Autopsies in Children

Are They Still Useful?

Praveen Kumar, MD; Jerome Taxy, MD; Denise B. Angst, DNSc; Henry H. Mangurten, MD

Background: Autopsy has traditionally been the criterion for determining cause of death and has played a major role in medical education and quality control. With increasing use of bedside technology, however, autopsy rates have steadily declined.

Objective: To identify (1) trends in pediatric autopsy rates during the past decade, (2) concordance between antemortem and postmortem diagnoses, and (3) patient characteristics influencing autopsy rates or diagnostic yield.

Methods: All pediatric deaths between January 1, 1984, and December 31, 1993, were retrospectively reviewed. Data collection included demographics for all patients, and length of stay, diagnostic imaging studies, antemortem diagnoses, and autopsy findings for patients with autopsies. Autopsy diagnoses were compared with antemortem findings and classified according to their concordance.

Results: Of 297 pediatric deaths, autopsies were performed on 107 patients (36%). Autopsy rates did not change significantly during the study period. Autopsies were not associated with patient gender, race, or insurance status, but increased significantly with age. Autopsies were performed in 26% of infants 12 months or younger, 60% of children between 13 to 60 months of age, and 100% of children 61 months or older ($\chi^2$; $P < .001$). In 34% of cases, new diagnoses were made at autopsy, including 7 cases where new findings, if known before death, would likely have resulted in a change in treatment or improved survival. There was no relationship between new findings at autopsy and age, length of hospital stay, or antemortem imaging studies.

Conclusions: Autopsy can provide additional information in more than one third of pediatric deaths. Pediatric autopsy continues to provide clinically significant data and remains a valuable tool in modern pediatric practice.


Editor's Note: This study is especially for those of you who thought autopsies were a dead issue. It would be interesting to combine the “new diagnosis” data from a number of centers to evaluate trends and possible altered diagnostic tests.

Catherine D. DeAngelis, MD

From the Department of Pediatrics, Lutheran General Children’s Hospital (Drs Kumar, Angst, and Mangurten), and the Department of Pathology, Lutheran General Hospital (Dr Taxy), Park Ridge, Ill. Dr Kumar is currently a staff neonatologist at Northwestern Memorial Hospital, Chicago, Ill.

Autopsy has traditionally been considered the criterion for determining the cause of death and has played a major role in medical education and evaluating the quality of medical care. In the pediatric population, autopsies may also help guide genetic counseling and assist grieving families. However, there has been a steady decline in adult autopsy rates in the United States from 50% in 1950 to 11.5% in 1992. This decline has been attributed to difficulties in obtaining consents, reduced reimbursement, and a loss of interest by both clinicians and pathologists, related to advances in diagnostic and imaging techniques.

A number of studies in both the adult and pediatric literature have highlighted the importance of autopsies in providing valuable information. Studies in adults have found that approximately 10% of autopsies revealed new major diagnoses that, if known before death, would probably have led to a change in management that might have resulted in cure or prolonged survival. Pediatric studies have yielded similar findings, and have provided valuable information that has led to improved clinical practice. For example, autopsy studies of children with malignant neoplasms have led to increased awareness of the prevalence of fungal infections in these patients and to a better understanding of the toxic effects of various chemotherapeutic agents. However, most pediatric studies have focused on discrete populations such as neonates, chil-
METHODS

This study was conducted at Lutheran General Children's Hospital, Park Ridge, Ill, and was approved by the institutional review board. Lutheran General Children's Hospital is a tertiary care hospital with freestanding pediatric residency and fellowship programs. It has a large pediatric referral base that is supported by an array of more than 40 medical and surgical pediatric subspecialists. The hospital is a level III pediatric trauma center and offers a wide spectrum of pediatric services, including extracorporeal membrane oxygenation and open heart surgery for infants and children with complex congenital heart disease. The inpatient facilities include a 9-bed pediatric intensive care unit, a 46-bed neonatal intensive care unit, and 43 inpatient beds for children and adolescents up to 18 years of age. Pediatric outpatient services include primary care and a variety of subspecialty and multidisciplinary clinics.

