Socio-cultural aspects of leprosy among the Masalit and Hawsa tribes in the Sudan

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Summary  Social and cultural factors influencing knowledge, attitudes and practices (KAP) towards leprosy in two communities in eastern Sudan were studied to determine their effects on treatment seeking and compliance. The study was qualitative using focus small group discussions, personal interviews and direct observation. The target populations were Masalit and Hawsa, the two main tribes in the area. Knowledge about the pathological cause of leprosy was lacking but the clinical manifestations were well recognized, particularly among the Masalit, in whom the disease is more common than the Hawsa. Among the Masalit there was a widely held belief that leprosy was caused by eating meat of the wild pig and a certain type of fish. The Hawsa, who are more devout Muslims, do not eat pig and associate leprosy with consumption of two types of fish. Between both tribes, the stigma of leprosy was not strong and the degree of rejection was more towards those with severe disease, particularly patients with ulcerated lesions and severe deformities. Patients were cared for by the family and lived in a separate hut within the families’ housing compounds. In this remote area where medical services are scarce or non-existent, those interviewed did not realize that leprosy was treatable by modern medicine. This influenced the treatment-seeking behaviour of patients, who were often treated by spiritual healers and other traditional medicine practices. With the introduction of multidrug therapy and health education of patients and society, many more patients are now seeking medical treatment, indicating a change in health seeking behaviour.

Introduction

Leprosy is endemic in several parts of the Sudan; the main foci are the Southern Sudan, the western part of the country near Chad and an area bordering on Ethiopia. Sporadic cases have been reported from almost all states of the country. It is reported that leprosy was described in slaves from the Sudan as long ago as 1350 BC. In the past, patients were
confined to leprosaria, many of which have now been closed. Very little attention was paid
to the disease until the 1990s when the National Leprosy Control Program of Sudan was
started as part of the global effort to control leprosy by the year 2000 through multidrug
therapy (MDT). As Stanley Brown 2 had stated, ‘in no other disease do social and
psychological factors loom so large as in leprosy’. These factors relate mainly to the attitude
of the community to leprosy and the attitude of the patient towards his/her own disease.
Misconceptions and myths about the disease and the stigma that goes with it not only cause
untold misery to the patient, but to his family as well. Where the stigma is strong the patient
may quit home permanently, joining the anonymous society of street beggars, a not
uncommon phenomenon in the towns and cities of endemic countries. The family is also
tainted with the stigma, particularly in societies where the disease is thought to be inherited.
Furthermore, lack of knowledge about the true cause of the disease and that it can be
successfully treated medically makes the patient seek help from spiritual healers or resort to
the use of harmful traditional remedies that are not only ineffective but may add to the known
mutilating effects of a neglected disease. The success of a leprosy control program and
rehabilitation of disabled patients depend to a great extent upon an understanding of the
socio-cultural aspects that affect knowledge and attitudes of patients and the society towards
the disease. 3 Rehabilitation can be achieved by building on the expertise of professionals or
by identifying the caring capacity available in the family and the community and to reinforce
it. Rehabilitation also seeks to change the attitudes that prevail in the community under
study. 4 Questionnaires are usually used to determine the impact of socio-cultural factors on,
and also to predict the chances of compliance with, leprosy control measures. 5 Since 1990 we
have been working on visceral leishmaniasis under a primary health care setting in a cluster of
hamlets and small villages in Gedarif State along the Rahad river about 600 km south east of
the capital, Khartoum. We soon found that several cases of leprosy reported to our field clinic;
with time their number increased and by the end of 1997, we were caring for 400 patients.
Many studies have been conducted in Africa and elsewhere to study the socio-cultural aspects
of leprosy and their impact on control programmes. 3,5–12 This paper reports on the socio-
cultural aspects of leprosy in villages inhabited by two ethnic groups, the Hawsa and Masalit
in the Sudan.

Materials and methods

OBJECTIVES OF THE STUDY

The objectives of this study were first, to gain information about patient and community
knowledge, attitudes and practices concerning leprosy, and second, to use collected
information to correct misconceptions about the disease and to motivate patients to seek
treatment.

METHODS, STUDY DESIGN AND RECRUITEMENT OF PATIENTS

All patients were seen in temporary field clinics established in Um Salala and Koka villages,
Gedarif State, eastern Sudan. The clinics were established during our field visits in April
and November each year. Patients from the two villages and the surrounding villages self
reported to the clinic. One hundred and ninety consecutive patients were included in the
study.
This was a comparative study of the levels of knowledge, attitudes and practices among patients with leprosy in two distinct ethnic communities in eastern Sudan.

STUDY AREA

The village of Um Salala (population 1400) was founded in 1969 on the eastern bank of the Rahad River by members of the Masalit tribe who migrated from Darfur State, which borders on Chad. Leprosy is endemic in their original homeland. With the drought that hit Darfur in the mid-1980s, many more tribes in addition to the Masalit arrived in increasing numbers in the area. The inhabitants of Um Salala are labourers and subsistence farmers living in grass huts under conditions of poor hygiene. People in the village mix quite freely and women work in the fields and at other jobs such as woodcutting in addition to their household duties. Koka village (population 1000), 35 km north of Um Salala, was established 50 years ago by Hawsa from Northern Nigeria. They are farmers, fishermen and traders. Their standard of living and level of nutrition are much higher than the Masalit of Um Salala. The Hawsa are quite conservative and men dominate the society. Young girls marry at the age of 12–14 and once married they stay at home and are not allowed to do any work outside their homes.

