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Case Report

A Case Study of the Experience of Performing a Pathological Autopsy on a Patient Without Surrogate and Decisional Capacity: A Clinical Ethics Mediation Perspective

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Abstract:

A pathological autopsy was scheduled to confirm the clinical diagnosis and to search for the cause of progressive anemia in a terminal cancer patient who had no relatives and was also suffering from hepatic encephalopathy due to alcoholic cirrhosis. In this case, the patient lacked decision-making capacity and a surrogate decision-maker could not be determined. In other words, it was impossible to obtain consent from the patient and family. Therefore, ethical considerations were made with the intention of conducting a pathological autopsy. In addition to the review at our own institution, we were asked by a clinical ethics mediator at another institution to conduct an ethical deliberation on whether or not to perform the pathological autopsy. As a result, we concluded that it was appropriate to conduct a pathological autopsy after collaborative dialogue and deliberation with the parties concerned. Based on this conclusion, we performed the autopsy. Through this experience, we reaffirmed the importance of respecting the autonomy of the patient and ensuring the appropriateness of the physician's actions and the possibility of postmortem verification when performing a pathological autopsy on a patient who lacks decision-making capacity. We also considered that the key to the ethical issues in this case was the orientation toward collaborative dialogue through ethical mediation based on respect for autonomy as the foundation for such an ethical stance and conduct.

Keywords: Absence of a surrogate willing person; diagnosis cause of death; clinical ethics mediations; consultation support for pathology autopsy

Introduction

The majority of bereaved families in Japan tend to resist autopsies due to the cultural and historical background of Japan, including the desecration of the dead. Therefore, it is important to have a relationship of trust and mutual consent between the physician and the patient/family. There are four types of autopsies performed in Japan: systematic autopsy, judicial autopsy (to determine the cause of death of a corpse suspected of having been involved in a crime), administrative autopsy (to determine the cause of death of a corpse not involved in a crime), and pathological autopsy. Of these, the pathological autopsy is the one that tends to receive the least ethical consideration. The Japanese guidelines for pathological autopsies and the law on the preservation of cadaveric autopsies stipulate that, in cases of incomplete decision-making capacity and in the absence of a substitute decision-maker, a pathological autopsy must be performed on an unclaimed corpse 30 days after confirmation of death, or when two or more physicians (one of whom may be a dentist) are treating a patient who has died. In the case of the death of a patient who was under the care of two or more physicians (one of whom may be a dentist), the need for an autopsy to

determine the cause of death is permitted [1,2]. Of course, the consent of the bereaved family is a prerequisite. In this case, in the absence of a proxy decision-maker with no relatives, what ethical considerations are required in terms of respect for autonomy and the responsibility of the pathological autopsy, even if legally secured, in a case where the person is judged to lack decision-making capacity? This case is an illustrative example of this point [3,4,5]. This case study is an example of the usefulness of ethics mediation assistance for ethics consultation in this regard.

The purpose of conducting the pathological autopsy in this case was to bridge the difference between the image-centered clinical diagnosis and the definitive diagnosis after the pathological autopsy, and to utilize this difference for future diagnosis and treatment decision-making policy.

Case Study

The Case
57 years old, unemployed, male.
Medical history: alcoholism, fatty liver (noticed at age 30), type 2 diabetes, compression fracture, right sciatic fracture, macrocytic anemia (folate deficiency macrocytic anemia).

Recent medical history:
About 2 years before his death, he visited the Department of Internal Medicine, X Hospital, complaining of abdominal distension and leg pain due to lower leg edema, which made it difficult for him to walk. He was admitted to the hospital because of ascites caused by alcoholic cirrhosis. He was discharged on the 16th day of illness.