The present study examined all pediatric inpatient deaths, outside the neonatal intensive care unit, between January 1, 1984, and December 31, 1993. Neonatal intensive care unit deaths during the same period were analyzed separately. For all cases, demographic data were collected through the hospital's computer database and included patient age, gender, race, and insurance status. For patients with autopsies, medical records and autopsy reports were reviewed and additional data were collected on length of stay, antemortem imaging studies, antemortem diagnoses, and autopsy findings. Antemortem imaging studies included ultrasound, echocardiography, and computed tomographic scans.

All autopsies were performed after obtaining informed consent from parents. Autopsy examinations were done at no charge to families and included review of clinical records; anthropometric measurements; external gross examination; examination of the brain and organs of thoracic, abdominal, and pelvic cavities; and recorded weight and microscopic examination of organs. Aerobic and anaerobic bacterial cultures and viral cultures were obtained selectively when indicated by history or findings.

Antemortem diagnoses included all diagnoses listed by the physician on the death certificate before autopsy and all diagnoses in the medical record that either had been established, or appeared sufficiently likely for specific treatment to have been instituted, before death. According to the criteria of Goldman et al, diagnoses were classified as either major or minor. A major diagnosis was defined as the basic underlying disease that was the primary cause of death. The primary cause of death referred to that process that was the direct cause of death, and excluded terminal events (eg, cardiac arrest). Minor diagnoses were defined as conditions that may or may not have contributed to death, and may or may not have been related to the primary disease process.

PATIENT 1

A 16-year-old girl with glioblastoma multiforme of the midbrain and spinal cord died secondary to respiratory failure due to direct extension of the tumor to the respiratory centers in the brainstem. She also developed bronchopneumonia before her death. In this case, glioblastoma multiforme was the major diagnosis and primary cause of death; bronchopneumonia was a minor diagnosis that contributed to the patient's outcome.

PATIENT 2

A 3-month-old male infant died as a result of respiratory failure secondary to extensive bronchopneumonia with bilateral pneumothoraces. Autopsy confirmed clinical diagnoses and identified the presence of a small atrial septal defect and a horseshoe kidney. In this case, bronchopneumonia was the major diagnosis; atrial septal defect and horseshoe kidney were minor diagnoses.

Autopsy diagnoses, including histological and microbiologic results, were obtained from the final autopsy report. Autopsy reports and medical records of all patients with autopsy were reviewed by 1 of us (P.K.). Subspecialists were consulted as needed to verify the significance of autopsy findings and to assess their impact on clinical outcomes. Based on the classification scheme of Goldman et al, autopsy diagnoses were categorized as either major or minor, and were assigned to 1 of 5 classes used to reflect the concordance between antemortem and postmortem findings (Table 1). All cases with class I and II findings, and a representative sample of patients with class III, IV, and V findings were reviewed by 2 of us (J.T. and H.H.M.). There was complete agreement about the classification of diagnoses among the 3 reviewers.

Statistical analyses were conducted using the Statistical Package for Social Sciences. For categorical variables, the proportion of events were compared using the χ² statistic with Yates correction. All results with a P value of less than .05 are reported as significant. Changes in autopsy rates and class V findings during the study period were evaluated with statistical process control charts (p-Charts) using the Statistical Analysis System.

RESULTS

AUTOPSY RATES

There were 297 pediatric deaths during the 10-year study period. Autopsies were performed on 107 (36%) of 297 patients. Table 2 provides the number of pediatric deaths, autopsies, and classification of autopsy findings for each study year. The number of deaths, autopsies, and class V diagnoses for each study year are shown in Figure 1. Autopsy rates did not change significantly during the study period, and exhibited only expected (ie, com-
mon cause) variation by p-Chart. There was no significant change in the autopsy rate between the first and second half of the study period. The autopsy rate for the first 5 years was 40.5%, and for the latter half of the study period it was 32% (P=.14). Autopsies were not associated with patient gender, race, or insurance status (Table 3). There was, however, a significant association between patient age and autopsy rates (P<.001). Age was analyzed by 3 categories corresponding with development: infancy (≤12 months), toddler-preschool (13-60 months), and school-age (≥61 months). Autopsies were performed in 26% (60/229) of infants 12 months or younger, 60% (31/52) of children between 13 and 60 months of age, and 100% (16/16) of patients 61 months or older (Table 3).