Malaria, visceral leishmaniasis and leprosy are the most important infections in Um Salala. In Koka malaria is meso-endemic but visceral leishmaniasis and leprosy are much less than in Um Salala. The total number of leprosy cases in Um Salala and Koka by December 1995 were 22 and 4, respectively.

OPEN INTERVIEWS WITH THE VILLAGERS

Focus group discussions

From each of the two villages, a group of 12 men and 10 women were selected to represent individuals of various ages and standing in the community. Males and females were interviewed separately. It was important to include not only community leaders but also others. This was an easy task to do because we had personal knowledge of all villagers from our long contact with the community. It was essential to exclude patients with leprosy for fear that this might influence the discussion. The discussions were under the guidance of one of us who had longest contact with the community. The questions were open-ended, the moderator making sure that his role was to guide the discussions and give every individual the opportunity to express his or her own point of view. The moderator was aware that he should not in any way indicate his approval or rejection of any of the views expressed by the participants. The objectives of the study were made clear to the group and it was emphasized that the results would help in promoting health education regarding leprosy and thus help in preventing the disease and in the proper management of individual patients. At the end of the session, the participants were encouraged to put questions to the moderator. The latter re-discussed the views expressed by the participants and informed them about the cause of leprosy, how it is transmitted, methods of diagnosis, the importance of reporting early and the availability and efficacy of modern medical treatment. Success of treatment was shown in pictures taken of patients from the area who had been successfully treated. Misconceptions and myths about the disease were carefully tackled in order not to offend the participants while at the same time making sure that misconceptions about leprosy
were corrected. At the end of the discussion, responses were recorded in the form of notes as it was felt that using a recorder might inhibit discussions.

Interviews with individual patients

This was conducted in a questionnaire-based form on patients attending the clinic. The questionnaire included demographic data, the form of leprosy the patient had, history of medical or traditional treatment, the patient’s view as to the cause of his disease and what social or economic effects the disease had on his/her life. Patients were also asked about their knowledge about availability of treatment (MDT) for the disease. Since most patients were illiterate the questionnaires were read by the interviewer and the answers recorded. The patients were interviewed and examined as part of a general practice clinic along with patients reporting with other diseases.

Direct observation

Visits were paid to the homes of patients who failed to report to the clinics. It was then possible to confirm the information obtained from the group discussions and interviews with the patients.

Health education

Health education was started following group discussions and/personal interviews to correct misconceptions and to enlighten the patients. The cause and manifestations of leprosy and its treatment were explained. It was stressed to the patients that leprosy was now a treatable condition and that it was important for him or her to take the drugs regularly and to report for follow up. It was essential to inform patients with severe disabilities that the treatment would arrest their progress, but return to full function was not possible. They were taught to exercise affected muscles and how to avoid injuring anaesthetic parts of the body. Methods of avoiding dryness and cracks in the feet by soaking in water and rubbing with oil were also prescribed. Masalit females work in farms and collect wood from woodlands in addition to the house duties. A cause of disability, in addition to injuries sustained during their outdoor activities, are burns acquired during cooking, particularly the preparation of Kisra, which is sorghum bread prepared in the same way as Chapati in India. They were advised not to engage in this activity if another unaffected female could do the job. Another item of food that is equally common in the area is Aseeda, which is a form of porridge prepared from sorghum and eaten with stewed fish or meat and vegetables. Its preparation is less hazardous than Kisra and patients were encouraged to eat Aseeda rather than Kisra.

Results

Cause of leprosy

In the group discussion the participants of Um Salala stated the following as the cause of leprosy:

1. All participants believed that leprosy is caused by eating meat of wild pig, ostrich, monkey, python and a certain type of fish known locally as Um Kur.
2. A third of participants believed that eating Dalaib (*Borassus aethiopium*) was the cause of leprosy. They deduced this from the fact that they observed a high frequency of leprosy in the village of Dalaib where this fruit is abundant.
3. Ninety percent believed that the disease tended to run in families.
4. They did not believe that leprosy was due to witchcraft or the evil eye.

All participants from the Hawsa tribe believed that eating two particular types of fish known locally as Garmut (*Clarias lazera*) and Surta (*Heterobranchus bidorsalis*), especially if accompanied by drinking milk during the meal, was a major cause of leprosy. The Hawsa diet consists mainly of fish but they eat only *Telapia* and Nile perch. Another cause mentioned was having intercourse during menstruation. Some mentioned witchcraft and evil eye but there was no general agreement on this.

Both the Masalit and Hawsa believed that leprosy could be transmitted from a patient with ulcers or nasal bleeding either by flies or direct contact. However they did not know what was actually being transmitted.