One year and seven months later, he was hospitalized for hematemesis after drinking alcohol. The hematemesis was due to ruptured esophageal varices. The patient was treated by hemostasis with a clip. Considering the activities of daily living） （ADL）, chemotherapy was started, but the patient was put on best support care (BSC) during the treatment. The patient felt he had been kicked in the foot, refused treatment, and continued to drink alcohol. Approximately two months later, the patient presented to the emergency room with increased left back pain. The pain was caused by compression of the Th6 nerve root due to a compression fracture. The patient was admitted to the hospital and the pain was controlled with opioids and steroids. On the 22nd day of hospitalization, the patient presented with confusion and fluttering tremor, which were diagnosed as hepatic encephalopathy based on various investigations, and drug therapy (laczulose, rifaximin, and BCAA preparations) was administered. The symptoms of hepatic encephalopathy improved. From the 44th day of admission, congestive heart failure with anemia and dyspnea was observed, and the patient was transfused with red blood cell concentrate. Her symptoms improved. However, the cause of the anemia could not be determined. The anemia progressed. The cause of the anemia was thought to be persistent or recurrent small bleeding in the gastrointestinal tract due to peptic ulcer or other causes. Dyspnea was observed on day 82, and Hb 2.4 g/dL was observed on day 83. He died on the 88th day of hospitalization.

2 Clinical Diagnosis and Treatment Issues

1) Is the cause of death consistent with pancreatic tail cancer? What was the status of invasion and metastasis of the cancer?
2) Ascites effusion, upper gastrointestinal bleeding, and hepatic encephalopathy were observed, but what was the degree of liver injury?
Is there a contradiction with hepatic encephalopathy in terms of clouded consciousness?
3) Was the progression of anemia due to gastrointestinal bleeding? Has intertumoral hemorrhage been observed? Is spinal carcinomatosis possible?
4) Is the occurrence of dyspnea consistent with heart failure due to anemia progression?

A postmortem autopsy was scheduled while the patient was alive to address these questions. The conscious state of the patient confirmed that he was incapable of making his own decisions [6,7].

3 Addressing Ethical Issues

First, we asked a clinical ethics mediator from another institution to deliberate with the other institution's ethics committee about performing a pathological autopsy on this case, after obtaining approval from the hospital administration to confirm the validity of the pathological autopsy for deliberation with our own institution's ethics committee. The name of the deliberation study was "Postmortem Pathological Autopsy of a Terminal Stage Cancer Patient with No Relatives" [8].

This time, when the understanding and consent of the family could not be obtained in the end, the clinical ethics mediator and the attending physician team made a firm conclusion on the principle of biomedical ethics to respect the patient's wishes and the necessity of the argument that a pathological autopsy must be performed, and followed the procedure to obtain consent for a pathological autopsy. In this case, the purpose of the autopsy could hardly be achieved if we waited for the consent of the family because their whereabouts were unknown or they lived far away. As mentioned above, if it is clear that the purpose of the autopsy cannot be achieved, the autopsy may be performed if two or more physicians, including the attending physician, decide that it is necessary. However, in addition to emphasizing respect for autonomy in this indication, the procedures for how the decision is made by two or more physicians could be made more transparent so that responsibility does not fall on two or more physicians. We consulted an ethics mediator and reported to the ethics committee.

We also asked an outside committee member to increase transparency. We shared information about the case, such as age, gender, current level of awareness, understanding, judgment, etc., with the ethical standards and four principles at departmental conferences, multidisciplinary conferences of concerned parties, the hospital's ethics consultation team, etc., based on the ethical principles of sharing information about the case [9,10,11]. As a result, it was decided to record the fact that there was an argument for pathological autopsy by two or more doctors to clarify the pathological condition of the patient. In this case, on the advice of the ethics mediator, it was noted in the medical record that the

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doctors and nurses themselves contacted the family several times to try to confirm their wishes, even though they could not contact the missing sister (also noted in the nurses' record) [12,13]. Thus, by describing in the preliminary consultation that there was a procedure of explanation and consent process to the pathological autopsy for clarification of the pathological condition to the sister and the administrative caseworker, even if it is not so important to confirm the patient's living will when consenting to the pathological autopsy, it was still meaningful as a principle of respect for autonomy.

After preliminary consultations, the main review was conducted with the participation of internal and external members (lawyers and priests).

The ethics mediator suggested that the attending medical team perform a pathological autopsy using the four-compartment table proposed by Albert R. Jonsen et al. to organize the ethical issues of the case (Table 1) [14].

