Autopsy Consent Practice at US Teaching Hospitals

Results of a National Survey

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Background: Autopsy rates continue to fall despite the enduring benefit of the procedure to families and medical science, yet there are few data about the consent process itself.

Objective: To evaluate the current practice of obtaining autopsy consent, by assessing the consent forms currently in use, the knowledge and attitudes of chief residents on the procedure, and the expert opinion of pathologists in those institutions.

Design: Cross-sectional survey.

Settings and Participants: One hundred twenty-seven US teaching hospitals.

Results: Of all autopsy consent forms we surveyed, 84.7% contained 7 of 10 elements recommended by the College of American Pathologists. Only 7.1% of institutions supplied educational materials for the physician, as recommended by the College of American Pathologists. Overall, 50.1% of chief residents reported deficiencies in their knowledge of the autopsy procedure. Correspondingly, greater than 74.5% felt that educational materials would be beneficial for physicians and the family. Finally, 93.3% of chief residents believed that a limited autopsy should be offered to families, while 68 (90%) of 76 pathologists at these institutions believed that limited autopsies are an unsatisfactory alternative to the complete procedure.

Conclusions: Chief residents at US teaching hospitals reported substantial deficiencies in their knowledge about autopsy and desire more training on the consent process. Autopsy consent forms are often lacking information that might help physicians and families in making an educated choice about autopsy. Teaching institutions need to reevaluate the training for the autopsy consent practice.

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The autopsy, once a familiar component of medical practice, is now infrequently used. The most recent data indicate that autopsies are performed in less than 1 of 10 patient deaths in US teaching hospitals, a dramatic drop from the middle of this century, when autopsies were performed in half of all deaths. Because of budgetary constraints, the National Center for Health Statistics suspended further reporting of this statistic in 1995. Explanations that have been advanced for the decline in autopsy rate include the decision by the Joint Commission on the Accreditation of Health Care Organizations to delete a minimum autopsy rate as one of its standards for accreditation; improvements in pre-mortem diagnosis made possible by advances in medical imaging; the de-emphasis of gross anatomy as a method of teaching, research, and quality assurance by medical educators; and the lack of interest in autopsy by clinicians requesting consent. In addition, the provision of inadequate information to families at the time of autopsy consent has been proposed as a possible reason for decline.

While the rate of autopsies has fallen at US teaching hospitals (and equally so in most European nations), studies continue to substantiate the value of the procedure. Recent advances in understanding human immunodeficiency virus, sudden infant death syndrome, hantavirus, Legionnaire disease, and toxic shock syndrome, among others, have been attributed to findings made at autopsy. Moreover, the rate of unexpected but clinically significant findings at autopsy has remained stable at 22% to 33% during the past 30 years, despite advances in medical science and the increased use of sophisticated diagnostic technology.

Given the ample evidence of declining autopsy rates despite the continued benefit of the procedure to families and...
MATERIALS AND METHODS

SETTINGS

We sampled 20% of all internal medicine and pediatric residency programs in the United States. Programs were selected by enrolling the first 2 programs, for both internal medicine and pediatrics, as listed alphabetically for each state, from the 1996/1997 Directory of Graduate Medical Education Programs. The final list represented a total of 46 states that had programs for both internal medicine and pediatrics. Each of the internal medicine and pediatric programs sampled represented different institutions.

CONSENT FORM–BASED DATA

Between May 1 and June 30, 1997, we contacted by telephone the intensive care unit at each hospital to request autopsy consent forms and any associated educational materials for either families or clinicians. The consent forms were then analyzed as to whether they adhered to the CAP minimum guidelines (Table 1). In addition, we assessed whether the forms contained specific references to any limitations to the standard autopsy procedure (eg, limited incision, biopsy only, in situ examination) or contained or referred to any associated educational material for the family or for the physician. We also noted whether the consent form was available in languages other than English.

