

Revisiting the death of Eleanor Roosevelt: was the diagnosis of tuberculosis missed?

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SUMMARY

Controversy has surrounded the death of Eleanor Roosevelt in 1962. There has been a persistent sense that doctors missed the diagnosis of miliary tuberculosis, thereby jeopardizing her life. This article, using Roosevelt's medical chart and other previously unreviewed documents, revisits her illness and death. What disease actually killed Eleanor Roosevelt? Did her physicians miss the diagnosis? These questions are of particular impor-

tance in light of the recent Institute of Medicine report estimating that almost 100 000 Americans die each year from medical mistakes. Why has the possibility of error clouded the care of Roosevelt for almost 40 years? What can Roosevelt's case reveal about ongoing efforts to reduce mistakes in clinical practice?

KEY WORDS: famous persons; tuberculosis, miliary; history of medicine, twentieth century; medical errors

CONTROVERSY has surrounded the death in 1962 of Eleanor Roosevelt. Although it is known that Roosevelt died of miliary tuberculosis, and that her physicians treated her for this condition, there has been a persistent sense that the former First Lady received suboptimal care. Early misdiagnosis, the story goes, jeopardized her medical care and perhaps caused her death.¹

This paper, using Roosevelt's previously unreviewed Columbia-Presbyterian Medical Center hospital record, revisits this controversy. Based on an agreement between Roosevelt's family, Columbia-Presbyterian Medical Center and the Franklin D Roosevelt Library in Hyde Park, New York, her chart was sealed in 1965 for 25 years.² In 1990, because the 'facts should be available for historians of the distant future',² the record, including a case summary and the autopsy report, became available at the library,² but it has not been scrutinized until recently. This piece will examine Roosevelt's final illness and medical care, analyzing how the diagnosis of miliary tuberculosis was made and asking whether physicians should have figured it out sooner.

ONSET OF ANEMIA

Eleanor Roosevelt was a healthy 75-year-old woman in April 1960 when a routine blood test revealed that she was anemic, with a blood hemoglobin level of only 10 g. Given this finding, Roosevelt's personal physician and close friend, A David Gurewitsch, referred her to a hematologist for bone marrow aspira-

tion in June 1960. Although there were 18% myeloblasts in a hyperplastic marrow, Roosevelt's doctors ultimately concluded that she had aplastic anemia rather than leukemia. Undaunted by the diagnosis, Roosevelt continued her frequent journeys around the globe, traveling to Switzerland, Poland and several other countries. She stated that she wanted 'nothing to do with doctors or tests'.²

Roosevelt remained stable for nearly 18 months. During this time, according to her friend and biographer Joseph P Lash, she experienced periodic pains, fevers and chills, which she dismissed as a 'bug' or the 'flu'.³ She apparently did not experience persistent fevers, weight loss, night sweats or other symptoms of miliary tuberculosis.

In September 1961, Roosevelt was admitted to Columbia-Presbyterian for vaginal bleeding requiring dilatation and curettage. Admission blood tests revealed that the anemia was worsening: the hemoglobin level, not helped by the bleeding, had decreased to 8 g. Both the white blood cell and platelet counts were also below normal, and the erythrocyte sedimentation rate (ESR) was 50. A repeat bone marrow aspiration performed at this time was hypocellular, with 5% myeloblasts, consistent with pancytopenia. The doctors decided to transfuse Roosevelt with two units of blood to raise her hemoglobin level. During the transfusions, she suffered the first of many allergic reactions that would result from blood products, experiencing a high fever and chills. But during the rest of the 3-day hospitalization, Roosevelt's temperature was no higher than 37.5°C.

In February 1962, Roosevelt traveled to Europe for the last time, visiting Israel and Switzerland. Then, in April 1962, her doctors, principally Gurewitsch and George Hyman, a Columbia-Presbyterian hematologist, made what turned out to be a crucial decision. Given a hemoglobin level of 7.9 g, a platelet count of 87 000 and increasing bruising, they added 20 mg of prednisone to Roosevelt's regimen in order to stimulate the growth of red blood cells and platelets in the bone marrow. But doctors were well aware of the downside of steroids: they suppressed the body's ability to fight off infection.

