
Familial transmission of leprosy in post-war Britain—discrimination and dissent

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Summary

A Polish immigrant, who was resident in the United Kingdom (UK), presented with lepromatous leprosy and was detained in two hospitals against his wishes in the late 1940s. The public reaction to his diagnosis was remarkable, with street riots and questions in the Houses of Parliament about 'this leper'. His wife was persecuted and had to change her name. The index patient died of tuberculosis during enforced isolation in hospital, and several years later his daughter (who had never left the UK) presented with a left median nerve palsy and probable lepromatous dactylitis of the left third

finger, eventually requiring amputation and prolonged dapsone treatment. Her disease resolved slowly but completely.

We believe these two familial cases represent the first documented episode of autochthonous leprosy transmission in the UK since the early 1920s. They also demonstrate the ability of this disease to engender fear, dissent and discrimination amongst the public. Parallels are drawn with reactions to the cholera epidemics in nineteenth century Britain, and to HIV/AIDS, SARS and multi-drug resistant tuberculosis in more recent times.

Introduction

Leprosy is a chronic granulomatous infection with many neurological and dermatological manifestations. It is endemic in many parts of Asia, Africa and South America, and can be profoundly disabling with significant social stigma.

This report discusses two cases of leprosy in North-West England in the 1940s and 1950s, identified while conducting a retrospective case-note study of 50 such patients between 1947 and the present.¹ These cases are highly significant from medical, sociological and historical viewpoints. The extreme social reaction led to local street riots, and the cases demonstrate what we believe to be the most recent autochthonous transmission of leprosy in the UK by over 20 years.

Case reports—father and daughter

The index case was a Polish national who worked in Brazil from 1928 to 1941. He then served in the Polish armed forces in the UK, until his discharge when he was found to have pulmonary tuberculosis. In 1945, four years after arriving in the UK, he noticed skin lesions on his neck, face and wrist, which became increasingly prominent and spread to other parts of his body. He was seen by a number of dermatologists before being referred to the Liverpool School of Tropical Medicine (LSTM) in June 1946 at the age of 46.

He was described as having 'obvious and well-developed lepromatous leprosy'. The skin of his face and neck 'was thickened and corrugated and there were large numbers of lepromatous macules all over

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the trunk'. He also had 'an early leonine countenance'. A biopsy of the lesions revealed 'enormous numbers of acid fast bacilli' and nasal scrapings were also positive. He was diagnosed as suffering from 'rapidly progressive lepromatous leprosy.'

Although he and his wife were reluctant to be separated, he was hospitalized and treated with weekly intradermal injections of Moogrol, a derivative of Chaulmoogra oil.² This oil had long been used in parts of Asia for the treatment of leprosy and was the only treatment available until the Second World War, although its effect was thought to be minimal in cases of lepromatous leprosy. After approximately 1 month, the treating doctor was able to obtain promanide (a sulphone), which was given concurrently with the chaulmoogra. All visible skin lesions were infiltrated with intradermal promanide, which was continued until the small supply ran out after 4 months. Treatment was maintained with thrice daily diasone (aldapson),³ which after pressure on the Ministry of Supply, was imported from America. The diasone was stopped for 5 days as he developed anaemia, and he was given 'intramuscular injections of liver extract'. He was reported to have some temperature spikes at this time, which were attributed to his tuberculosis. His health was reported to be improving by November 1946, but he unfortunately died of pulmonary tuberculosis in September 1948, after being moved to a larger hospital, even more distant from his family.

The index patient's wife and daughter had been advised to attend regularly in order to be examined for signs of infection. They were known to be well in 1952, before the wife went into hiding and changed her name due to local persecution (discussed below). However, in 1954 the daughter, now aged 9 years, presented to a surgeon with numbness in her fingertips. He found evidence of median nerve paralysis and a swelling over her left wrist. An X-ray showed calcification anterior to the distal radius and in one of the metacarpopharyngeal joints. On exploration of the nerve, the operative notes reported:

'On incising the deep fascia 2 3/4 inches of the cutaneous nerve were found to be enlarged with a sacular swelling about the mid-forearm. There were obvious calcified plaques in it. The nerve and sheath had been stretched over the tumour and this had to be incised to remove a mass 2 1/2 inches long of yellow degenerated material which was easily removed, being non-adherent to the nerve. Some fluid was removed and this was sent for culture. Tumour sent for section.'