Further analysis of the sample characteristics of the 16 children with autopsies who were 61 months or older at the time of death revealed no statistically significant differences compared with younger patients with autopsies (Table 4). Children 61 months or older with autopsies were equally distributed across gender, were primarily white (n=14), and were principally covered by private insurance (n=12). Most of these children died more than 24 hours after admission (n=11). In this group, the major antemortem diagnoses included neoplastic disorders (n=7), infectious processes (n=5), congenital malformations (n=3), and diabetes mellitus (n=1).

**CONCORDANCE BETWEEN ANTEMORTEM AND POSTMORTEM DIAGNOSES**

In 34% (36/107) of the patients with autopsies, a new diagnosis was made at autopsy (classes I-IV). In the remaining 66% of patients, there was complete concordance between antemortem and postmortem diagnoses (class V). Table 2 provides the number of patients in each class of autopsy findings for each study year. During the 10-year study period, 7 patients (6.5%) with autopsy had class I findings, indicating that significant new findings were revealed at autopsy. Two of these patients also had one class III and one class IV finding. Table 5 describes these patients and their antemortem and postmortem findings.

Classes II, III, and IV findings were observed at autopsy in 29 patients (27%). Class II findings were identified in 7 patients (6.5%), including 2 patients who each had a class III finding. Class II findings included infection (n=2), postoperative myocardial infarction (n=2), infarcted volvulus (n=1), metabolic disorder (n=1), and alveolar hemorrhage (n=1). These 7 patients with class II findings could be further classified into subclasses IIb (n=4), IIC (n=2), and IId (n=1) (Table 1). Twelve patients exhibited class III findings at autopsy and 9 patients evidenced class IV findings.

**CLINICAL CHARACTERISTICS OF PATIENTS WITH AUTOPSIES**

Of patients with autopsies, 12 patients died within 6 hours of admission, 23 patients died between 7 and 24 hours of admission, and 72 patients died more than 24 hours after admission (Table 2). Eighty-nine patients (83%) had at least 1 antemortem imaging study. Fifty-nine patients

---

### Table 1. Classification of Autopsy Diagnoses and Findings*

<table>
<thead>
<tr>
<th>Class</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>I</td>
<td>A diagnosis that had it been detected before death, would probably have led to a change in management that might have resulted in cure or prolonged survival.</td>
</tr>
<tr>
<td>II</td>
<td>A diagnosis that had it been detected before death, would probably not have led to a change in management or survival for the following reasons: (a) No appropriate therapy was available at the time. (b) Appropriate therapy was given even though the diagnosis was unknown at the time. (c) The patient suffered an acute cardiopulmonary arrest that was appropriately managed but did not survive for definitive management. (d) The patient had “do not resuscitate” status.</td>
</tr>
<tr>
<td>III</td>
<td>A diagnosis unrelated to the outcome and that may or may not have affected the eventual prognosis of the patient.</td>
</tr>
<tr>
<td>IV</td>
<td>A diagnosis that had it been detected before death, would probably not have led to a change in management or survival.</td>
</tr>
<tr>
<td>V</td>
<td>Complete concordance between antemortem diagnoses and autopsy findings.</td>
</tr>
</tbody>
</table>