Despite the prednisone, Roosevelt continued to require periodic blood transfusions during the summer of 1962. When, in early August, she developed four days of fever as high as 40.5°C following one such transfusion, she was again admitted to Columbia-Presbyterian Medical Center. Although Gurewitsch remained her primary physician, the doctors in charge of the case were Hyman and a cancer specialist named Alfred Gellhorn. Gellhorn's admission note, dated 4 August 1962, described several days of fever, chills and night sweats as well as a few weeks of a dry cough. Admission laboratory tests were at baseline except for the ESR, which had increased to 128. Among the possible causes of the fever, Gellhorn wrote, was 'activation of acid-fast infection'.

Gellhorn's reference in this note was to pulmonary tuberculosis. Tuberculosis was no longer the formidable infection it had been at the turn of the twentieth century, when it had been the leading cause of death in New York City. By 1961, doctors had three medications to treat the disease—streptomycin, para-aminosalicylic acid (PAS) and isoniazid. But tuberculosis had not disappeared, and it remained an important possibility given Roosevelt's symptoms.⁴

Roosevelt's admission chest film was negative, however, making pulmonary tuberculosis unlikely. There were old scars on the X-ray, indicating that Roosevelt had been exposed to tuberculosis decades before, probably when she had an attack of so-called 'pleurisy' in 1919. Roosevelt received 4 days of empiric penicillin and streptomycin while doctors waited for the results of her blood cultures, all of which were negative. Another bone marrow aspiration was unchanged. By 10 August 1962, Roosevelt's temperature had fallen under 37.5°C and she was discharged from the hospital. The cause of the fevers remained unknown. The Columbia physicians speculated that the high temperatures might have stemmed from the aplastic anemia itself; some cases of the disease, it was believed at the time,⁵ caused periodic fevers. As a result, the prednisone dose, which had been gradually decreased since May, was raised to 25 mg daily.

FINAL ADMISSION

Unfortunately, Roosevelt continued to decline at home. Her fever and chills persisted and she devel-

oped black, tarry stools indicative of blood loss. On re-admission to Presbyterian Hospital on 26 September 1962, Roosevelt was described as extremely pale. Her hemoglobin level had dropped to 5 g. There was also another new finding. The chest X-ray obtained at admission showed 'a generalized ill-defined nodularity' within both lung fields.

Given her persistent fever and chills, doctors now termed Roosevelt's case a fever of unknown origin (FUO). This term, coined in 1961, referred to a fever of undetermined etiology that was at least 38°C and had lasted for 3 or more weeks.⁶ One of the most common causes of an FUO was tuberculosis. Thus, it is not surprising that Columbia physicians holding a 'group consultation' on 27 September 1962 decided that they needed to rule out the possibility that Eleanor Roosevelt had tuberculosis. Among the physicians participating were Gellhorn, Hyman, Gurewitsch, internist J Randolph Bailey, infectious disease specialist Yale Kneeland, and David Karnovsky of Memorial Sloan-Kettering Cancer Center. By this point, the doctors were no longer considering pulmonary tuberculosis, but rather miliary tuberculosis that had possibly spread throughout Roosevelt's body. The new nodular densities on the chest X-ray, Roosevelt's doctors believed, might be evidence of this disseminated variety of tuberculosis. The presumed source of this infection was a reactivation of the walled-off tuberculosis bacteria that had remained dormant in her lungs since 1919.

The procedure chosen to rule out miliary tuberculosis was another bone marrow aspiration, followed by smear and culture for acid-fast bacilli (AFB). The aspiration revealed a similar picture to previous studies, with hypocellularity and 6% blasts. The smear was negative for AFB. Nevertheless, knowing that such smears were often falsely negative, the Columbia physicians decided to treat Roosevelt empirically with streptomycin and isoniazid while awaiting the results of the bone marrow culture. Interestingly, it was Gurewitsch, whose specialty was the rehabilitation of polio patients, who pushed the diagnosis of tuberculosis most aggressively, perhaps because he himself had been successfully treated for the disease in 1947. Gurewitsch had also been influenced by a visiting South African hematologist, Moses Suzman, with whom he had discussed the case. Suzman, without ever having seen Roosevelt, boldly predicted that Gurewitsch's anonymous patient had miliary tuberculosis.³ Except for a 5-day period between 11 and 16 October, during which the streptomycin was stopped due to a question of a drug allergy, Eleanor Roosevelt received two-drug tuberculosis treatment for the remaining 6 weeks of her life. Meanwhile, given the intestinal bleeding and a very low platelet count, doctors continued the prednisone.