The histology from the section showed necrosis and infiltration 'consistent with a nerve abscess in a Hansen's infection'. Caseation was present, although no acid-fast bacilli were seen. Experienced leprologists from Liverpool and London, including the medical secretary of the British Empire Leprosy Relief Association⁴ reviewed the sections and the patient and agreed that the median nerve lesion was due to tuberculoid leprosy. Advice was given regarding treatment with dapsone, and the mother was advised of the non-infective nature of tuberculoid leprosy.

She was seen regularly over subsequent years, and was noted to be doing well on varying doses of dapsone. Towards the end of 1955 she developed a septic finger and axillary adenitis, and an X-ray revealed osteomyelitis of the terminal phalanx of the affected finger, which was eventually amputated. Unfortunately there was no histological report regarding the presence of leprosy bacilli in the amputated tissue that could confirm a diagnosis of leprotic dactylitis. She developed a further swelling over the proximal phalanx of her middle finger, and attended in February 1959 concerned about a further lesion. This was monitored and the finger lesion largely resolved spontaneously, despite erratic compliance with medication. She was last seen in clinic in October 1969, aged 24, when she was noted to be 'very well' other than having persistent sensory loss in the median nerve distribution of her left hand.

Medical and social responses

*'The community is imperilled by the presence of a sufferer from this disease... he goes out but seldom, and when he does he takes every care to avoid contact with other persons'*⁵

Two aspects of this case are particularly interesting—first the lack of travel history in the daughter and her acquisition of infection within the UK and second the enormous stigma associated with the father's infection, and the strong discriminatory response to his diagnosis.

At the time of diagnosis the index patient was living with his wife and their young daughter, and while conjugal infection was thought to be unlikely as adults are relatively resistant to leprosy, it was felt that he should be removed from the child. Due to the relatively high infectivity of his leprosy, attempts were made to admit the father to an inpatient leprosy treatment centre in the South of England, referred to in the local press at the time as 'a colony

for lepers'.⁶ However, leprosy was not then a notifiable disease, and therefore forced segregation and treatment were not thought to be possible. As the local press noted,

*'Corporation health authorities have no legal powers to deal with victims of leprosy, as the disease is not covered by British legislation ... The official attitude was that the matter should be dealt with by the Polish government. But efforts made in that direction had brought no results'*⁷

The attempts to have the patient admitted to the leprosy treatment centre were unsuccessful as 'the unfortunate man is an alien, and therefore not qualified for admission to an institution'⁵ to which 'only British subjects could be admitted'.⁷ Sadly, while his admission was being negotiated in early 1947, the diagnosis became known to the townspeople and there was a riot in the streets leading to questions in the Houses of Commons.⁸ However, the local press reported that there were no 'powers to deal with the case, as leprosy was not covered by British legislation'.⁶ One local newspaper reported 'two cases of leprosy in a neighbouring borough',⁶ one of whom was reported to have committed suicide. The other was 'still in confinement, and it was suggested that our patient could be sent to keep him company.' These are probably two cases referred to in medical correspondence in 1953, one of whom was notified to central health authorities. One of these was reported to have recently died, and the other was reported to be suffering from 'gross lepromatous polyneuritis, and an erythema nodosum reaction ... in a dreary institution in the middle of a large city'. Interestingly, the correspondence stated that 'it looks as though nothing will be done until some sort of public scandal is ventilated'.

A representative from the Ministry of Health attended the patient in March 1947, and within a week he was admitted to a small isolation hospital^{9,10} (Figure 1) where, according to the doctor who attended him, 'conditions were grossly inadequate'. It was noted in correspondence at the time that 'the greatest benefit of his admission to this hospital will accrue to the Minister of Health in enabling him to answer any further questions which might arise in parliament',¹¹ highlighting the political rather than medical motivation behind this patient's incarceration. It was also noted that there was 'no reason why the man should not have continued to live in his own home, with the child removed, if it had not been for the unfortunate publicity which has occurred'.¹¹



THE NEW DISPENSARY, MILL LANE.

Figure 1. Part of the isolation hospital, photographed in 1949.⁹ This was the 'fourth-rate institution' scathingly referred to by Adams—and the birthplace of one of this paper's authors (G.V.G.)!

The local press reported that this admission was 'not intended to form a permanent solution, as it could not be considered at all satisfactory'.¹² Indeed, the chairman of the Local Health Committee stated that 'the man himself would be happier in a colony'.¹² There was regular coverage of the matter in the local newspapers, and these reports were generally benign, compared with the reported hysteria on the part of the public (Figure 2).

