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Observations

The week in medicine

Bad blood

Rebecca Coombes, *journalist, London*

rcoombes@bmjgroup.com

An inquiry has begun into the infection of thousands of people with haemophilia in the United Kingdom who contracted hepatitis and HIV in the 1970s and 1980s. ***Rebecca Coombes*** *brings the story up to date*

What's the story

An independent inquiry into how thousands of UK people with haemophilia came to be infected with contaminated blood in the 1970s and 1980s opened last week. The opening was rather dramatically marked by allegations aired on the BBC that UK doctors ignored warnings that could have prevented these patients becoming infected with HIV and hepatitis C. Several patients also claimed that they were unknowingly placed in trials to test the infectivity of blood products, were secretly tested for HIV infection, and were not informed of positive results until years later in some cases.

The story has been unfolding for decades. In the 1970s and 1980s in the United Kingdom 4670 patients with haemophilia were exposed to hepatitis C through contaminated NHS blood and blood products, and of this group 1243 were also exposed to HIV. So far 1757 of these patients have died, and many more are now terminally ill. Haemophilia, the condition in which one of the clotting proteins in blood (most commonly factor VIII) is either missing or insufficient, is treated by injection of the missing protein. The protein can now be created through recombinant technology. However, in the period when the infections occurred it was derived from the pooled plasma of many thousands of donors. So, if any of the sources were infected with a bloodborne virus, the whole batch would be contaminated. During this time large amounts of the clotting agent factor VIII were imported from the United States, where commercial suppliers paid high risk donors (widely called "skid row donors"), such as prisoners, for their blood.

Who's saying what?

Successive UK governments have refused to hold a public inquiry, saying that politicians, civil servants, and doctors did not know of the dangers of factor VIII in time for its use to be stopped. This assertion was disputed by several of the patients and relatives giving their account of what happened at the independent inquiry in Westminster last week.

One GRO-A said: "They are saying they didn't know about the AIDS virus. I'm sorry, but by June 1983 the European commissioners put out a warning that all haemophiliacs in Europe were to be informed of the risks of AIDS. Why weren't we warned of the risks?"

GRO-A told how her late husband GRO-A was given blood contaminated with HIV and hepatitis C. He was given diagnoses of HIV in 1985 and hepatitis C in 1994, and he died in 2005, at the age of 47. Mrs GRO-A told the hearing that doctors "failed properly to explain the danger to patients and explain where the treatment was sourced so patients could be part of the joint decision making process." She drew comparisons with the Tuskegee syphilis scandal in the US, in which some patients were not told they had syphilis so that doctors could monitor the progression of the disease.

What has the media coverage been like?

To coincide with the opening of the inquiry in Westminster, the BBC current affairs television programme *Newsnight* ran a special film last week, which used official documents that have only recently resurfaced after being "lost" for decades to back up claims that UK doctors, scientists, civil servants, and politicians were aware of the threats to patients but failed to stop transfusions (http://news.bbc.co.uk/1/hi/programmes/newsnight/default.stm).

The documents were obtained by relatives of some of the people who have died. Of greatest note was a letter from the head of the UK's public health surveillance centre warning the health department about the risk of HIV infection from factor VIII after Britain's first case in Cardiff. The letter, dated May 1983—before most haemophiliac patients became infected with HIV—says that all US blood products made from donations after 1978 should be banned. However, the health department continued to allow imports to be used, saying that the risks were outweighed by the need to keep people with haemophilia supplied with factor VIII.

The UK had a desperate shortage of factor VIII. Despite calls from the World Health Organization in the mid-1970s for countries to be self sufficient in blood products, all UK efforts failed dismally, because of underfunding and lack of political will.

Timeline

1966: The first blood clotting products for haemophiliacs are produced. The first commercial factor VIII concentrate is produced by Baxter's Hyland division

1970s: Britain imports huge quantities of factor VIII from the US (*BMJ* 1998;316:489-90)

1974: The World Health Organization warns Britain not to import blood from countries with a high prevalence of hepatitis, such as the United States

1976: A drive to invest in making the UK self sufficient in blood products begins, but the initiative is not followed through

1982: First UK patient with haemophilia to be given diagnosis of AIDS

1983: US Food and Drug Administration regulations for the collection of plasma exclude donors from high risk groups

May 1983: Dr N Galbraith of the Public Health Laboratory Service writes to Dr Ian Field of the health department: "I have reviewed the literature and come to the conclusion that all blood products made from blood donated in the USA after 1978 should be withdrawn from use until the risk of AIDS transmission by these products has been clarified." Nevertheless, a health department letter the same month concludes that the suggestion "is premature in relation to the evidence and unbalanced in that it does not take into account the risks to haemophiliacs of withdrawing a major source of their factor VIII supplies." No restrictions are placed on imported concentrates, except on those for children under the age of 4 years and for people with mild haemophilia

April 1989: A number of people with haemophilia begin a civil action against the health department

Documents released last week by a group called Tainted Blood (www.taintedblood.info), made up of relatives of deceased patients, show that fears about blood products being infected with hepatitis C were circulating as early as 1976 and that similar fears about HIV were around by 1982. The *Newsnight* programme questioned scientists' and doctors' motives in keeping quiet about the risks of imported blood products. It pointed to one official document that reflected the need to find "virgin haemophiliacs," those who hadn't already received any possibly contaminated blood products from abroad. These patients would be very valuable in testing the infectivity of newer, heat treated products, which had just come on the market and were supposed to be safer.

What happens next?

The new inquiry will investigate the circumstances surrounding the supply of contaminated blood to patients. Although not an official public inquiry, it has considerable weight. Chaired by a member of the House of Lords and former solicitor general, the inquiry sits in the Palace of Westminster and, for the next four months, will hold public hearings in which evidence will be provided by civil servants, patients, and politicians, among others. (www.archercbbp.com). Lord Morris of Manchester, credited with getting the inquiry off the ground, said that the inquiry "seemed the only way to restore public confidence in the safety of blood supplies and Whitehall's ability to react to new viruses."