On 2 October 1962, Roosevelt's physicians consulted J Burns Amberson, chief of the legendary Bellevue chest service and New York City's foremost expert

in tuberculosis. Amberson opined that the nodules on Roosevelt's chest X-ray were too irregular and had materialized too quickly to represent miliary tuberculosis. Yet, noting that Roosevelt had defervesced after being placed on anti-tuberculosis medications several days earlier, he advised continuing this treatment.

Within a few days, however, Roosevelt's fever had returned, reaching 40.5°C on 12 October. Meanwhile, she was experiencing other medical problems, such as continued blood loss from the rectum and allergic reactions to the frequent blood transfusions she was receiving. Roosevelt underwent two barium enemas in search of a cause of the intestinal bleeding.

Gracious to those around her, Eleanor Roosevelt was nevertheless very unhappy about being hospitalized. Indeed, Gurewitsch had promised her that she would not die in the hospital.³ By 16 October, Roosevelt had made her wishes eminently clear, informing her daughter Anna that she refused further testing and wished to go home. Her discharge medications on 18 October 1962 included both anti-tuberculosis drugs and 60 mg of prednisone. Although she was to remain under the close watch of her physicians, both family and doctors agreed that her prognosis was poor.

Despite fevers as high as 40°C, Roosevelt was alert and agreeable after discharge. Then, on 26 October, the laboratory reported that her bone marrow culture was indeed growing tuberculosis. No one was happier at the news than Gurewitsch, Roosevelt's physician and dear friend, who optimistically estimated that her chances for survival had gone up by 5000%. Perhaps because he had suspected tuberculosis from the start, Gurewitsch pushed the hardest for continued aggressive treatment, despite his promise to his patient. But Anna Roosevelt, her physician husband James Halsted, and other family members believed that heroic efforts should cease. The prolonged suffering, they argued, was exactly the way their mother did not want to go.³ Ultimately, the physicians simply doubled Roosevelt's dose of isoniazid to 600 mg per day.

This discussion became moot on 4 November 1962 when Roosevelt appeared to suffer a major stroke that rendered her comatose. She stopped breathing at home on 7 November 1962. Roosevelt was 78 years old. The family gave its consent for an autopsy, which was performed the next day.

MILIARY TUBERCULOSIS 'ACUTISSIMA'

On 12 December 1962, the doctors involved in Roosevelt's case gathered for a clinical pathological conference at Columbia-Presbyterian. The pathologists conducting the autopsy had confirmed the diagnoses of aplastic anemia and military tuberculosis. But the extent of the tuberculosis was impressive. Bacteria were found in Roosevelt's lungs, liver, spleen, kidneys, and, obviously, bone marrow. Even more extraordinary was the fact that Roosevelt had appar-

ently been entirely unable to fend off the infection. There were no granulomata, indicative of a body's normal response to tuberculosis, but simply vast numbers of microorganisms and dead tissue.

The extent of the disease was so dramatic that the pathologists did not call it miliary tuberculosis but disseminated tuberculosis acutissima.^{7,8} This term connoted overwhelming infection. The physicians speculated that Roosevelt's immunocompromised state, secondary to both the longstanding bone marrow failure and the prednisone treatment, had led to reactivation of her dormant tuberculosis and her subsequent inability to fight the infection. Because there had been so little immune response, the chest X-ray had not shown the characteristic pattern of miliary tuberculosis. Hence, Amberson and the other doctors had temporarily been fooled.

But the story does not end here. After identifying tuberculosis in the bone marrow specimen on 26 October, the Columbia laboratory had also tested the bacteria for drug resistance. These tests, plus additional studies performed by the New York City Department of Health, confirmed that Roosevelt's tuberculosis had indeed been resistant to the two drugs that she was receiving. The presence of drug resistance was not entirely surprising. In one 1961 study, more than 15% of cases of tuberculosis in New York City displayed resistance to at least one medication.⁹ The vast majority of drug resistance occurred when patients took their anti-tuberculosis regimen in an irregular fashion. As a result, many of these cases emanated from New York's downtrodden Bowery section, with its population of alcoholics and drifters.⁴

But the presence of drug resistance complicates the explanation of Eleanor Roosevelt's case. If her tuberculosis had resulted from activation of a dormant infection acquired in 1919, well before the advent of antibiotics, the organisms in question would have been drug-sensitive. True, Roosevelt had received 5 days of streptomycin in July, but this should not have induced resistance. It is possible that Roosevelt simply acquired drug resistance during her 6 weeks of two-drug treatment beginning in September 1962, but this would also have been atypical.

