

PAPER**PATHOLOGY AND BIOLOGY**

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A Policy for the Retention and Extended Examination of Organs at Autopsy*

ABSTRACT: Recent organ retention scandals and law suits have created a focus on the practice of saving postmortem tissues for extended examination or research purposes. The New Mexico Office of the Medical Investigator (OMI) established a policy to notify families about organ retention and the subsequent disposition of the tissue. The OMI examined the success of this policy in regards to the retention of brains for extended examination by analyzing data abstracted from verbal consent forms from 2003 to 2006. During this time, 715 cases were identified as needing an extended examination of the brain. The percentages of brains saved in any given year, as a percent of the total number of autopsies performed that year, were: 2003 6.5%, 2004 10.4%, and 2005 11.8%. The disposition was cremation in 79% of cases, release with the body after a determined period of time in 14%, and cut fresh in 4%. In conclusion, the instigation of a policy on the verbal notification of the next of kin when organs are retained can be successfully implemented.

KEYWORDS: forensic science, brain, organ retention, extended examination

Recent organ retention scandals, both in the United States and internationally, have focused public attention on the practice of saving tissues for extended examination or research purposes. Not infrequently, pathologists wish to keep entire organs for maximal formalin fixation, consultation with a specialist, or to keep as archival materials for teaching purposes. These practices are most pertinent in the examination of hearts and brains. Retention of entire organs is distinct from tissue samples kept in "stock jars," paraffin blocks, and laboratory specimens. Retention of organs at the discretion of the pathologist is the standard of practice in autopsy pathology and has been legally based upon state statutes and consent provided within autopsy permits.

In the United Kingdom, a large scandal ensued in 2000 after the discovery that doctors routinely removed and stored the organs of children as part of autopsy examinations. This resulted in dramatic reports in the media and even in the medical literature. For example, one author in *The Lancet* commented, "It was discovered that thousands of organs and body parts of babies and children had been stored after postmortem examination. (T)he scale of this unused and apparently wanton hoarding shocked the local population" (1). Not surprisingly, there was a resultant outcry from the public and incredible outrage and dismay from the parents of the decedents.

As a result, Burton and Underwood noted, "Necropsies have never been under as much scrutiny from the public, the media, the government, and the medical profession" (2). This scrutiny is particularly disconcerting given the worldwide decline in autopsy rates (3). Various studies have looked at the autopsy rates in the U.K. in the wake of these scandals and found that the controversy contributed, in part, to the continued decline in hospital autopsies (2,3).

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Long held as being within the purview of the pathologist to decide which tissues must be retained for a complete and thorough examination, this recent public scrutiny and legislation has mandated that pathologists rethink current protocols. In the U.K., the organ retention scandals were the impetus for the creation of the Human Tissue Act of 2004, which details the conditions of and protocols for the retention of tissues and organs after postmortem examination (4). However, no such nationwide legal movement has occurred in the United States, and coroners and medical examiners have faced an array of lawsuits and varied local government reactions to the retention of organs (5,6).

These controversies are particularly pertinent to the examination of the brain. Brains require special, lengthy fixation in order to maximize the diagnostic yield. Prolonged fixation and examination of the brain by or in conjunction with a neuropathologist has been shown to greatly enhance the detection of subtle neuropathologic findings (7). In many intracranial causes of death, such as seizure disorders and neurodegenerative diseases, the findings may be very subtle grossly and are only appreciated with examination of carefully and accurately selected microscopic sections (7,8). However, keeping a brain for 2–3 weeks for an examination means either releasing the body without the brain or delaying the release of the body for a very lengthy period. So, in the past, and for many offices currently, the method of choice is to release the body without the brain.

In 2001, the Office of the Medical Investigator (OMI) in Albuquerque, NM had two cases in which families were informed that complete organs had been kept for extended examination after a significant period of time had passed since the release of the body. Both of these cases resulted in the returning of the organs to the families in unorthodox procedures and significant stress was placed upon the families and the office staff. This sparked the development in 2002 of a standardized protocol for the verbal notification of next of kin via telephone on the day of an autopsy exam when it is determined that an extended neuropathologic exam is necessary.