Table 1 Comparison of clinical diagnosis and pathological autopsy findings

Clinical diagnostics	Pathological autopsy findings
# Cancer of pancreatic tail cT2N0M1 (PUL,HEP,ADR) stageIV # Alcoholic cirrhosis # Alcoholism # Th6 fresh compression fracture # Type 2 diabetes mellitus # Anemia # High cardiac output heart failure	# Pancreatic caudal carcinoma (4.5 cm large nodular lesion with invasive pancreatic ductal carcinoma, direct invasion of posterior wall of stomach, splenic vein, left adrenal gland, left kidney, cancerous peritonitis (30 mL of ascites, seeding nests in Douglas fossa, etc.), lymph node metastasis around pancreas and in left inguinal area, liver (adenocarcinoma, extension in portal region) and right lung metastasis (adenocarcinoma) # Cirrhosis of liver (weight 1230 g, no jaundice. Small nodular cirrhosis) Findings related to portal hypertension: spleen weighs 128 g, esophagus; hard to note varices grossly. No hemorrhage is noted. Liver shows ballooning, Mallory-Denk body formation, and partial neutrophilic infiltration. # Osteoporosis; vertebral bodies in non-involved areas show thinning and loss of continuity of the bony beams. Vertebral compression fractures (11th and 6th thoracic vertebrae, 3rd lumbar vertebrae). # Bone marrow: hematopoietic disorders unlikely, no cancerous metastases. No splenic hyperfunction. Stomach: contents are coffee residue. Mild petechial hemorrhage in gastric mucosa. Black stools in ileum and colon. No definitive diagnosis. Pulmonary edema: Weight increased to 870g on the left / 820g on the right. Heart failure: heart weight is 402 g. Enlargement in the left ventricle is seen, suggesting congestive heart failure.

HEP:Hepatic, UL:lung, ADR: Adrenal Glands

The results of the preliminary discussions were as follows.

1) Continue the approach to the patient.

2） Respect the ACP (Advanced Care Planning) of the patient in question [15,16,17,18].

3）Communication of the fact that contact with the patient could not be made by all parties involved / notation in the medical record

4) Approval by the hospital organization of the appropriateness of the pathological autopsy and a decision/record of a review by at least two physicians, including the attending physician, as to whether or not the autopsy should be performed.

The results of this review are presented in Table 2. Based on the above process, pathological autopsy was considered ethically feasible and was performed. A comparison of the clinical diagnosis and the pathological autopsy is shown in Table 3. The patient had underlying alcoholic cirrhosis and diabetes mellitus with pancreatic tail carcinoma. He was 163 cm tall, weighed 42.9 kg, and his left pupil was dilated. The immediate cause of death was considered to be hemorrhage rather than cancer.

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Table 2 Quadrant Table

Medical Indication

- Stage IV pancreatic tail cancer
- Treatment is symptomatic and palliative.
- Alcohol dependence.
- Delirium, no indication for cancer chemotherapy.
- He is blind in his left eye due to glaucoma and cataract.
- Rapid progression of anemia.
- There is no histological diagnosis of pancreatic cancer.
- The diagnosis of pancreatic cancer is difficult to determine by blood tests and imaging studies alone.

Patient Preferences

- "I have no desire to go home. I feel safer in the hospital." Sometimes they say, "I don't want to go home," but then they turn around and say, "I want to go home. I'll do anything if I'm alive. Or, "How about another hospital?" Their intention changes depending on their condition on that day.
- Waiting for death with pain control. The patient does not know the meaning of life at this moment.
- The patient's character before his illness (he is not cooperative with medical treatment, such as refusing to abstain from alcohol, etc.) makes it unlikely that he will agree to a pathological autopsy.
- The patient's acceptance of death is in a constant state of transition, and since he has no friends or relatives, it is not easy for doctors to determine his presumed intention, as he is expected to suffer from hepatic encephalopathy and clouded consciousness due to anemia.
- Even if the patient's opinion is obtained on a day when his/her condition is good (i.e., when he/she is able to make a normal decision), there is a possibility that the answer will differ from day to day.

QOL Quality of Life

(The medical staff is considered the "party" to the autopsy. The QOL of the patient is not an issue because the autopsy is a pathological autopsy.) The patient's wishes, views on life and death, and religious views must be respected.

