death

Final cause of death (ICD9)	Infants less than 28 days old		Infants 28 days to 1 year old (total 549 infants)		Total
	Number certified by coroner	Number certified by doctor	Number certified by coroner	Number certified by doctor	
343.9	0	0	14	62	78
416.0	6	132	3	47	188
425.4	4	17	17	57	95
427.5	1	1	14	11	27
466.1	1	4	50	82	137
486.0	36	52	75	76	239
Others	5	14	20	21	60
Total	53	220	193	356	822

$p = 0.001$) and other primary cardiomyopathies (16% versus 9%, $p = 0.02$).

DISCUSSION

As diseases become rarer with successful immunisation programmes, inaccuracies in the mechanisms for monitoring the burden of disease become more important. Laboratory surveillance of pertussis is known to be incomplete because culture is at best 80% sensitive, and not all infants are investigated. Deaths may not be detected through HES because the infant died before they could be admitted or after leaving hospital, because the diagnosis was not suspected, or because of data errors. As expected, all of the identified deaths from pertussis took place during a hospital admission, so the incompleteness of HES is likely to be caused by error. Some deaths will not be identified as being caused by pertussis in any routine system. Sudden infant death syndrome may be caused by pertussis but is unlikely to be accurately ascribed to pertussis and unlikely to be detected through HES, laboratory, or ONS mortality data.³

Death registration only identified 18 deaths from pertussis in 1994–99. This is 55% of the deaths identified using multiple sources, and only 40% of the estimated total of 46 deaths. Under ascertainment of pertussis in mortality statistics is a long standing problem.⁴ Virtually all deaths are registered in England and Wales, which requires a certificate of cause of death from a doctor or a coroner. Thus if deaths from pertussis do not appear in the mortality database, this is because of inaccuracy or imprecision in the certified cause rather than because the database is incomplete. The largest number of deaths was identified through surveillance of culture positive cases. However, culture may underascertain pertussis in infants by over 300%.⁵ This under ascertainment may occur to the same or greater extent in infants who die with pertussis. Many infants are assigned a cause of death which is compatible with pertussis (table 2), so even if a small proportion of these are in fact caused by pertussis, there is potential for the number of pertussis deaths to be significantly greater than found in this study. Deaths may be ascribed to vague respiratory causes or the contribution of pertussis may be ignored in favour of co-pathology. Co-pathology such as congenital heart disease is recognised to increase susceptibility and was identified on death certificates in this study (table 1).

The cause of death is normally certified by a doctor who was looking after the patient in their final illness. Deaths which are sudden and unexpected, or for which the cause is not known, must be referred to the coroner. Around a third of deaths in England and Wales are referred to coroners, and a quarter certified by them.⁶ Virtually all deaths certified by coroners undergo postmortem examination, which is generally assumed to provide a more accurate cause of death. However, most coroners are not medically qualified and their role is primarily to exclude foul play rather than to provide accurate

epidemiological data. Comparatively few coroners' postmortem examinations include bacteriology, and coroners may not always obtain pathology reports from specimens taken before death by clinicians. Some of these results, particularly microbiological investigations, may only become available some time after death. In most of the cases certified by doctors, antemortem bacteriology established the cause as pertussis, either before the death was certified or subsequently. In the eight deaths certified by coroners, the postmortem examinations did not include bacteriological examination. In seven of these, bacteriology showed pertussis. However, the coroners and their pathologists apparently did not have access to this information, either at the time of certification or later. Whoever certifies the cause of death, whether doctor or coroner, should ensure that they obtain the results of any relevant antemortem investigations. If these cannot be obtained quickly, and the death is not suspicious, they can certify it with the most accurate cause they know, but should indicate that further information may be available later. If the certifying doctor or coroner indicates that results may be available later, ONS will write to them to get this information and amend the coded cause of death on the mortality database. Similar problems may affect other infectious diseases such as meningococcal infection. Coroners should be enabled and encouraged to provide an accurate cause of death for infectious diseases where the data are used for the surveillance of major public health interventions such as mass immunisation programmes.

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