QUESTIONNAIRE-BASED DATA

Between July 1 and July 31, 1997, we contacted the chief residents and the pathologist responsible for autopsy procedures of each institution from which we had obtained an autopsy consent form (n = 127). A cover letter signed by us explained the purpose of the study and asked the chief resident or pathologist to complete an anonymous, self-administered questionnaire. Each packet also contained a stamped return envelope. Survey development occurred in 4 steps: literature search, focus groups, instrument creation, and clinical sensitivity assessment. The instrument was then assessed for face and content validity, clarity, redundancy, and utility by attending physicians, including pathologists, as well as residents at our institution.

The study targeted chief residents as surrogates for physicians who obtain autopsy consent, since residents are the physicians most likely to request autopsy. In addition, because chief residents are typically selected on the basis of their clinical competence, we believed that their responses would generally reflect a high level of academic achievement, including education on autopsy. The chief residents’ self-administered questionnaire asked respondents to complete 19 closed-format questions (response options were yes, no, and don’t know) designed to elicit their understanding of the autopsy procedure; the extent of their medical education about autopsies; educational materials on autopsies available in their institutions; and their opinion as to whether limitations to the standard autopsy should be offered to families.

The questionnaire administered to the pathologists was similar in format to that administered to the chief residents, but different in content. Each pathologist was asked how frequently the performance of an autopsy at his or her institution discloses clinically significant findings for families and clinicians, as well as how often an autopsy is used for teaching or research purposes. In addition, pathology respondents were asked how frequently alternatives to the standard autopsy procedure were used at their institution, as well as their opinion of the usefulness of a limited autopsy as compared with a complete autopsy.

RESULTS

AUTOPSY CONSENT FORMS

Autopsy consent forms were requested from 165 programs. A response rate of 68.9% (82/119) for internal medicine programs and 98% (45/46) for pediatric programs was obtained. Our request yielded consent forms from 20.2% of all internal medicine programs and 21.7% of all pediatric programs in the United States, representing institutions from 46 states.

We found that 84.7% of all autopsy consent forms we surveyed contained 7 of 10 elements recommended by the CAP (Table 1). The statement that organs would be “removed” or “retained” appeared in 94.7% of the consent forms. A space for inserting potential limitations on the autopsy procedure was provided in 92.2% of the consent forms. Only 27.2% mentioned a final disposition of the organs (“destroyed,” “disposed,” or “permanently removed”), and 7.1% of all the consent forms had a statement of informed consent (“I have been informed about the general nature and purpose of the procedure and all questions asked about the procedure have been answered in a satisfactory manner”) as recommended by the CAP. A mere 2.7% of the forms had associated educational materials for the family, and 7.1% had some educational materials for the physician obtaining consent. Only 0.8% listed specific limitations to the standard autopsy procedure (biopsy only, in situ examination, limited incision, etc), and 5.7% of the forms were available in a language other than English.
As seen in Table 2, 51.8% (59/114) of the internal medicine chief residents and 60% (52/86) of the pediatric chief residents completed and returned the surveys. Regarding training and education, 64.9% of all chief residents said there was no instruction on the autopsy procedure or the disposition of organs in their institution, 45.1% said there was no instruction on how to obtain consent to autopsy, and 81.6% said there was no instruction related to religious or cultural issues around autopsy or postmortem care.

Regarding the autopsy procedure itself, 93.8% of all chief residents did not feel knowledgeable about how organs are discarded at their institution, 96.4% did not feel knowledgeable about how long organs are retained, 74.8% did not feel knowledgeable about the range of alternatives to the complete autopsy, 50.1% did not feel knowledgeable about surgical procedures used in the removal of tissues or organs, and 51.3% did not feel knowledgeable about the types of tests done on tissues or organs.

Only 6.6% of all chief residents believed that information for physicians about the autopsy consent would not be helpful, only 9.5% believed materials for physicians about the autopsy procedure would not be helpful, and 25.5% believed that educational materials for the family about the autopsy procedure would not be helpful.

