Leprosy: myth, melodrama and mediaevalism

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In northern Europe, amongst the genetic pot-pourri of our own ancestors and for at least the past millennium, leprosy has been an enduring, unchanging human experience, sufficiently dramatic to serve as an anvil on which to strike attitudes [1, 2]. The leper’s disfigurement and isolation became the symbol not only of the horrible and hopeless but also of the sinful—a defect of soul as much as of body [3].

Leprosy is in a sense a mediaeval coelacanth. The importance of the coelacanth is not that it existed but that it has survived. Little of the fossil record can be confirmed at living first hand today, but some can; some of history’s record can be confirmed directly from archaeology. Much, however, depends on the written record, but that has its limitations, not least because recorders of events have had to earn their bread, and like most of us they preferred it buttered. But the written record achieves greater credibility if it contains, often peripheral to its main purpose, objective markers clearly recognisable today.

Leprosy has not changed in a thousand years; it presents therefore a double opportunity. It provides a marker of the accuracy of social history and a chance to observe human reaction to a constant stimulus at different places at different times. More than this, the horrible appearance of the advanced disease, its slow, eventually fatal progression and its religious significance have brought to notice people whom history would otherwise have passed by.

Myths and realities

There are two common myths about leprosy: first, that it was prevalent in Europe in the Middle Ages although widely misdiagnosed; second, that the high profile of the disease arose from fear of infection. There is, however, evidence that leprosy was not common and was diagnosed accurately, at least in the lepromatous form. Further, while the advanced disease is undoubtedly disfiguring, the stigma resulted above all from the teaching of the church that lepers were spiritually unclean; there is little evidence of fear of catching the disease—but there is some.

Once firmly diagnosed, mediaeval lepers were sent to hospital. At their peak in the 14th century there were about 200 leper hospitals in Britain; they were small, most having a staff of about three and accommodation for about 10 lepers, but a few were larger, such as Harbledown near Canterbury, which could accommodate 100, and Sherburn near Durham which had room for 65. Even if all were at one time full (and there is no record of any being full) there might have been, at the very most, 3,000–4,000 lepers in hospital in a population of 3 million people. Even in 1344, before the Black Death (which, according to another myth, decimated lepers), St Julian’s leper hospital near St Albans was nearly empty.

Leprosy can be identified with reasonable confidence from descriptions in the early Middle Ages; it continues to be reported in England and Denmark until the 16th century, in Scotland until the end of the 18th, and in Iceland and Scandinavia until the 1950s. In the 19th century leprosy was a major public health problem in Scandinavia and was even exported to the United States from Norway.

The very fact that the disease which keeps cropping up over the centuries is, at the end of the chain of reports, leprosy as we recognise it today might be enough evidence that the disease was correctly recognised throughout. On the other hand, a central core of truth might have become very blurred at the edges.

Descriptions and diagnosis

Mediaeval medical descriptions were standard, but Guy de Chauliac in his Inventarium ... of 1363 divided the clinical features into certain and uncertain signs, recognising the need for degrees of confidence in diagnosis, with corresponding strictness of isolation. He recommended three stages in diagnosis: suspicion, with observation at home and continued review; strong suspicion, with ‘sentence’ and stricter isolation at home; and certain diagnosis, with consignment to hospital. Anyone declared free of the disease was entitled to receive a certificate of freedom from it.
The certain signs according to de Chauliac were thickening and tuberosity of the eyebrows with loss of their hair, disfiguration and obstruction of the nostrils, scarring around eyes and ears, and a horrible satyr-like appearance (Fig. 1). He also referred to a harsh and nasal voice. Other medical authors described a leonine appearance of some lepers.

Mixed up with these firm criteria were more fanciful features, and one may well object that it is very dangerous in medical diagnosis to take what one wants and to leave the rest; it is the details which do not fit which are so often the clue to the real answer.

It is not, however, valid to compare modern diagnostic reasoning to mediaeval reasoning. Mediaeval physicians were deeply subservient to rediscovery of the truths of the ancients, however much these were at variance with their own experience. It was not open to them to describe precisely what they saw without embellishment with what they had been taught they should see. Even an anatomist of the stature of Vesalius would fudge the detail rather than confront ancient authority. The world had to await William Harvey to declare the cardiac septum impenetrable and to take the consequences in the shape of the circulation of the blood.

We know little about the clinical diagnosis of leprosy in mediaeval Britain. Records of only a handful of diagnostic panels have survived: the members of these panels were distinguished physicians and the criteria they used were not recorded.

The clue to how leprosy would ordinarily have been handled comes from the Åland islands in the 17th century, after the Reformation but when still thoroughly mediaeval in their approach to leprosy.