With the recent legal maneuvers in various states regarding the subject of organ retention and the lack of a national standard, we sought to examine this office's success with verbal notification of brain retention as a reflection of our office's policy regarding the retention of any organ.

Methods

A formal protocol for the verbal notification of the next of kin in cases where extended examination of organs is necessary was enacted at the OMI in 2002. Which cases require retention of the brain for extended examination is not dictated by the policy and is completely at the discretion of the pathologist. Prior to 2004, the brains for hospital and family consult cases were retained without notification, because implicit consent was given in the autopsy consent form. However, in 2004, the verbal notification policy was extended to include all autopsies. In cases where the pathologist deems the retention necessary for a full investigation, such as in homicides or child abuse cases, the next of kin are not asked their opinion as to the extended examination, but are instead merely notified that the brain is being retained for further examination and are consulted on their preferred disposition of the tissue after the examination.

Options given to the family for the disposition of the brain include: (i) immediate release of the body and extended examination of the brain with standard cremation of remaining tissue; (ii) immediate release of the body and extended examination of the brain with release of the tissue to the funeral home; (iii) delay of body release until after a variable (24 h to 2 weeks) of formalin fixation of the brain and return of tissue to the body after examination; or (iv) immediate, fresh examination of the brain, return to the body, and release of the body. The notification process and verbal consent, when appropriate, is documented on a "brain sheet" that is filled out by the pathologist and indicates who was called, the desired outcome, the cause and manner of death, and the importance of the extended examination.

After notification, the brain is suspended in 20% formalin for *c.* 2 weeks. The brain is then rinsed and cut at a weekly neuropathology conference with the forensic pathology fellow, resident, or attending that performed the autopsy and a neuropathologist.

Brain sheets from January 2003 until July 2006 were collected, and all of the available data were extracted. An example of the brain sheet is provided in Fig. 1. Information gathered from the brain sheets included the putative reason for the extended examination, whether the cause and manner of death were known at the time of the contact, the agreed upon disposition of the brain after examination, the time frame the brain was kept if it was to be returned to the body, who was contacted as the next of kin, the number of attempts required to contact that person, and the race and age of the decedent. The files were then reviewed on all of the cases in order to extract the final cause and manner of death.

In addition, for 2005–2006, the lists of all of the brains examined at the weekly neuropathology conference were compared with the brain sheets to find out how many brains were kept but were missing the required paperwork. In order to examine the standardization of the decision of whether or not a brain is kept for extended examination, the OMI database was searched for all cases with a seizure disorder listed as the cause of death or as a pathologic diagnosis during 2005.

All data were entered into an Excel spreadsheet, then analyzed using SAS version 9.1 (SAS Institute, Inc., Cary, NC). Categorical variables were compared using chi-square tests or Fisher exact tests and continuous variables were analyzed using Wilcoxon rank-sum

tests. *p*-Values of 0.05 or less were considered statistically significant.

Results

From January 2003 to July 2006, 715 cases were identified as needing an extended examination of the brain. The mean age of the decedents whose brains were saved was 40.5 years with a median of 45 years. The distribution of ages is displayed in Fig. 2. The percentage of brains saved in any given year, as a percent of the total number of autopsies performed that year, were as follows: 2003 6.5%, 2004 10.4%, and 2005 11.8%.

The most common reasons listed for saving a brain for extended examination in order of decreasing frequency were: to identify a putative cause of death, the documentation of a known condition, the case being a hospital or consult case, to explore a condition of academic interest, and to document an obscure cause of death. Out of the 350 sheets where the question was answered, 53% indicated that the cause of death was known, and of the 343 sheets where the question was answered, 52% said the manner of death was known at the time of family contact.