*Based on the classification scheme developed by Goldman et al.1

---

### Table 2. Number of Pediatric Deaths and Autopsies, Classification of Autopsy Findings, and Patient Characteristics

<table>
<thead>
<tr>
<th>Year</th>
<th>Total No. of Deaths</th>
<th>Total No. of Autopsies (%)</th>
<th>Class of Autopsy Findings</th>
<th>Admission-Death Interval, h</th>
<th>No. of Patients With Antemortem Studies</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td>I II III IV V</td>
<td>≤6  7-24 &gt;24</td>
<td></td>
</tr>
<tr>
<td>1984</td>
<td>27</td>
<td>12 (44)</td>
<td>0 1 1 2 8 3 3 6 8</td>
<td>8</td>
<td></td>
</tr>
<tr>
<td>1985</td>
<td>36</td>
<td>15 (42)</td>
<td>2 1 2 1 9 2 4 9 13</td>
<td></td>
<td></td>
</tr>
<tr>
<td>1986</td>
<td>16</td>
<td>6 (38)</td>
<td>2 0 1 0 3 0 0 6 5</td>
<td>5</td>
<td></td>
</tr>
<tr>
<td>1987</td>
<td>37</td>
<td>12 (32)</td>
<td>0 0 2 1 9 1 3 8 11</td>
<td></td>
<td></td>
</tr>
<tr>
<td>1988</td>
<td>27</td>
<td>13 (48)</td>
<td>1 1 1 1 9 3 1 9 12</td>
<td></td>
<td></td>
</tr>
<tr>
<td>1989</td>
<td>25</td>
<td>10 (40)</td>
<td>0 1 0 1 8 0 3 7 8</td>
<td>8</td>
<td></td>
</tr>
<tr>
<td>1990</td>
<td>41</td>
<td>15 (37)</td>
<td>1 1 4 1 8 1 6 8 11</td>
<td></td>
<td></td>
</tr>
<tr>
<td>1991</td>
<td>38</td>
<td>8 (21)</td>
<td>0 1 0 0 7 0 1 7 8</td>
<td>8</td>
<td></td>
</tr>
<tr>
<td>1992</td>
<td>24</td>
<td>6 (25)</td>
<td>1 1 0 0 4 1 1 4 5</td>
<td>5</td>
<td></td>
</tr>
<tr>
<td>1993</td>
<td>26</td>
<td>10 (38)</td>
<td>0 0 2 2 6 1 1 8 8</td>
<td>8</td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td>297</td>
<td>107</td>
<td>7 7 13 9 71 12 23 72 89 89</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
had a single study, 29 had 2 studies, and 1 patient had all 3 studies (Table 2). There was no statistically significant relationship between either the admission-death interval or the use of antemortem imaging studies and the incidence of new major (classes I and II) or minor findings (classes III and IV) on autopsy.

In patients with autopsy, major antemortem diagnoses (principal underlying diseases and primary cause of death) most commonly involved the cardiovascular system (n=50), central nervous system (n=25), respiratory system (n=18), gastrointestinal system (n=14), and genitourinary system (n=6) (Figure 2, top). The most common antemortem findings included congenital malformations (n=49), infectious processes (n=29), neoplastic disorders (n=11), and vascular accidents (n=8) (Figure 2, bottom). New diagnoses established at autopsy involved the cardiovascular system in 13 patients, respiratory tract and genitourinary systems in 9 patients each, gastrointestinal tract system in 7 patients, and central nervous system in 5 patients (Figure 3, top). The majority of unexpected autopsy findings included undiagnosed congenital malformations, infection, and vascular accidents such as hemorrhage, thrombosis, and infarctions (Figure 3, bottom).

**COMMENT**

Although autopsies were once considered to be critical to medical education, clinical practice, and quality assurance, current declines in adult autopsy rates are well documented.1,3,7,16 Adult autopsy rates in US hospitals have declined from about 50% in the 1950s to an estimated...
10% to 15% in the 1990s. In Sweden, autopsy rates declined from 80% to 39% during a 10-year period. There is little information, however, on changes in the rates of pediatric autopsy. No previous studies within a single institution have examined general pediatric autopsy rates over an extended period.

In our study, autopsies were obtained in 36% of all pediatric deaths without significant change during the 10-year study period. This autopsy rate is similar to the 40% pediatric autopsy rate reported by Kay et al from Ohio and a little higher than the 26% rate reported by Stambouly et al from New York. Our autopsy rate, however, is significantly lower than the pediatric autopsy rates reported in other developed countries during the same period. In Australia (1982-1991), Koszyca et al reported an autopsy rate of 75.4% for nononcology patients at a children's hospital. Similarly, in Canada (1985-1989), Whitehouse et al reported a 75% autopsy rate at a children's hospital. We speculate that the lower rates of pediatric autopsy observed in the United States may be related to financial constraints and fears of malpractice litigation; however, this merits further investigation.