Sitting at the cross-roads of the Baltic between Sweden and Finland, the Åland islands, then as now, were part of Finland, but Swedish-speaking. In 1651, in response to repeated requests over several years, a leper hospital (no more than a refuge, for there was neither medical nor nursing care) was set up on an otherwise deserted small island called Gloskar in the parish of Föglö, an island half a mile long and a few hundred yards wide, deeply indented by the sea. There is just one small flat area, part rock, part meadow, and here the hospital stood. It looks nice in summer but from December to April the sea is frozen and the snow is deep. One of the duties of the rural dean, Boetius Muur, vicar of Saltvik, was to audit, on his regular inspection visits to the parishes, the diagnosis of those suspected to have leprosy. His records over about 20 years were discovered in Saltvik church and published a century ago by a Finnish student, L. W. Fagerlund [4].

Diagnosis began with a public inspection. In 1648, for example, a woman called Kaisa, who had already been under observation at home, was ordered to 'present herself by the church wall on the next Sunday so that the people can decide whether she is leprous or whether she should remain under observation'; the 'verdict' on that occasion was for continued home isolation. Two years later she was again 'going to be inspected on Sunday and either be freed or confirmed'. Had she been able to afford the journey to Stockholm she might have been able to obtain a medical certificate of freedom from the disease, according to best mediaeval practice. Several suspects did make the journey but only one is recorded as returning with a certificate.

There appears to have been no dispute about the definite features of leprosy which were used to justify 'sentence', and therefore no need, alas, to record them, but it seems likely that, as the diagnostic procedure itself was out of a mediaeval medical textbook, the same would have been applied to the diagnostic criteria. There are some indications of these criteria in reports of doubtful cases, such as the instruction in 1650 by the sheriff's officer at Sund that men of the parish should examine a woman with particular reference to 'her skin, voice and limbs, those parts of the body where leprosy is found'.

What medical audit was there of parish diagnosis apart from occasional voyages to Stockholm? In 1671 the lepers from Åland were transported lock, stock and barrel to a leper hospital on mainland Finland. The professor of medicine from nearby Turku was sent to examine them, not out of medical curiosity or for natural justice but to see whether any might be discharged to reduce the cost of their support at public expense. Despite this incentive none was discharged. It was one of this professor's successors who in 1738 published the first Scandinavian case report of undoubted leprosy, and there is every reason to suppose that his
knowledge was based on his own experience and that of his predecessors. In Iceland a few years later a priest described and recognised in himself unmistakable symptoms of the disease which were confirmed later by the local district physician.

The competence of the church in the diagnosis of leprosy was demonstrated in Norway in the 19th century. A system of case reporting was introduced nationally involving district physicians and local priests. These records have recently been re-examined [5]; the grounds for diagnosis and subsequent course of the illness have proved a very high accuracy of diagnosis.

Aland might seem remote but it was not a world on its own. Both the tradition of accusation of being a leper and of needing a certificate of freedom from the disease to clear one’s self continued in England at about the same time, years after leprosy had probably died out here. In 1620, Nicholas Harris, footpost of Tottes in Devon, was, in his own words, after nearly 40 years of ‘long, faitefull and painfull service’, accused of being ‘an unclene manne and a leaper, not fitte to come or to be admitted into the company of clean persons’, ie the almshouse to which he had been recommended [6].

Nicholas Harris travelled to London in search of a certificate of freedom from the disease. First he visited St Bartholomew’s Hospital where, apparently without any undue commotion, he was examined by ‘ye right worshifull the President and chirurgions’ and was declared free of leprosy. Cautiously, he then sought a second opinion from ‘the President, Censores and the rest of the learned and juditious Doctors of Physick of that famous and renowned College of the Hon. Cittie of London.’ Nicholas Harris’ petition was endorsed

Fig. 2. John Berns of Shetland in the Royal Infirmary, Edinburgh, 1798.

Fig. 3. Olof Pettersen, aged 21, in St. George’s Hospital, Bergen, in 1816.

‘Wee whose names are underwritten upon this petition have viewed the body of this petitioner and in our censurrs he is free from ye imputed disease’.

Pictures

The first picture generally accepted to be diagnostic is of John Berns of Shetland from the Royal Infirmary in Edinburgh in 1798, showing nodulation over his eyebrows, with loss of their hair, papules on cheeks and forehead and possibly a facial palsy—although he may have a hare lip (Fig. 2). There is no doubt at all, however, about the diagnosis in many of a large series of paintings from Bergen in Norway by the hospital chaplain, J. A. Welhaven. The leonine appearance, referred to in mediaeval descriptions, was drawn to illustrate how leprosy could transform a man of 21 into the appearance of ‘an evil wrinkled old man’ (Fig. 3). The woman shown in Fig. 4 displays advanced neurological involvement in face, hands and feet, together with oedema of her legs, which may be the result of leprous infiltration or possibly of associated nephrotic syndrome.