Only 27.1% of all chief residents believed that families should not be informed of the specific organs or parts of the body dissected, only 6.7% believed that families should not be informed of the general nature and purpose of the procedure and all questions asked about the procedure have been answered in a satisfactory manner.

As stated in the College of American Pathologists guidelines, all consent forms should have a statement of informed consent, such as, “I have been informed about the general nature and purpose of the procedure and all questions asked about the procedure have been answered in a satisfactory manner.”
should not be informed about the possibility of limiting the autopsy procedure, and only 10.9% believed that families should not be informed about the disposition of organs after autopsy (Table 3).

PATHOLOGISTS’ SURVEY

A response rate of 66% (76/114) was obtained for the survey mailed to the pathologists. As seen in the Figure, pathologists reported that alternatives to the standard autopsy often give less-than-satisfactory results. Twenty-nine (38%) of the 76 pathologists believed that an autopsy with exclusions (eg, the typical procedure but no examination of the head) produced results equivalent to those of a complete autopsy, while 45 (60%) believed that autopsies with these exclusions were less informative but satisfactory. Eight pathologists (11%) believed that a selective examination (ie, a procedure restricted to 1 or more organs) produced results equivalent to those of a complete autopsy, while 46 (61%) believed that it was less informative but satisfactory. Even fewer pathologists believed that other limitations produced satisfactory results. Seven pathologists (9%) considered the results of in situ examination and biopsy equivalent to those of a full autopsy, while 43 (56%) considered this alternative less informative but equivalent, and 27 (35%) considered it less than satisfactory. Pathologists reported high rates of insufficient experience with percutaneous organ sampling by biopsy, autopsy performed by thoracoscopy and laparoscopy, and presence of a religious representative at the autopsy.

Our results describe substantial deficiencies in the information that is likely conveyed to the family at the time of request for autopsy at US teaching hospitals. First, more than half of the chief residents surveyed reported that they do not feel knowledgeable about the actual procedures used in the removal of organs or about the tests done on routine autopsies. In addition, we found that, while consent forms used by 85% of institutions surveyed contain 7 of the 10 elements of autopsy consent as recommended by the CAP, only 7% of forms contained (or were accompanied by) educational materials for the family and the physician as recommended by the CAP. The lack of knowledge about the basic elements of the autopsy procedure described by chief residents and the lack of educational resources available at the time of autopsy consent raise the concern that families are not being well informed of the benefits of the autopsy procedure. For example, while 93% of chief residents believe that options to the standard autopsy (a limited autopsy) should be offered to families, 90% of the pathologists reported that limited autopsies are less than satisfactory or do not yield results equivalent to those obtained from complete autopsies. If families are offered a limited autopsy without a clear explanation that the information obtained may be incomplete, because a complete examination is not performed, then the family may be deprived of a significant benefit of the autopsy.

THE TRADITIONAL VIEW OF INFORMED CONSENT

In the context of medical treatment, the purpose of the informed consent process is to provide sufficient information to the patient (or surrogate) so that the patient (or surrogate) can make a choice based on their wishes and values from among the options available.

The requirement that consent be obtained before treatment derived from the legal principle that a person has the right to be free from unconsented touching and that such touching constitutes a battery for which the patient can seek legal redress. Over time, the concept has evolved into a requirement to obtain informed consent...
sent to treatment, and failure to obtain such consent has come to be considered professional negligence.21-24 Under this theory, a physician has a professional responsibility to provide the patient with all information the physician possesses (or should possess) that would be material to a reasonable patient in making an informed choice about whether to consent to treatment.25,26 The information to be provided includes the following: the proposed treatment and its likely outcome; the risks and benefits of the proposed treatment; the alternatives to the proposed treatment and the likely outcome, risks, and benefits of these alternatives; and the risks and benefits of doing nothing.27

