3. Results of study

Causes of death

Towards the end of an autopsy report is the pathologist's opinion as to the cause of death, which should be presented in the standard manner prescribed by the Office for National Statistics (ONS)[28]. The main pathology, or the underlying cause of death, is the bottom line used in part one of the statement; significant contributing diseases are placed in part 2 of the statement. If no cause of death is discovered when the report is written, it is usually stated to be 'unascertained' or 'unascertainable'. In general, an unascertainable death would be where the pathologist is unable to establish a cause of death. This may be because the body is autolysed, or the pathologist only has part of the body to autopsy. It may also be because the death is caused by probable natural causes that cannot be proven (e.g. cardiac arrhythmias or epilepsy with no pathological findings). A cause of death can also be recorded as unascertained either because it is truly unascertainable (for the reasons above) or because the cause of death was unable to be established at autopsy and had not since been established at the time the autopsy report was prepared. For the latter, an inquest may be held and further evidence may be produced that does lead, with the autopsy findings, to a satisfactory cause of death.

All the reports gave a cause of death except 13 (<1%) cases where the cause of death was noted to be unascertained or unascertainable. In 99% of cases (1,678/1,691), the cause of death noted on the autopsy report followed the usual manner prescribed by the ONS (as judged by the advisors). This was better than the standards of death statement noted in previous reports (e.g. An Acute Problem? which dealt with complex intensive care cases)[11], and reflects two factors. First, the majority of deaths occurred in the community, and second, the commonest cause of death was ischaemic heart disease. Formulating this into a satisfactory cause of death sequence is relatively straightforward.

Were the listed causes of death appropriate?

The advisors were then asked to consider whether the cause of death given took into "appropriate account the clinical course and autopsy findings as presented in the report and in the supporting documentation". It was found that 18% (310/1,691) of cases did not meet this criterion, i.e. the advisors considered that the given cause of death may not be correctly written in context from the evidence available in all the paperwork present for the case. (This is lower than the figure found in another study examining medical certificates of the cause of death, which showed that 30% were wrong[24]). The degree of disagreement with the given cause of death varied, from disagreement with the fundamental pathological process depicted (n=59), to the belief that the pathologies listed in the two parts of the cause of death statement were wrongly ordered for significance, and that important other diseases were not stated as appropriate.

From the assessment of the causes of death, there were seven specific areas where the advisors believed them to be incongruent with the information available (history and autopsy examination). The most common was the issue of cardiac enlargement (hypertrophy) as the

cause of death without appropriate investigations and correlation. Hypertension or a primary cardiomyopathy were possibilities that should have been pursued further. The other areas were cancer, infection, alcohol, possible suicide, perioperative deaths and epilepsy. The following subsections specifically discuss three of these specific areas: 1) heart disease, 2) epilepsy and 3) perioperative deaths.

Heart disease

Many of the cardiomyopathies are inherited (research progressively reveals genetic linkages in these conditions), and families may be screened when an index case is diagnosed. There is increasing concern over the apparent increase in incidence of unexpected sudden cardiac deaths (sudden adult death syndrome (SADS), which is a label for this group of heterogeneous underlying cardiovascular pathologies), where coronary artery atheroma, valvular disease and hypertension are not the underlying pathologies. One obvious potential cause for the 'increase' is that the diagnoses were not being made at autopsy previously, but instead another cause of death offered (pathologists have traditionally not liked to be seen unable to provide a positive cause of death, and in many cases of SADS, the diagnosis is made because exhaustive studies have revealed no positive findings).

Sudden unexpected cardiac deaths suspected to be related to cardiomyopathy and arrhythmias are included in the Department of Health's National Service Framework on Coronary Heart Disease[30], as part of the increasing awareness of SADS and to enable families who have suffered fatalities to be screened for the possibility of heart disease in asymptomatic members. Chapter 8 of this framework refers to cardiomyopathy and arrhythmia and makes reference to the RCPath best practice scenario[24]. Thus it is critical that all such potential cases that present as sudden unexpected death are properly investigated, in order to confirm another non-SADS diagnosis or to provide evidence for a SADS death. The RCPath's best practice scenarios include the protocols that should be followed in such cases[24].

Case study 17 illustrates a case where SADS could have been considered.

Case study 17

A teenager was found dead at home. The given medical history was of "headaches, fainting, ?epilepsy, ?atrial fibrillation". The pathologist had added in the history that the cause of the fits was never discovered. At autopsy, the heart was noted to be 244g, with pericardial effusion, congested myocardium, normal valves and coronary arteries. The lungs were oedematous. The brain was congested but healthy. The comment was "Death consistent with natural causes. No toxicology or organs retained". No histopathology samples were retained either.