The first authoritative illustrations appeared in Danielssen and Boeck’s work Øm Spedalskhed (On leprosy) in 1847, a monograph which established Norwegian doctors at the centre of the clinicopathological study of leprosy for the next half century [7]. One illustration is of a 13-year-old boy (Fig. 5) and another shows a 26-year-old woman with nodular lesions,
including one on her eye, and a facial palsy (Fig. 6). They also illustrate a severely mutilated and deformed claw hand. It was no accident that in this environment Hansen discovered the leprosy bacillus 25 years later, but it is a great tribute to him that he interpreted the bacteria as the infective cause of the disease, notwithstanding the authoritative view of his world-famous senior colleagues, Danielssen and Boeck, that leprosy was hereditary, not infectious.

Osteological evidence

There can be no reasonable doubt that leprosy, as we know it, was a well recognised if not common disease in northern Europe in the Middle Ages, but only by examining the bones of those thought to be lepers and those thought not to be can the accuracy of diagnosis of advanced disease be established.

A decree of the Lateran Council in 1179 required lepers to be buried in separate graveyards. Two large mediaeval monastery graveyards, in which one would therefore not expect to find lepers buried, have been excavated in Denmark, one at Øm in the 1930s and the other at Æbelholt in the 1940s. A large number of traumatic injuries were found, including war wounds, also osteomyelitis, tuberculosis, cancer and syphilis. Only one skeleton at Øm had mutilated limbs consistent with leprosy; it was buried in the deepest layer of the cemetery, which was first used in 1172, ie 7 years before the order that lepers should be buried apart. At the time of excavation nobody knew what leprosy would look like in mediaeval bones. Only one skeleton at Æbelholt showed mutilations but they were different and later attributed to chronic ergotism.

By a remarkable piece of detective work, a Danish school-doctor and amateur archaeologist, who had assisted with the Æbelholt excavation, discovered in the 1950s the site of the mediaeval leper hospital, its chapel and its graveyard, at Naestved in Denmark. A farm now stood on the site but Møller Christensen persuaded the farmer to permit his farmyard and garden to be excavated.

Møller Christensen discovered mutilated feet (Fig. 7) and hands quite unlike anything found at Æbelholt and identical to the one mutilated skeleton at Øm. Further, some of the skulls of these skeletons showed unique changes: resorption of the alveolar margin of the maxilla (Fig. 8), loss of the anterior nasal spine, or both. The same changes were found in the skull of the mutilated Øm skeleton (Fig. 9). These skull lesions were not found in any of the remaining 632 skulls from Øm or in the 760 from Æbelholt from the same period in the same country. Identical changes have since been found on radiographs of living lepers—first, appropriately, in Bergen and then in the Far East.

Fig. 4. Anna Nils Dotter, aged 64, in St. George’s Hospital, Bergen, in 1816.

Fig. 5. A 13-year-old boy who had been suffering from leprosy for 7 years in Bergen in 1847.
Since then, other smaller mediaeval leper hospital graveyards have been excavated in Denmark, north Germany, and south Sweden, with similar findings. Not all lepers are mutilated and not all develop skull changes, termed ‘facies leprosa’ by Møller Christensen. The fact that 155 out of 202 individuals (77%) buried in the leper hospital graveyard at Naestved over a period of 200 years had one or other of these changes indicates a very high degree of diagnostic accuracy [8].

**Reasons for separation**

Separation of lepers in the Middle Ages was essentially a requirement of church law. Whether the church was correct to equate biblical leprosy with leprosy as it existed in the Middle Ages and as we know it today is of no consequence to the present discussion. The fact is that it did make that association and, according to Levitical law, the leper was considered dead to the world, without rights to marriage or property, and required to live apart.

It would be easy, but probably wrong, to suggest that prevention of infection was the reason for the instruction that a leper should move downwind before conversing with anyone. Indeed, if containment of infection was the purpose of seclusion in leper hospitals, why let inmates out at all (they were allowed out for farmwork and begging), and how can the punishment of expulsion from hospital for misbehaviour be explained? No, the regulations of the hospital of St Julian, near St Albans, put the general position with...
brutal simplicity: ‘Since amongst all infirmities the disease of leprosy is held in contempt, ...’. The regulations continue by quoting Leviticus, ending that ‘when he is leprous and unclean he is to dwell alone without the camp’.

The extent to which fear of infection, however poorly understood, came to build upon, or even to supplant, the ritual uncleanness is a complicated matter. In 15th century Scotland fear of ‘contagion’ is specifically mentioned, and the hospital on Åland was set up expressly to control the ‘infectious plague and disease of leprosy’. Erik of Norboda on Åland, who was suspected of leprosy, was forbidden (more than once) to make and sell gloves lest they should spread the disease.