INFORMED CONSENT FOR AUTOPSY

Obtaining consent for autopsy presents a number of unique challenges to this paradigm of informed consent. Consent for autopsy is atypical in that the autopsy procedure is completely elective and there is no medical benefit or risk to the deceased on whom the procedure is performed. Instead, it is the family, the medical profession, other patients, and society as a whole that stand to benefit. Benefits of the procedure to the family include knowledge of inherited or communicable disease, reassurance that treatment decisions were well founded, and emotional solace in advancing medical science for the benefit of others. The autopsy provides benefit to the medical profession by serving as a teaching tool and as a source for expanding our understanding of disease. These in turn are beneficial for other patients and for society.8,11-14

The deceased also faces no medical risk from an autopsy. Instead, the potential risk from the autopsy procedure is that the family will experience emotional and/or spiritual distress if the body of their loved one is treated in a manner that violates their values or the values of the deceased. This distress can range from feelings of deep mistrust of the medical profession to a feeling of spiritual violation, if the body is treated in a way contrary to religious beliefs.28-34 In addition, consent to autopsy is always requested at a time when the family has just experienced the death of a loved one. The nature of the information provided (or not provided), and the manner in which the information is conveyed, may exacerbate the family’s grief.35,36

INFORMATIONAL ASPECTS OF ALTERNATIVES TO AUTOPSY

Alternatives to the standard autopsy include no autopsy and an autopsy procedure that is limited in some way. There are no uniform definitions of a limited autopsy in the medical literature. In general, a limited autopsy involves any variation from the complete autopsy. This may include limiting which organs are dissected, needle or wedge biopsies of the organs of interest, thorascopic or laparoscopic examination of the organs, or a limitation on the use of the organs (eg, requiring that the organs be returned to the body after the autopsy).37-40

Presumably, families understand that they can refuse to consent to an autopsy. However, based on the fact that many chief residents expressed a lack of understanding of the autopsy procedure, it is likely that many families do not understand the procedure or the risks and benefits of limitations to the procedure.

The benefit of no autopsy is that the body of the deceased remains inviolate. The family need not fear that they have consented to a procedure that may violate their or their deceased’s beliefs. The major drawback to the family is the loss of additional information about the death of their loved one and its potential implications for them. They also derive no benefit from serving others. The opportunity to advance medical knowledge is gone.

The major benefit of a limited autopsy is that its availability may reduce the stress experienced by the family contemplating a standard autopsy and in fact may enable families to consent to autopsy who might otherwise refuse on the basis of religious and cultural beliefs. For example, while there is no absolute prohibition on autopsies by any of the major religions (most branches of Christianity and Judaism consider it a matter of individual conscience), under traditional Jewish, Islamic, and Eastern Orthodox teachings, complete autopsies may be seen as a violation of human dignity and bodily integrity with serious spiritual implications.27,41-45 Limited autopsies, on the other hand, have been permitted by traditional Jewish and Islamic law, as long as certain conditions are followed.46-48

The major risk of a limited autopsy is that the information obtained will be incomplete or inaccurate, because a thorough examination is not performed. Available data from the medical literature shows that most pathologists believe that the complete autopsy remains the criterion standard and that limitations on the autopsy procedure greatly increase the risk of incomplete or inaccurate results.6,18,49-52 Because of the substantial risk that incomplete or inaccurate information will result from a limited autopsy, there may be a reluctance to describe limitations to the autopsy procedure. In addition, there is a risk that a family will infer that, because the option of a limited autopsy is offered at all, such an option will produce answers equivalent or nearly equivalent to those a complete autopsy would produce.

Conveying all of the information needed to weigh the risks and benefits of a limited autopsy to a grieving family is difficult. The amount of information about the autopsy procedure that would need to be conveyed in order for a family to give full, informed consent to a limited autopsy is not intuitively obvious, and providing details about the autopsy procedure may itself create serious distress.31 The physician also may not be aware of the family’s religious or cultural beliefs, or of the implications of these beliefs for an autopsy. Nonetheless, while it may be difficult for a family to absorb information about autopsy in the midst of grieving, a physician must be cognizant of the importance of belief systems if he or she is to give (or to offer access to) information about autopsies that is meaningful and relevant to families. Religious and cultural belief systems, which are often of heightened importance at times of acute illness, hospitalization, and death, may be the source of the values that the family will apply to decisions about whether to consent to autopsy.37,34-36
Another important risk of conducting limited autopsies is that the societal goals of research and teaching will be compromised. At hospitals engaged in training and research, or caring for a high concentration of relatively rare disorders, the obligation to advance knowledge about disease and toxic effects of therapy through the frequent use of autopsy examination may be greater than at a nonteaching hospital.