The cause of death was given as:
1a. Acute pulmonary oedema
1b. Chronic atrial fibrillation

The advisors considered this examination and evaluation unacceptable. The underlying diagnosis offered is not one that, unqualified, could occur in an adolescent. A cardiac abnormality is a distinct possibility, which might be inheritable, and deserves proper examination, possibly with the involvement of a specialist cardiac pathologist. Another

possibility is sudden unexpected death related to epilepsy which could be considered if all other investigations proved negative.

Recommendation

Sudden unexpected deaths suspected to be related to cardiomyopathy and arrhythmias (i.e. SADS) should be investigated according to best practice autopsy guidelines.

Epilepsy

In the study sample there were seven cases who, from the history, were known to suffer from epilepsy. In two cases, epilepsy was mentioned in the autopsy cause of death. As with SADS (above) there is concern that deaths in such patients are imperfectly evaluated in order to establish whether or not epilepsy played a role in their deaths[31]. Of particular concern are those who die suddenly and unexpectedly, where an epileptic seizure - indirectly affecting the heart - can be the cause of death. These patients require careful examination of all the internal organs, with histology, neuropathology and usually toxicological analysis of blood levels of anti-epileptic medication, in order to provide the best possible explanation of what happened. Whilst only a minority of brain examinations in patients dying of or with epilepsy reveal significant and specific lesions (abnormalities) that inform on the pathogenesis of the disease in each case, these examinations should be performed routinely. Positive and negative information is important both to evaluation of the cause of death and to help families come to terms with an epilepsy fatality. A significant neuropathological finding may also prompt clinical examination of other members of the family. The RCPath has published a best practice scenario on the autopsy examination of those with known or suspected epilepsy[24].

The seven cases included a child aged under 10 years, a teenager, and the rest were adults over 50 years. All died at home or in the community, and in all it was a sudden collapse with or without an observed seizure. In one case, there was a careful gross examination, including the brain, with reference to a known pre-mortem diagnosis of Lewy body dementia with epilepsy, and the cause of death was given as those diagnoses.

Four of the reports gave the cause of death as ischaemic heart disease or hypertension, based on varying degrees of coronary artery disease and myocardial scarring or hypertrophy. In two of the cases the brain was not examined at all and in the other two it was grossly normal, and no samples were taken.

Two case studies (18 and 19) illustrate the problems of the proper analysis of possible epilepsy deaths. The second case study also highlights a problem that is inherent in this type of autopsy review study, which depends solely on paper records taken at a fixed point in time.

Case study 18

A teenager who was receiving treatment for epilepsy, had no other known illnesses, was found dead in bed one morning. The brain was described as congested and mildly swollen and the heart (385g) was dilated and mildly hypertrophied in association with a narrow aortic valve ring (measured as 5.4cm). No histology or toxicology samples were

taken. The comment made was "Death was due to natural causes".

The cause of death was given as:
1a. Pulmonary oedema
1b. Epilepsy
2. Aortic stenosis

The advisors considered this poor because there was no proper histological examination of the brain to better categorise the epilepsy and its consequences; nor of the heart to determine how severe the valve disease was or to exclude other cardiac lesions; nor any toxicology analysis of the blood to determine whether the patient had been taking the anti-epileptic therapy correctly.

Case study 19

A middle-aged known epileptic with a history of a previous myocardial infarction aged 35, was found dead on a settee. There was evidence of vomit and scalp and facial bruising. At autopsy a skull fracture was identified and a subdural haemorrhage had compressed the brain, which had cortical surface contusions. The heart was enlarged and showed old scarring.

No toxicology samples appear to have been taken, but there was histological confirmation of lung oedema. The autopsy report contained no clinicopathological correlation and the cause of death was given as:

1a. Intracranial bleed
1b. Head injury

Epilepsy was not mentioned, apart from in the history.

The problem in assessing such a case is the likelihood that it will go to inquest and more death scenario information provided then. Questions could be asked about the likelihood that epilepsy prompted the evident injuries, and about the recent pattern of the patient's epilepsy and its management, whether the cardiac problem might have precipitated a traumatic fall - and also about the possibility of third party involvement in the death. If the autopsy report as presented were, in contrast, to be the final word on the case, then the advisors considered it to be grossly deficient because it did not give consideration to all the relevant possibilities.

Recommendation

Deaths suspected to be related to epilepsy should be investigated properly, according to the Department of Health National Service Framework for Mental Health action plan: "Improving services for people with epilepsy".

