

The Stigma of Leprosy— A Personal Experience*

A MEDICAL MAN

(who, for obvious reasons, writes anonymously)

Leprosy is one of several conditions which the majority of people place in a category apart—and “place apart” is what they do their best to achieve.

From the time when I worked in a leprosarium in Africa, and since then as a doctor in general practice, I have had many opportunities of discussing attitudes to illness, speaking at length and in depth with people who were suffering from infectious diseases which others shun. Leprosy is probably the most feared of all diseases, feared even by those who have never met anyone actually suffering from it.

The potential ravages of leprosy, vividly overdrawn by certain advertisements and fund-raising propaganda, evoke a complex of fears and reactions which other diseases may partly share but none can match. Most of the patients I knew in Africa were outwardly stoical from childhood, taught not to reveal their feelings. As we lived among them, friendship grew and later we gradually learned their inner thoughts. Their experiences differed, naturally. Some had known of several cases of leprosy within their immediate family, or in the locality. Although skin injuries and blemishes are very common, when a pale non-itching area on an African's skin persists or enlarges, the probability grows that it could prove to be serious. A knowledgeable friend or a visit to a dispensary would allay the suspicion, or confirm it. Sometimes patients were so terrified that they hid themselves until signs of advancing disease made their appearance. In that event, they were usually urged to seek treatment at the leprosarium.

For the patient himself, the future might be bleak and the prospects unthinkable. With little to show in the way of physical signs, they found it difficult to believe that the disease was really leprosy, and some patients refused to believe it for weeks or months.

Then what? Much depends on the family and on local feeling. Some patients were from the first excluded from the family, and deprived of possessions and inheritance. A few had their children taken away and shared out, like orphans, among relations. The wife might be sent back to her own home, possibly in disgrace. In any case, the other members of the family who remained at home shared in the disgrace, and also the fear that they, in their turn, might show the signs of the disease. In some areas, despite willingness on the part of the healthy members of the family to look after a sick relative, local opinion could be so hostile that he or she was forced to leave, to avoid personal danger and the risk of harm to the rest of the family. Sometimes a small group of patients from the same area would travel together to the leprosarium. They had been rejected, sometimes

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reviled, deprived of inheritance, and could look forward to no future. As they met and began to share their troubles, the painful experience of one became the feared expectation of the others.

About 70% of our patients came on foot, some from comparatively nearby, some from distances of up to 300 miles; others managed to obtain lifts on lorries. On the way, they found little sympathy. If they admitted they were going to the leprosarium they would be told stories of hunger and wild animals on their way, to add to their misgivings.

Leprosy patients the world over know despair and bitterness. For them, what is there left to live for? The depth of bitterness they feel has to be experienced personally to be appreciated. You are unwanted, separated from your family, unable to get work; you lose the ownership of your land which provides your food; you have an illness which won't kill you, like typhoid or malaria, but which is likely to destroy your feet, your hands, and perhaps your face.

For those who arrive at the leprosarium with just a patch or two on the skin and are otherwise perfectly fit physically, it comes as a dreadful shock, as they mix with other patients, to see what might happen to themselves. On the other hand, some were quite unmoved on being told that they had leprosy. There were even patients who seemed pleased. "No more income tax to pay: a blanket free every year; and food when I'm a cripple. I'm better off than I used to be."

What a cruel disease! True, many are fortunate enough to get treatment, a treatment that is by no means expensive or complex by Western standards, and for the sequelae (such as anaesthesia of the hands, or feet) there are simple remedies such as gloves, wooden holders for kitchenware and cups, easily made sandals, etc. For the more serious complications, such as claw hand, dropped foot, loss of eyebrows, etc., ingenious operations are being devised. With the correction of these obvious marks of leprosy, the cured patient will be much more likely to be accepted in the community.

Regrettably, for the majority of leprosy sufferers in the world today, the attitude of society to the physical disabilities of leprosy and to the sufferer himself is scarcely that to be expected in the 20th century. The title of this article refers to the "stigma" of leprosy. "Stigma" is "a mark branded on a slave; disgrace, infamy, etc.". I am sad that this still is applied to those with leprosy; it is completely undeserved. Though on the one hand I am ashamed that many continue to suffer physically when medicines and skilled help exist, on the other I am glad that the fight against this disease is steadily being won with advancing research and new treatment. More stable politics and economics, and better health education, would ensure more progress than there is at present.

Many of those who now care for sufferers from leprosy were inspired by Christian motives. They are now being joined by government Health Departments and international relief organizations, as they tackle the huge task of diagnosing and treating the disease and educating ordinary people to admit the innocent sufferers of this slightly contagious disease into the circle of humanity where they belong.