A PROPOSED POLICY

The autopsy procedure at teaching hospitals continues to offer the last chance to gain important and frequently unexpected information that is of great potential value to the living. Despite the continued decline in the performance of autopsies in both pediatric and adult teaching hospitals, the value of autopsies appears to be recognized by our society. For instance, several studies of family attitudes toward autopsy have shown that, when approached before a family relative has died or well after the initial grief period, up to 83% of people believe autopsy is beneficial.3,5,35,60 The discrepancy between the beliefs about autopsies expressed before and after the initial grief, and the unwillingness to give consent to autopsy at the time of death, may in part be explained by our data that show growing deficiencies in consent practice, including lack of firsthand knowledge of the procedure by those most likely to approach families for informed consent, lack of training in obtaining consent, and lack of information available to families.5,17,35

We recommend first that residents, and others who may be involved in obtaining consent to autopsy, receive education on (1) the autopsy procedure; (2) limitations to the procedure; and (3) the storage, use, and disposition of organs. To obtain consent, which requires informing the family of the nature of the autopsy procedure, its risks and benefits, and its alternatives, the physician must first be knowledgeable about the procedure. Not only are physicians who are poorly educated about autopsies likely to misinform families, and potentially generate subsequent medicolegal issues, but they are also more likely not to request autopsy.3,35 Nurses should also receive education about autopsy procedures and policy, as families frequently ask nurses for information.

Second, residents should receive education and training on the unique elements of autopsy consent so that they are able to discuss in a sensitive manner the details of the procedure that the grieving family may consider relevant and important. One challenge to the clinician in obtaining informed consent for autopsy is eliciting the family’s (and deceased patient’s) religious, cultural, and ethical sensitivities, which determine what information is material to the family’s decision making. Rather than seeking to master the nuances of multiple cultures, we suggest that the clinician learn to ask open-ended questions, such as: “What are the most important results you would hope to receive from an autopsy? What are the most important concerns that you have about autopsy?”162 A clinician might also note the religious preference of the patient from the medical record and anticipate areas of potential sensitivity and concern. We believe, and several studies demonstrate, that more than 1 lecture on the subject inserted into the medical residents’ curriculum will be needed to help physicians handle this responsibility well.53-67

To accompany and reinforce the educational process, written material should be available to the staff. These materials should be clear about the benefits of autopsy, the details of the autopsy procedure, the use and ultimate disposition of organs at the institution, and the opinion of the institution’s pathologists on limitations to the standard autopsy procedure. The materials should also describe significant cultural and religious issues that arise in relation to autopsy. We recommend that the educational materials for the physician be attached to the consent form to promote recurrent self-education before obtaining consent.

Third, we recommend that the attending physician, who is typically the teaching physician, take renewed personal responsibility for the autopsy consent process.5,68 The teaching physician should ensure that the resident approaches a family about an autopsy only after the resident has demonstrated competence in the autopsy consent process. Teaching physicians must also guarantee that the requesting physician has earned the right to request an autopsy by virtue of his or her involvement in the care of the patient and his or her relationship with the family. More value should be placed on having the requesting physician view the autopsy procedure and discuss the preliminary findings with the pathologist.

Finally, hospitals should reevaluate their autopsy consent form to ensure adherence with the minimum guidelines as proposed by CAP. In addition, forms should more clearly explain the general procedures that will be followed in an autopsy and use language that heightens the awareness of the possibility of requesting restrictions to the autopsy but also makes clear that limitations will increase the likelihood of incomplete information.

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