The disposition agreed upon by the contacted next of kin was standard fixation and cremation in 79%, release with the body after a determined period of time in 14%, release to the funeral home in 2%, and for the organ to be cut fresh in 1% of the cases. For 1% of the cases there was another arrangement made, and the disposition was not documented in two of the cases. Examining the dispositions with respect to race, the dispositions for Native Americans, white non-Hispanics, and white Hispanics (subsequently referred to as White and Hispanic, respectively) are presented in Table 1. The percentage of brains cremated was significantly lower for Native Americans than for Whites ($p < 0.0010$) and Hispanics ($p = 0.0002$).

The number of attempts made to contact the next of kin was documented on 462 sheets (65% of total). Of those, 48% required one attempt, 17% two attempts, 10% three attempts, 6% four attempts, and 2% required five or more attempts. In addition, 17% of the cases had no attempts documented. This was primarily due to the receipt of a hospital autopsy consent form, and in these cases the next of kin was neither contacted nor documented on the brain sheet. This was only possible in cases from 2003 and early 2004. The next of kin was examined on all 715 cases. Most commonly, the next of kin was a parent (32%) with spouse, child, and sibling making up another 42% of the cases. For 12% of the cases, the next of kin was not documented due to the use of a hospital autopsy consent form, as discussed above. The remainder of cases had a next of kin documented as other (7%), no known next of kin (1%), or unknown (7%).

Final causes of death were obtained for all of the 715 cases. These were then grouped into related categories. The most common cause of death was natural disease, not due to intracranial disease. This made up 40% of the cases and included atherosclerotic coronary artery disease, malignancies, and pulmonary and systemic infections. Blunt force injuries of the head and neck, not including child abuse, was the next most common cause of death, making up 10% of the cases. All of the causes of death and the frequency with which they were found are listed in Table 2.

The manners of death for the 715 cases were: natural 60%, accident 21%, homicide 10%, pending 3%, undetermined 3%, suicide 2%, unknown 1%.

In order to evaluate the integrity of the data from the brain sheets, lists of the brains examined at brain cutting were compared to the brain sheets for 2005. In that year, 253 brains were cut and

TABLE 1—Disposition of brain as agreed upon with next of kin by race of decedent.

Disposition	White (%)	Hispanic (%)	Native American (%)
Cremation	277 (82)	218 (80)	31 (56)
Release with body	47 (14)	31 (11)	13 (24)
Release to funeral home	4 (1)	5 (2)	3 (5)
Cut fresh	4 (1)	15 (5)	7 (13)
Other	0	2 (1)	0
Unknown	5 (1)	2 (1)	1 (2)
Total	337	273	55

TABLE 2—Causes of death of all brains retained for extended examination during the study period.

Cause of Death	Number (%)
Natural disease without a neurologic/intracranial process	285 (40)
Blunt force injury to the head or neck, not child abuse	74 (10)
Natural intracranial disease (infection, vascular, neurologic)	64 (9)
Seizure disorder	55 (8)
Intoxication/poisoning	43 (6)
SIDS	33 (5)
IUFD/prematurity	31 (4)
Injury, not involving the head, neck, or spine (drowning, hypothermia, choking, etc.)	29 (4)
Blunt force injury to the head or neck, child abuse	25 (4)
Pending	21 (3)
Undetermined	15 (2)
Congenital anomaly	14 (2)
Injury to the head, neck, or spinal cord (quadriplegia, overlay, stabbing, etc.)	12 (2)
Gunshot wound to head or neck	7 (1)
Unknown	5 (<1)
Other	2 (<1)

Total number of cases = 715.

comments from that survey, practices in offices across the country vary widely and range from placing comments in the autopsy report that an organ was retained, returning a small portion of the organ to the body so that no organs were legally retained in full, and not utilizing any procedure at all for the notification of organ retention. Interestingly, some pathologists commented that, due to the recent controversies, they were reticent to keep any organs and did all or the majority of the examinations of all organs, including the brain, fresh.