※In case of pathological autopsy

The patient's intention is unknown. The patient does not have the capacity to make decisions. There is no substitute decision-maker. The pathological autopsy will allow us to examine whether the treatment was effective by clarifying the pathological condition, and to consider the examination/treatment plan when we encounter similar cases in the future. It is clinically meaningful to conduct pathological autopsies on all deaths to examine the treatment before death.

※If no pathological autopsy is performed

Since the clinical diagnosis of the cause of death has been completed up to the imaging diagnosis, the correctness or incorrectness of the judgment and the excess or deficiency of the examination cannot be fully examined.

Contextual Features

- Social support, social workers, administration, and hospital contact the sister who is no longer a member of the family, but she is missing and unresponsive.
- The administration only handles the postmortem and leaves the decision to the medical staff if there is no financial burden.
- There is no substitute decision maker.
- The hospital to which the patient is transferred refuses to accept the patient every night at a related medical institution, and the hospital refuses to accept the patient even when the patient is ready for transfer.
- The pathological autopsy does not require the patient's will, but is decided by the bereaved family and medical staff.
- The Ethics Committee confirmed that at least two physicians are required to perform the pathological autopsy, that the Department of Gastroenterology is authorized to perform the autopsy, and that unanimous consent has been obtained.
- The ward staff who had daily contact with the patient stated, "I am not opposed to performing a pathological autopsy if the physician deems it necessary. However, we are not sure of the patient's intention to have a pathological autopsy before his death".

Table 3 Report of Discussion from the Ethics Committee

1. According to the Guidelines for Pathological Autopsies, the will of the deceased is not required for pathological autopsies, but the decision is made by the bereaved family and medical personnel, and can be carried out by the decision of two medical personnel.
2. Legally, the living consent of the patient is not required, but ethically, the patient's living will should be respected.
3. Even after the patient himself/herself has died, we want to convey that it is possible to contribute to others (e.g., future medical development) through pathological autopsy and that it can be "not just one death, but a valuable death for people in the future," so as a medical institution we will explain this to the witnesses and implement it.
4. In the future, we believe that psychiatry and psychologists need to intervene in the evaluation of cognitive function before death.
5. Although it is outside the scope of the palliative care team, we can consult with them regarding approaches such as "soul care, The team will receive support for cases in which pathological autopsies are necessary in terminally ill patients.
6. The hospital should summarize the experience and discussion of the present case as a guideline for the future, and formulate a plan for pathological autopsies. (It should not be a shortsighted understanding that pathological autopsies can be performed on patients without respect for their wishes if they have no relatives.)

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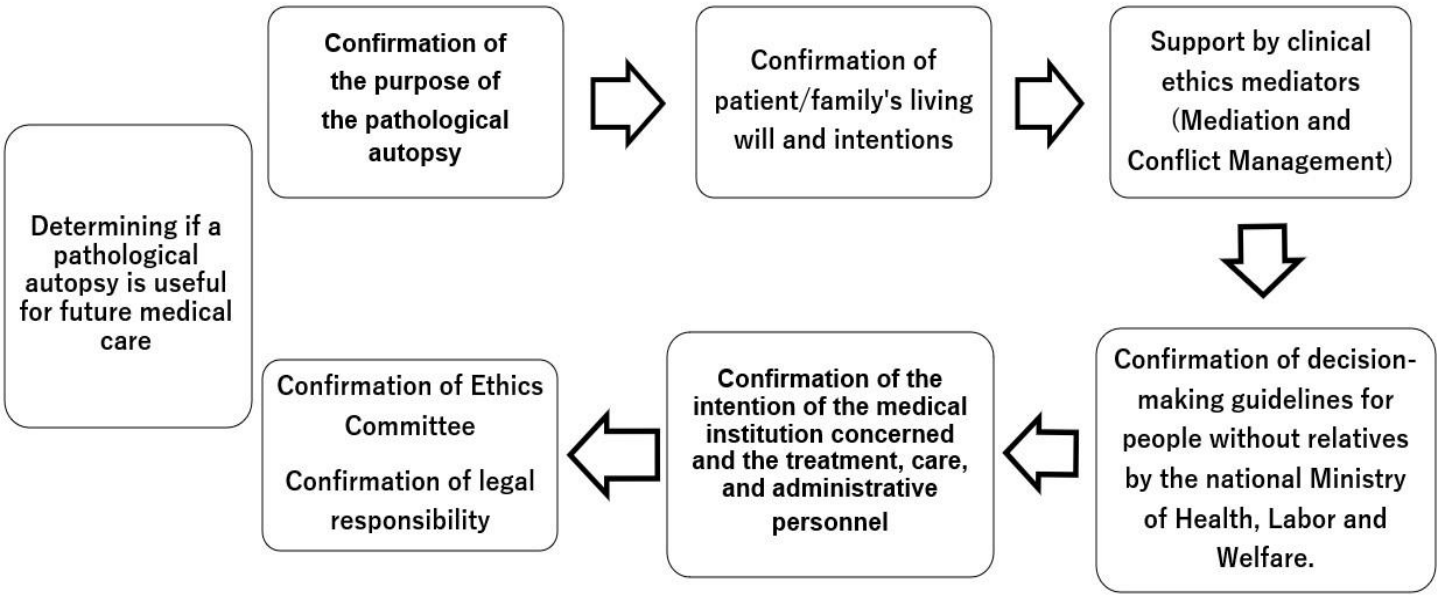
Discussion