Thus, the possibility must be raised that Roosevelt's tuberculosis acutissima had not resulted from reactivation of her old disease but from reinfection. Recent work with DNA fingerprinting has demonstrated that infection with one strain of tuberculosis does not preclude infection with another, particularly in immunocompromised persons.¹⁰ Given her poor immune status in mid-1962, Eleanor Roosevelt may have come into contact with a case of infectious, drug-resistant tuberculosis, which quickly spread throughout her body and was untreatable with the antibiotics she received. There is no documentation that a tuberculous individual spent time with Roosevelt during this period, but she was in contact with family, friends

and the public, including some of the down-trodden people most likely to harbor resistant disease.

There is one other possible scenario for what had happened. What if Roosevelt had been suffering from miliary tuberculosis since April 1960, and her bone marrow suppression all along had been due solely to tuberculosis? Physicians in the early 1960s knew that tuberculosis that had infiltrated the marrow could suppress the growth of both blood cells and platelets.^{8,11,12} This infection could lead to either a hypercellular marrow and a leukemoid reaction or to bone marrow failure with aplastic anemia or pancytopenia. The most ardent popularizer of this scenario was British hematologist F G J Hayhoe, who believed that occult tuberculosis caused many cases of 'idiopathic' bone marrow suppression.^{13,14}

One appeal of this explanation is that it unifies the Roosevelt case. Instead of hypothesizing that she had developed tuberculosis on top of idiopathic aplastic anemia, one disease, tuberculosis, can explain the whole picture. After all, Roosevelt's bone marrow specimens changed little over the course of 2 and a half years, suggesting that whatever was there at the end was also present at the beginning. One individual who ultimately believed that Roosevelt had had tuberculosis all along was David Gurewitsch. 'We could have had the same diagnosis a year ago,' he stated on 6 November 1962. Presumably referring to physicians at Harvard Medical School, he continued: 'The people in Boston would have done it and she could have been saved. It was left for me to make that diagnosis 40 days ago. Others should have made it, especially the hematologist. The dirty linen will come out'.³

Yet there are problems with this scenario as well. For one thing, bone marrow tuberculosis arising in 1960 would most likely have resulted from a reactivation of the old lung infection in an aging patient, so it should not have been drug-resistant. Moreover, while the literature did discuss isolated miliary tuberculosis of the bone marrow, such cases typically spread to the rest of the body within months of the diagnosis of anemia or pancytopenia.^{7,14} One would have to posit that Roosevelt had isolated bone marrow tuberculosis for a much longer period, from April 1960 (or earlier) until July 1962, when she developed the obvious manifestations of miliary disease. Even acknowledging the fact that Roosevelt may have had periodic fevers all along, 26 months of stable, low-level tuberculosis would have been quite unusual. Unfortunately, we will never know the actual duration of Eleanor Roosevelt's tuberculosis. As only bone marrow aspirations were performed, as opposed to biopsies, there are no tissue blocks available from the early portions of her illness.

DID MEDICAL ERROR OCCUR?

What about the claim that Eleanor Roosevelt died due to a medical error? Part of the reason this theory

became popular likely reflects the era in which Roosevelt died. In contrast to modern times, in which physician-patient confidentiality for famous individuals has all but disappeared, concealment was the norm 40 years ago.¹⁵ This reticence may have encouraged suspicion. For their part, Columbia-Presbyterian physicians were not eager to discuss the case openly, even within the institution. Attendance at the clinical-pathological conference was largely limited to those attending physicians involved in Roosevelt's care. In addition, there was a sense of culpability—likely inevitable—among the Columbia staff. While treatment with prednisone had been a reasonable measure at the time, in retrospect it had likely exacerbated the tuberculosis and probably hastened death.