Lengthy discussions have been generated recently regarding the necessity of keeping organs after postmortem examinations. From these discussions, the key issue arises of whether consent is necessary and, if so, then in what form and from whom should it be obtained. As pointed out by Brazier, the chair of the Retained Organs Commission in the U.K., “the complexity and obscurity of the current law will be manifest to all” (9). In this country, it had been generally accepted that a pathologist or hospital has the implicit authorization to remove organs as deemed necessary. This has now been challenged based upon an individual’s right to a decent burial and claims of emotional distress. Generally, the consent for a hospital or private autopsy was assumed to give consent for the retention of tissues as needed for a complete examination. However, medicolegal autopsies are performed under the medical examiner or coroner state statutes, and thus authorization is not on the basis of consent of the next of kin. While some state statutes specifically provide for the retention and disposition of organs, most do not.

In the case of consented autopsies, it has recently been asserted that rather than simply ensuring that there are no objections, the

pathologist must receive actual authorization to keep such organs (10). This consent has been called the physicians’ “flak jacket” protecting them from legal shrapnel (9). The current controversy arises from how to best obtain that consent.

The second key factor that has arisen recently is the emotional harm that is done to families when they find out after a burial or cremation that organs were retained. Brazier comments,

The injury done to a family whose religion requires burial of the body intact, or cremation of every speck of bodily material, when organs are taken without their permission is a violation of religious freedom. It is not just that. It harms the surviving relatives, whose ability to work through the gradual process of bereavement is impaired. They believe that they have (albeit through no conscious act of theirs) let that relative down. They failed to safeguard his and their fundamental values. The injury done to families whose personal values require burial or cremation is no different (9).

It appears that the procurement of explicit consent to retain organs, while a variation from the historical practice of the post-mortem examination, serves to protect both the physician and the relatives of the deceased. However, concern arises over the possible hurdles faced by pathologists and coroners in the procurement of that consent.

The current study addresses only the retention of entire brains as an indicator of the success of policy for the notification of the next of kin in the retention of any complete organ. While brains are routinely kept for extended examination, other organs are also affected. In particular, hearts are frequently kept for examination and consultation with a specialist in cardiac pathology. Usually this can be accomplished in a timely manner without significantly impacting the release of the body since prolonged fixation of the heart is not as crucial for an optimal examination. However, the hearts are only retained indefinitely for teaching and research purposes with consent of the next of kin. Of course, as with brains, in any medicolegal case where the pathologist deems the retention of an organ essential for a complete and thorough medicolegal death investigation the next of kin should be merely notified of the retention of the organ and not asked if the organ retention meets with their approval.

The results of this study reveal that a standardized protocol of notification of families about brain retention, obtaining verbal consent on appropriate cases, and documenting such notification has been successful in this state. Rather than contributing to the stress of the grieving family, numerous comments on the “brain sheets” indicated that the next of kin appreciated being involved in the decision making process and having their wishes considered. Thus, it appears that this policy helps to facilitate rapport and trust with families as well as providing an element of legal protection for the pathologist and the office.

Importantly, the implementation of this protocol does not seem to have deterred the pathologists from saving brains, as might be expected. In 2003 and part of 2004, the brains were routinely saved on all hospital and consult cases. This changed during 2004, and the pathologists began calling for consent on these cases as well. Despite this change in policy, there has been a consistent increase in the total percentage of brains saved per year from 2003 to 2005. This is likely also a reflection of the addition of a pathologist board certified in neuropathology and forensic pathology to the office in 2005.

In New Mexico, there is a large Native American population, and many tribes have traditions contrary to autopsy and organ

retention. Sensitivity to cultural beliefs was part of the impetus in the development of a more formal protocol for organ retention. In the evaluation of our data, the families of decedents of Native American race were significantly less likely to allow retention of the brain with standard cremation. However, for 57% of Native American cases, the next of kin allowed brain retention. In addition, 24% requested that the brain be released with the body and 5% for release to the funeral home after a period of fixation, potentially still allowing for a more optimized examination of the brain. Thus, a total of 86% of Native American cases had some form of extended examination, and the next of kin in only 13% demanded that the brain be cut fresh. So, it certainly behooves the pathologist to call the families on all cases.