In general, declining autopsy rates have been attributed to various factors, including elimination of autopsy requirements by the Joint Commission on the Accreditation of Healthcare Organizations, a lack of interest in autopsies among clinicians and pathologists based on the belief that advances in antemortem diagnostic procedures have reduced the value of autopsy, and the lack of direct reimbursement for performing autopsies. The importance of the reimbursement factor depends on how autopsies are indirectly reimbursed, if at all, by the hospital to the pathologist. In our own institution, an audit of recent records demonstrated a cost to the hospital of $1456 per pediatric case, including labor, materials and indirect costs, but excluding a professional (physician) component. A detailed discussion of the reimbursement issue is beyond the scope of this article. Still, at a time of diminishing resources in health care, future studies of autopsies need to address the issue of financial reimbursement. In order that limited resources be best spent, attempts have been made to identify patients in whom autopsies would yield the most value. Predicting these high-yield cases, however, can be difficult. In a study of 233 adult autopsies, neither the authors nor the patient’s physicians were able to accurately identify, based on clinical data, patients with high yield on autopsy. In another study of 100 adults, there was no relationship between length of stay in the intensive care unit and diagnostic discrepancies at autopsy. Similarly, in a study of 50 pediatric autopsies, there was no relationship between new findings at autopsy and either the patient's age or length of stay. The results of our study are consistent with these observations. In our study, there was no association between new findings at autopsy and patient age, length of stay, or antemortem imaging studies.

Rates of autopsy, however, may be influenced by patient characteristics. In the present study, although autopsy rates were unrelated to gender, race, or insurance status, autopsies were significantly related to the child’s age (P<.05). Autopsies were more common in older chil-
children and occurred in 100% of children 61 months or older (n = 16). This higher autopsy rate among older children was somewhat surprising to us. Our presumption, based on another study of autopsy among neonates, was that the autopsy rates for infants might be higher than that for older children. The higher autopsy rates we observed in older children may reflect greater parent willingness to consent to autopsy based on a number of potential factors: a longer illness course, a closer relationship between the family and the treating physician, and increased understanding of the importance of autopsy. Most previous studies of pediatric autopsy have not examined whether there is a relationship between the child’s age and autopsy. In the only other pediatric study evaluating the relationship between patient characteristics and consent for autopsy, Whitehouse et al did not observe any relationship between the child’s age and autopsy rates. Further study is needed to determine those factors that influence pediatric autopsy rates and to explore the relationship between the child’s age and pediatric autopsies.

It is clear from this and other studies that autopsies continue to provide clinically significant information. In adults, previous studies have found significant major findings (class I) in approximately 10% of the cases. Similar research has documented the value of autopsies in children. In children with congenital heart disease, autopsies revealed new information in 60% of the cases, and major diagnoses in 6%. In children with leukemia, autopsies revealed new information in 49% of the cases and major diagnoses in 16%. In the present study, which focused on a more general pediatric population, autopsy continued to be an extremely valuable tool. Autopsy provided additional information in 34% of pediatric deaths, and revealed new major pathological findings (classes I and II) in 13%. Our results are comparable to the 33% yield at autopsy, reported by Whitehouse et al, although none of their patients had class I findings. Stambouly et al documented additional findings in 74% of pediatric deaths, including class I findings in 10% of their study patients. The results of our study reinforce that pediatric autopsy, despite the use of modern antemortem diagnostic methods, continues to provide valuable information, including findings that if known prior to death may have resulted in improved survival.

We also believe that autopsies have several other benefits, not directly addressed by the present study, such as medical education, quality assurance, and family counseling. Even an autopsy without new or unexpected findings can be of great assistance to the family in answering questions surrounding the death of a child, particularly those questions about missed diagnoses or the appropriateness of clinical management. An autopsy can also help clinicians answer these questions, clarify misconceptions, and allay unwarranted feelings of guilt in the family and health care team. Thus, the results of our study emphasize the value of autopsy as an integral component of modern pediatric practice. Further efforts should be aimed at increasing autopsy rates through education of clinicians and pathologists, improved funding for autopsies, and systematic monitoring of the concordance between antemortem and postmortem diagnoses as a mechanism for quality assurance.

Accepted for publication December 18, 1997.

Presented in part as a poster at the Society for Pediatric Research Meeting, Washington, DC, May 6-10, 1996.

We acknowledge the assistance of Sandy Maik in the preparation of the manuscript, Pam Lantz for assistance with p-Charts, and Ken Scholz, PhD, for assistance with graphic displays.

Reprints: Denise B. Angst, DNSc, Lutheran General Children’s Hospital, 1775 Dempster St, Box 296, Park Ridge, IL 60068 (e-mail: denise.angst@advocatehealth.com).

REFERENCES


©1998 American Medical Association. All rights reserved.