It is said that there are not many pathological autopsies in Japan because of the Japanese view of life and death. The number of autopsies per year by the Japanese Society of Pathology was 28,086 in 1974 and 6,557 in 2022. However, pathological examination remains the foundation of medicine. In Japan, most of the standard medical practice is to ask the family immediately after the death whether or not to conduct a pathological autopsy, and this is done by proposing and implementing the standard medical practice. However, as mentioned above, pathological autopsies are often refused due to the view of life and death. Another reason is the lack of trust between the patient's family and the doctor. On the other hand, there is also the question of the doctor's proactivity. This is due to the small number of physicians who can perform pathological autopsies, the busyness of the medical field, and the high accuracy of diagnostic imaging such as CT and MRI, as well as the high rate of equipment use. The number of pathological autopsies performed on patients without relatives in Japan has been declining in hospitals nationwide, despite the fact that it is a requirement for obtaining board certification in internal medicine (see literature), and the reporting of pathological autopsy results takes several months or more.19）

In addition, family attitudes have changed (they want to contribute to medicine and want to know the cause of death), a fairly accurate diagnosis is confirmed immediately before death by MRI, CT, various test markers, and imaging records from various tests and surgeries, and in clinical practice, outcomes (such as survival) are tied to treatment interventions and the process is not easily discussed.20） This is partly due to the influence of the reliance on evidence-based medicine. 21）Despite the fact that pathological autopsies are useful in confirming a diagnosis and can be performed by two or more practicing physicians, less time is spent explaining to pathologists how to perform appropriate pathological autopsies. This may be due to factors such as health policy demands for shorter hospital stays.22）

In the present case, in cooperation with the patient's family and the government, we were able to clarify which problems in clinical treatment should be clarified by pathological autopsy by paying close attention to the patient even before the appearance of clouding of consciousness and discussing multidisciplinary cooperation between the clinical ethics mediator, pathologist, attending physicians, and other staff (Figure). Although "the patient's prior consent to pathological autopsy" is important, from the clinician's point of view, it is "hard to say" because it would express the limits of their clinical ability as a physician. (Even for pathological autopsies, the number of cases on the web seems to be small). 23）

Figure Ethical considerations of whether or not a pathological autopsy is necessary



For these reasons, we believe that the experience of this case was a meaningful ethical consideration.

Conclusion

The following points have been reaffirmed by this case
1) Pathological autopsy requires both legal and ethical justification.
2) It is useful to have an ethics mediator who can provide advice and conflict support before consenting to a pathological autopsy when the patient is judged to have lacked capacity before death.
3) If the patient has no relatives and lacks decision-making capacity, a bi-institutional ethical review is one way to proceed (and an ethics mediator should be used in this case).

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4) Consent should in any case consider how to achieve respect for autonomy and self-determination, including a viewpoint of coordination and legitimacy.

In other words, as clinicians, we believe that this orientation toward collaborative dialogue that respects autonomy in the foundation of our ethical stance and conduct was the key to resolving the ethical issues in this case.

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Conflicts of interest
Nothing to declare.

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