Adding to the sense that an error had occurred was the publication of a clinical pathological conference in the *New England Journal of Medicine* on 14 February 1963.¹⁶ The case was that of a 75-year-old widow with pancytopenia who received prednisone and subsequently died from miliary tuberculosis. The diagnosis of tuberculosis had been made only at autopsy. Although many of the details of the case differed from that of Roosevelt, and it was supposedly drawn from a presentation made at Yale-New Haven Medical Center on 28 September 1962, a rumor emerged that the case was an altered version of Roosevelt's final illness. Such a scenario served to validate Gurewitsch's claim that Columbia doctors had missed the diagnosis of tuberculosis masquerading as bone marrow failure.

It is surely true that Eleanor Roosevelt's miliary tuberculosis could have been diagnosed prior to October 1962. She definitely had the disease in July 1962, when she presented with fevers and an ESR of 128. And a bone marrow biopsy or an earlier acid-fast culture—as opposed to only aspirates—might have confirmed the infection prior to July.¹⁷⁻¹⁹ Yet even as they urged colleagues to always 'think TB', tuberculosis experts in the 1950s and 1960s admitted that the diagnosis of miliary disease, let alone tuberculosis acutissima, was extremely difficult to make during life.^{20,21} Moreover, it was far from routine to aggressively pursue the diagnosis of tuberculosis in patients with idiopathic bone marrow failure. Indeed, the longer that the anemic Roosevelt went without displaying the standard fever, night sweats and other symptoms of tuberculosis, the *less* likely the diagnosis became.

Perhaps we should replace the question 'Did Eleanor Roosevelt die due to a medical error?' with 'Why has the rumor of a medical error persisted for so long?' This latter question is particularly relevant given the recent attention to medical mistakes as a public health problem that claims the lives of tens of thousands of Americans annually.^{22,23} The Roosevelt case reminds us of the complicated nature of medical diagnosis. Findings that appear obvious after the fact may be

more opaque in the heat of the battle. Indeed, the Roosevelt family was pleased with the care given, never entertaining the possibility of medical error. 'I have personally never seen anyone receive better medical care in an extraordinarily complicated and exceedingly grave illness,' wrote Roosevelt's son-in-law James Halsted.²

Nor should we assume that a medical mistake has occurred just because someone dies of a potentially treatable disease such as tuberculosis. When Gurewitsch excitedly told Roosevelt on 27 October 1962 that she might be curable, his patient, seriously ill with tuberculosis, bone marrow failure and intestinal bleeding, told him 'I want to die'.³ Even as we strive to correct the problem of medical error, we should not forget a crucial lesson of Eleanor Roosevelt's case: death is not always a failure.

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RÉSUMÉ

La mort d'Eleanor Roosevelt en 1962 a fait l'objet de controverses. On a eu la sensation persistante que les médecins avaient manqué le diagnostic de miliaire tuberculeuse mettant ainsi sa vie en danger. Cet article, utilisant le dossier médical de Roosevelt et d'autres documents qui n'avaient pas été examinés antérieurement revoit sa maladie et sa mort. De quelle maladie Eleanor Roosevelt est-elle effectivement morte? Ses médecins ont-ils raté le diagnostic? Ces questions ont

une importance particulière vu le rapport récent de l'Institut de Médecine estimant que près de 100.000 américains meurent chaque année par suite d'erreurs médicales. Pourquoi la possibilité d'une erreur a-t-elle embrumé les soins de Roosevelt pendant presque 40 ans? Que peut nous révéler le cas de Roosevelt au sujet des efforts actuels pour limiter les erreurs en pratique clinique?

RESUMEN

La muerte de Eleanor Roosevelt en 1962 ha suscitado una controversia. Se ha tenido la sensación persistente que los médicos no hicieron el diagnóstico de tuberculosis miliar, comprometiendo así su vida. Este artículo, usando la ficha clínica de Roosevelt y otros

documentos que no habían sido utilizados anteriormente, revisa su enfermedad y su muerte. ¿De qué enfermedad murió realmente Eleanor Roosevelt? ¿Sus médicos erraron el diagnóstico? Estas preguntas cobran una importancia particular a la luz del reciente

informe del Instituto de Medicina que estima que alrededor de 100 000 norteamericanos mueren cada año a causa de errores médicos. ¿Por qué la posibilidad de un error ha oscurecido todo lo que respecta a la aten-

ción médica de Roosevelt durante casi 40 años? ¿Qué puede revelar el caso Roosevelt sobre los esfuerzos actuales para reducir los errores de la práctica médica?