Perioperative deaths

In the study there were several perioperative deaths, a topic on which the previous NCEPOD

reports summarised in the Introduction to this report have concentrated. The autopsies, judging from the reports, were evaluated to variable standards, as has been noted previously. In 10 cases, significant operations were not included in the cause of death statements. Case studies 20 and 21 illustrate the range the advisors observed.

Case study 20

A middle-aged patient was admitted to hospital for re-exploration of a right arterio-venous fistula, but died shortly after the procedure from intra-abdominal bleeding. The detailed clinical history from the coroner was not given in the autopsy report.

At autopsy there was no reference to the operation site although the internal examination of the abdomen showed "extensive extravasation of blood throughout the root of the mesentery". There was no mention of the fistula site at all. Other internal findings included "Large arteries shows severe calcific change with atheroma involving the main vessel generally and particularly the thoracic abdominal aorta".

The comment was "The cause of death is extensive intra-abdominal bleeding which appears to relate to the fistula site" and the cause of death was given as:
1a. Intra-abdominal bleeding
1b. Leakage from fistula site
1c. Widespread arterial disease with severe calcific atherosclerosis

Overall the advisor deemed the external and internal organ descriptions to be unsatisfactory. The advisor commented that the autopsy report did not bear any resemblance to the clinical circumstances and findings and marked the overall quality of the report as unacceptable. Also the operation was not indicated in the cause of death sequence, where it should be.

In contrast, Case study 21 illustrates a well evaluated case of perioperative death.

Case study 21

A middle-aged patient with a history of cirrhosis, underwent surgery for a pelvic abscess, and unfortunately suffered a perforation of the bowel. This necessitated re-operation but the patient died subsequently of sepsis.

The autopsy found that the cirrhosis was not grossly evident, there was peritonitis, and also a tumour of the sigmoid colon. Histopathology was taken. The cause of death was given as:
1a. Multiple organ failure
1b. Septic shock
1c. Perforation of the small intestine following surgery for pelvic abscess
2. Adenocarcinoma of the colon. Cirrhosis of the liver

There was a good clinicopathological correlation, noting that the cirrhosis was confirmed and how it contributed to the mortality of peritonitis.

Case study 22 illustrates a case of perioperative death where the conclusion of the autopsy shows - in the advisors' view - a short-sighted approach to the cause of death.

Case study 22

The history provided following the death of an elderly patient was, "In hospital for elective removal of ureteric stent and developed unknown post-op sepsis with multi-organ failure. There is no significant past medical history. The death was not suspicious".

The autopsy noted a laparotomy wound. The heart "showed ischaemic myocardium, otherwise unremarkable. Valves unremarkable. Coronary arteries triple vessel disease with severe atherosclerosis" The urogenital system "Kidneys showed general pallor and left hydronephrosis with PUJ [pelvi-ureteric junction] stricture, otherwise unremarkable. Ureters showed left hydroureter and stent in situ. Bladder was unremarkable". Other organs were reported as normal and the comment in the report was "Death is consistent with natural causes. There were no tissue or organs retained". There was no clinicopathological summary.
Cause of death: 1a. Coronary artery disease

The advisor marked the autopsy report as unacceptable as it did not address the multi-organ failure, clinical sepsis or the recent operation and how the death related to it. Also there were no organ weights and the comment about "ischaemic myocardium" in case study 7 could be repeated here.

The recommendation that has been the key point for previous NCEPOD reports when discussing the examination of patients who have died during or after surgical procedures is repeated.

Recommendation

Deaths following medical interventions and complications require detailed investigation and consideration, and should not be summarised merely as (e.g) 'ischaemic heart disease' or other underlying comorbidity. If the procedure contributed to the death, then this should be indicated in the cause of death sequence.

Other areas of concern including inappropriate causes of death

In their overall assessment of the quality of autopsy reports, the advisors made many heterogeneous observations, noting the excellence of some reports and highlighting deficiencies of others. Among the particular deficiencies that stood out were:

- 18 cases where there might have been foul play, third party involvement or another type of unnatural death that had not been indicated in the report;
- 11 cases where possible industrial injury, mostly to the lungs, had been insufficiently evaluated;
- 10 cases where an evident or possible malignant tumour was not investigated or included in the cause of death statement;
- 17 cases where significant infection was felt to be the cause of death (including three with likely MRSA infection) and were not properly investigated;

- 16 cases where alcohol was considered to be a major undeclared factor in causing death;
- 83 cases where the brain was not examined and should have been;
- One case in which the possibility of suicide appeared not to have been considered by the pathologist.