The fact is that attitudes differed in time and place. By the 19th century there seems to have been no popular fear of infection in either Norway or Iceland. The chapel of St George’s Hospital, Bergen, which still stands along with the hospital buildings unused since the 1920s, doubled as the parish church. The chaplain, Welhaven, who went straight from university to this daunting task, wrote in 1816 that parishioners and lepers shared the same pews and ‘in the extreme heat of summer pack themselves tight together even with the most ill of them without the least fear’. He also reported that relatives visiting the hospital ate with the lepers out of the same dish and slept in their beds immediately after they had got up and the bed was still warm.

Thirty years later, the experts, Daniellsen and Boeck, concluded that leprosy was not infectious, although several new hospitals had recently been opened or were about to open and the disease appeared to be increasing. Prevalence reached a peak of about 2 per 1,000 overall in Norway in 1857, but in some western districts up to 25 per 1,000 were lepers. The surge in the disease in the 19th century in Norway and Iceland has never been convincingly explained, nor has its subsequent decline, despite many theories. Figure 10 shows the number of new cases of leprosy recorded in Norway in 5-year periods from 1856 to 1935. With the exception of one small hiccup at the beginning of this century, the number of new cases has steadily fallen since the 1860s. Whatever else it was due to, the decline was not the result of isolation; only a small proportion of lepers were in hospital and they were not strictly confined.

Drama

A living death

The burial service for the living, which constituted the Office at the Seclusion of a Leper, exists both in the Sarum manual and in a French service book. The leper knelt beneath a black cloth stretched across trestles, ‘after the manner of a dead man, although by the grace of God he yet lives in body’. After Mass the priest cast earth from a spade on each of his feet saying ‘Be thou dead to the world, but alive again unto God’. The priest led the leper to and from church as for a funer-
al, chanting 'Libera me Domine' with the sick man covered with a black cloth.

On the Åland islands in the 17th century the message of death was brought home starkly in a different way. Each person entering the leper hospital had to bring, or be provided with by the parish, 'wood and nails for (his or her own) coffin'. In Bergen, 150 years later, Welhaven called the leper hospital 'a graveyard for the living ... with the doctors' best intention, insight and industry it is impossible to heal the living dead'.

A leper's divorce

The divorce saga took place in the cathedral chapter in Turku, Finland, on 15 December 1673 [3]. On at least one previous occasion a man had been given permission to remarry with the consent of his first wife while she was still alive but suffering from leprosy. Now a wife had petitioned for permission to marry again with the consent of her husband, Hans Mattson, who had been in the local leper hospital for 4 years.

The discussion in the cathedral chapter went as follows. Tammelinus, headmaster of the cathedral school, hedged; he would prefer to defer to the opinion of others but, if the highest ecclesiastical court were to grant dispensation, he would not be against.

Tunander, professor of theology, spoke next and made five points:
1. Her husband had no hope of recovery.
2. God had separated them and the husband was now dead to the world.
3. Leprosy was a unique disease and lepers must according to the Old Testament be segregated.
4. She had waited a long time already.
5. Her husband had given permission.

Conclusion: for, but did not actually say so.

Bång, also a professor of theology, disagreed with his colleague, making four points:
1. Marriage was a mysterious relationship and not altered by leprosy.
2. He disagreed with his colleague's interpretation of the Old Testament.
3. He noted that Christ compared his own relationship with the church to matrimony and did not lightly consent to divorce.
4. The woman did not suffer great hardship because, after all, she only wanted to marry a boatman.

Conclusion: she should not remarry as long as her husband lived.

Enewaldus, dean of the cathedral, tried to ensure he offended no one, making two points:
1. Marriage was a religious mystery and it was not entirely according to his conscience to separate them.
2. Decision should be deferred until Parliament reassembled.

Bishop John Gezelius the Elder, who presided, then summed up:

Such a marriage was not 'nowadays' permitted, although he had heard of two recent cases elsewhere and he would examine the circumstances and precedents when he next made an inspection visit there.
Resolved: to advise her pastor to persuade the woman not to marry another man but to remain chaste as long as her husband lived.

Hans Mattson died 6 years later; whether the boatman was still waiting patiently for his wife is not recorded.

Conclusion

Leprosy, as an endemic disease, is dead in northern Europe. It gave its last gasp in the 1950s. It had a long run, probably about 2,000 years. Around it has grown over the centuries an extraordinarily complex and deep tradition of prejudice and fear, mirrored in behaviour, language, and literature—a mediaeval tradition about to be taken over perhaps by a new disease, also not common but of high profile, AIDS.

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