Moreover, attempting to standardize when the brain should be preserved for further study remains an area deserving of further attention. At this time, it is completely up to the discretion of the attending pathologist, with many variables potentially affecting the decision. These include the specialty training of the pathologist, the workload of the day, and the perceived potential for family objections. Of the cases in 2005 in which the cause of death was a seizure disorder, 76% of the brains were saved. The diagnostic findings of a seizure disorder are subtle, if present at all (7), and this seems a very good example of a situation in which an optimal examination of the brain is essential to either document a seizure disorder or, in the absence of any findings, exclude another etiology of the seizures or an obscure cause of death. Thus, it may be beneficial for an office to outline the conditions under which a brain should be saved, such as cases with a history of seizures, SIDS, and homicides with blunt force injuries to the head.

Our office also has the advantage of an in-house neuropathologist. There is a neuropathology conference every week where all of the saved brains are examined grossly by the neuropathologist. However, even in the absence of a neuropathologist, a well-preserved brain still allows the general or forensic pathologist to more accurately select sections for microscopy or ancillary testing, improves the quality of histology, provides opportunities for photography and enhanced documentation of pathologic findings, and may create a greater opportunity for clinician involvement and the education of clinicians, pathology trainees, and medical students. Forensic pathology fellows, attending forensic pathologists, neuroradiologists, neurologists, neurosurgeons, psychiatrists, and other trainees and students on the autopsy rotation, regularly attend the Gross Neuropathology Conference at this office. Last, keeping the brain may be the only option that allows for complete neuropathologic consultation by a consultant neuropathologist.

This study is relatively small in scope and has some limitations. While the brain sheets appear to accurately reflect the brains that are fixed and cut at the neuropathology conference, the number of brains cut fresh after the family denies fixation may be underrepresented. There is no reliable way to confirm these numbers. Anecdotally, the 80% cremation disposition is compatible with the experiences reported verbally by the pathologists. Another difficulty with this study is the variability in the level of detail in the completed brain sheets. This indicates a need for this office to revisit the brain sheet and determine which information is essential. The current study also deals only with the retention of the entire brain. Legal and ethical issues that have arisen regarding the retention of tissues, such as portions of tissues retained in stock jars, tissue blocks, and fluids obtained for laboratory analysis are beyond the scope of this paper.

An important note is that, of course, there are always medicolegal issues that supersede this process and allow the pathologist to

determine that a relative's consent is not advisable or that a denial to retain an organ would hinder the completion of a forensic examination. This is exemplified by suspected child abuse cases where the next of kin may be the suspected perpetrator and would have ulterior motives for denying an extended examination. In such cases, many of the pathologists in our office elect to proceed with calling the next of kin to ask for their wishes in the disposition of the brain but do not extend an invitation to consent for or deny a complete examination. It is important to recognize the different challenges presented by forensic and medical autopsies and apply a policy for organ retention appropriately. Thus, in the current report, those cases where alternative options, such as a short fixation time or cutting of the brain fresh with prompt return of the brain to the body, were only acceptable when the pathologist deemed it appropriate.

Thus, the burden upon the pathologist is to balance the rights and expectations of the families with the responsibility to perform a comprehensive, accurate examination of the entire body and to ensure that adequate notification for most extended examinations is obtained (11). The issue of organ, tissue, and specimen retention and disposition is actively litigated in multiple states. The outcome of these lawsuits, and perhaps others to come, may have a profound impact on how components of forensic and autopsy pathology is performed. The data gathered in this project demonstrate that a formalized procedure regarding the acquisition of informed consent for the retention and disposition of organs from family members is not a deterrent to the procurement of organs for extended examinations, however. The procedure allows for the clinical judgment of the pathologist to be utilized in concert with the wishes of the next of kin and likely protects the office and the pathologist from future legal scrutiny.

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