He remained in the local isolation hospital for over a year, until in August 1948 his doctor refused to accept any further responsibility for his treatment in this 'fourth rate institution'. When the patient was told of a planned transfer to a larger hospital he made what was described as a 'rather theatrical' attempt to cut his throat. Nevertheless, he was transferred and isolated there, even further from his family, until his death in September 1948. The post-mortem report named the cause of death as disseminated tuberculosis (known to be associated with leprosy in Brazil and elsewhere¹³).

After his death, his wife and daughter continued to live in the area until 1952, when local persecution caused the wife to go into hiding and to change her name. She was last known to be working as a stewardess on a ship. When her daughter was diagnosed, the mother was advised that tuberculoid leprosy was not infectious and that the child could continue school and life as normal. Maximum discretion was advised by all parties involved in the case, and it was noted that:

'... [the mother] all but committed suicide owing to persecution by the press, the Wallasey Housewives' League and by other



Figure 2. Extract from the *Wallasey News* of 1 February 1947 concerning the 'Wallasey Leper Scare'.⁵ The paper covered the story frequently, and was generally supportive and sympathetic. Items sometimes appeared in the paper's 'Talk on the Boats' column (a gossip column referring to the local ferryboats).

agencies when the nature of her husband's illness was broadcast'.

Fortunately this discretion appears to have been effective, as there are no reports of the daughter's disease becoming known to the community or causing significant personal or social disruption.

Discrimination and dissent

These cases highlight, in the recent past, not only the highly stigmatizing nature of a diagnosis of leprosy, but also the level of misinformation among both the public and the authorities regarding the nature of the risk. It was thought that there were 'probably over 300' cases of leprosy in the UK at the time of the index patient's diagnosis, and it was noted that most of these were living unrecognized in the community and were not singled out for such discrimination and prejudice.¹¹

The diagnosis of the index case provoked a particularly vigorous adverse public response, stirred up by rumours and misinformation. The local media emphasized the infectious nature of the disease, although transmission is unlikely in all but the closest

contacts of severe lepromatous disease. Despite reassurance from the authorities regarding the low infection risk to casual contacts, the public response of fear and stigmatization was similar to that seen early in the HIV epidemic, during the 1980s, when lack of understanding about the condition and its mode of transmission led to demonstrators being arrested by police wearing long yellow rubber gloves.¹⁴ This was accompanied by scapegoating and attempts to identify and name a 'patient zero', and the labelling of various high risk groups led to discrimination and social rejection similar to that seen with our index case and his family.

Little information is available regarding these leprosy-related riots, but parallels can be drawn between these and the cholera riots of 1832 in several British and European cities, where public misunderstanding and fear led to mistrust and anger at the medical fraternity and government.^{15,16} Much of the correspondence and media attention related to the patient reported here focused on his nationality, and it is likely that at least some of the public reaction was due to his status as an immigrant. One newspaper reported two other patients with leprosy in the area, but there is no record of a significant public reaction to them and it appears that they were living undetected. This demonstrates the significance of our patient's external manifestations of disease—he was described as 'having an early leonine countenance', which would clearly mark him as different from other members of society, and single him out for discrimination.

The forced segregation and treatment of the index case demonstrates the paternalistic role of the medical profession at this time, as well as disregard for his human rights and autonomy. It was acknowledged that public hysteria was the impetus for his segregation, rather than any significant risk of transmission, and that the situation was far from ideal. His physician was eventually so disgusted with his treatment that he refused to continue his care in the original institution. As a result of the father's unfortunate experiences, extreme discretion was advised when the daughter was diagnosed. It does not appear that the daughter's diagnosis ever became widely known, and there is little information available other than her medical details. It is unclear why she was lost to medical follow-up in 1964, or whether her leprosy caused any further problems in later life.

Quarantine of suspected cases and forced isolation of patients with plague, leprosy and syphilis has been practised for centuries.^{17,18,19} The isolation of patients with leprosy was strongly influenced by attitudes of society, state and church to the role and function of the early lazarettos,²⁰ and in many

countries this has continued into modern times.^{21,22} In Japan, patients with leprosy have been compulsorily incarcerated since the early 1900s, with forced sterilizations and abortions commonplace.²³ This was formalized in 1853 by a law which remained in force until 1996, long after leprosy patients in other countries were being treated as outpatients, and over a decade after the World Health Organization declared leprosy curable. In 2001, the Japanese government introduced a leprosy compensation law and publicly apologized after a landmark ruling that this forced segregation was illegal.^{23,24,25} However, most of the patients living in sanatoria at this time chose not to leave because of continued stigmatization and fear of discrimination.^{21,23,25}

Comparison with HIV/AIDS and its associated stigma demonstrates a number of similarities. Association with being unclean and a culture of blame²⁶ led to overestimation of the significance of social contacts and restrictions of civil liberties.^{27,28} HIV was referred to as 'the leprosy of the 1980s',²⁹ and old leprosaria were used to isolate patients. HIV risk behaviour was criminalized in many US states, and a number of states authorized forced segregation orders.³⁰ Similar legal controversy accompanied the enforced isolation of patients in New York with multi-drug resistant tuberculosis (MDR-TB) a decade later,³¹ and this remains topical in South Africa where isolation has been proposed to prevent a 'potentially explosive international health crisis'.³² Risks to public health must be balanced against infringement of individual civil liberties, based on accurate information about infectivity and epidemiology, and evidence for effectiveness of any proposed control measures.³³

Autochthonous transmission?

Leprosy became a notifiable disease in Britain in 1951, and since this time there have been no definite cases of indigenous transmission in the UK.³⁴ In 1925, MacLeod described 'a contact case of leprosy... who was born in England, had never been abroad, and who contracted the disease from his father...'.³⁵ He also described two other patients over the preceding few years, who had been diagnosed with leprosy without ever having left the UK. There have been no confirmed clinical cases of autochthonous leprosy transmission in Britain since then, although 'good, though not conclusive evidence' of subclinical leprosy transmission was reported in two nurses at the Hospital for Tropical Diseases in London, who had prolonged contact with a known case.³⁶ These contacts had

positive lepromin skin tests and antibody responses to phenolic glycolipid, but no clinical symptoms of leprosy. A case of locally-acquired leprosy was described in France in 1995, though it was not confirmed that the patient had never been in an area endemic for leprosy.³⁷

It is important to consider tuberculosis as a differential diagnosis in the daughter; particularly as her father died of disseminated tuberculosis. Tuberculosis is more common and more readily transmitted than leprosy, but the treating physicians at the LSTM had extensive experience in both diseases (and one was the author of a major tropical textbook³⁸), and tuberculosis was considered in the casenotes as a possibility, but leprosy was favoured diagnostically. As the caseation was not adherent to the nerve and was 'easily removed', it is unlikely that the later median nerve sensory loss was due to operative trauma, and tuberculosis offers no other explanation for this paraesthesia. While she did have problems while taking dapsone therapy, this can be readily accounted for by the documented problems with compliance.

Our case, therefore, appears to be a rare epidemiological phenomenon, and the most recent of its type in the UK by over 30 years—tuberculoid leprosy, characterized by anaesthesia in a peripheral nerve distribution and peripheral nerve swelling,^{39,40} in a patient who had never left the UK, and who was a close genetic and household contact of a multibacillary leprosy patient. Transmission of disease from father to daughter in a non-endemic country is particularly interesting. Leprosy is relatively non-infectious to casual contacts,⁴¹ but several years of close daily contact increases the chance of infection, particularly if the index case has a high bacillary index.⁴² Leprosy is more contagious to children than to adults, and transmission is more likely between blood relatives,^{41,42} so the comment that 'conjugal infection was unlikely' was appropriate. In a prospective cohort study of 1037 leprosy patients and their 21 870 contacts, increased transmission was associated with closer genetic relationships, physical closeness and multi-bacillary disease⁴¹—all of which were applicable in this case. A recent survey in India found that most transmissions among household contacts occurred over a duration of 0–6 years,⁴³ in low-income families, with the father being the most common source of infection—conjugal infection was indeed found to be very rare.⁴¹ BCG vaccination is known to reduce the risk of infection,⁴⁴ but it is not known whether either of our patients had received this vaccine.

Conclusion

We describe what we believe to be the first autochthonous clinical case of leprosy in Britain since the 1920s, and highlight the extreme and damaging social and political responses to the diagnosis in the community. This reinforces the crucial role of a coherent policy on treatment and isolation of such patients, and the importance of strict confidentiality and public health education to avoid public hysteria. The treatment of our index patient and his forced segregation in a sub-standard facility raises important medical and ethical issues that are central to the management of many infectious diseases.³³ The ethics of compulsory detention in our patient have resonances in current approaches to multi-drug resistant TB, SARS and avian influenza. Local and national responses showed a lack of common sense or compassion in the face of irrational fears, and highlight important epidemiological and social aspects of infectious disease treatment, that are still highly relevant today.

Conflict of interest: None declared.

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