**MANIFESTATIONS OF LEPROSY**

All participants from the Masalit mentioned the following as signs of leprosy and recognized three forms:

1. Skin rash with a lighter colour than the rest of the body. The rash resembles Bahag (*Tinea versicolor*). This form is associated with loss of sensation and digits.
2. Swelling of the face and legs. This is associated with a blocked nose and hoarseness of voice, followed by loss of digits. Both types cause heavy sweating and the patient was unable to stand in the sun for long.
3. Complete loss of pigment but without deformity. They referred to this as Baras (vitiligo) and called it red leprosy. They believed that it was the least harmful form.

The knowledge of the Hawsa about the manifestations of leprosy was less detailed than that of the Masalit. Most participants mentioned swelling of the face, deformities, red eyes, hoarseness of voice and nasal voice, but they did not have a classification for the disease.

**ATTITUDES AND PRACTICES**

Among the Masalit, the patient lives with the family but in a separate hut and eats alone using separate utensils. A female relative washes his clothes separately. Infection, they believed, may spread through food, coitus or by flies, particularly when they had landed on the bleeding nose of the patient or his ulcerated skin. The majority would not employ a patient with leprosy, particularly those with ulcers and severe deformity. They would not allow their children to play with children of a leprosy patient, but we failed to confirm this by direct observation.

The same attitudes were voiced by the Hawsa, who added that they would employ a leprosy patient with a claw hand but not one with ulcers, since they believed that the former is not infectious. They would not marry an ex-wife of a leprosy patient even if she had no signs of disease.

Among the Masalit and Hawsa, an affected wife is rarely divorced but the husband does
not have intercourse with her. She is kept and cared for within the family. However, the husband may marry a new wife if he has not another already in this polygamous community. Similarly, the wife does not divorce the husband with leprosy. In this Muslim society, it is difficult for a woman to divorce the husband and the legal procedures in the Muslim courts are cumbersome. It is much easier for the husband to divorce the wife by simply declaring this to her directly. Among the Masalit, three of our cured patients remarried.

Before our group introduced MDT, the patients did not realize that there was medical treatment for leprosy. This attitude changed dramatically after they witnessed the results of medical care. Patients used to be treated by traditional healers. One such method is Mihaya: verses from the Holy Koran are written in ink on polished wood (Loah). The writings are washed with water and the resulting fluid is drunk and or used to bathe the affected parts of the body (Figure 1). Roots of certain plants are cockaded and usually rubbed on the affected skin. Some patients used cautery. The use of roots and cautery were often followed by keloids, which caused further disfigurement.

KNOWLEDGE, ATTITUDES AND PRACTICES AMONG PATIENTS

Ninety percent of patients believed that they became infected from eating items of food mentioned by representatives of the community. They referred to leprosy as ‘disease of the blood’, avoiding the word leprosy. Except for those with severe deformities, patients were usually self-employed as traders, subsistence farmers or worked in the local charcoal industry. Those with advanced lepromatous leprosy and severe disability were unemployed and were cared for by the family. They spent most of their time in their huts and did not mix with people outside the family circle. They accepted their isolation without bitterness. Among the Masalit, women work as farm labourers in addition to their household duties if they are not severely disabled. Young unmarried girls were anxious to hide their disease from others. The worst time for the patients was when they developed a reaction. They became extremely depressed and needed encouragement and support from the family and the treating team. Eighty percent of patients refrained from eating goat or camel meat, under the mistaken belief that this made their disease worse.

Discussion

The Eastern State of the Sudan is endemic for leprosy. The Masalit and the Hawsa migrated respectively into the area from Western Sudan and Northern Nigeria, both of which are areas endemic for leprosy. Not surprisingly, therefore, their knowledge about the manifestations of leprosy is remarkably good, particularly among the Masalit. They confused leprosy with vitiligo, which is also the case in many parts of the Sudan. Although they realized that leprosy was infectious, they lacked knowledge about the infectious agent and associated the infection with consumption of certain items of food. Among the Masalit, eating meat of wild pig was considered the main cause of leprosy. When asked why they ate this if they knew that it caused leprosy, they stated that they bought dried meat from poachers of wild animals, who sometimes sold pig’s meat as gazelle’s. The Hawsa, who are more devout Muslims, do not eat pig’s meat and consequently, do not buy any meat from poachers for fear of unknowingly being given this taboo food.

The association of the pig with leprosy is an old one. In ancient Egypt, where the pig was
sacred, it was believed that drinking pig’s milk caused leprosy. Analogous views are held by certain tribes about animals and plants that they hold most sacred. At one time in the island of Water (between New Guinea and Celebes), people believed themselves to be variously descended from wild pigs, crocodiles, turtles and that a person eating the animal from which he descended would get leprosy. The Syrians in antiquity, who held fish sacred, believed that eating fish would cause their bodies to break out in ulcers. Patients with leprosy do not eat goat or camel meat. In Senegal, even some healthy individuals avoid eating goat meat because of the belief that it can transmit leprosy or reveal incubating diseases.

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**Figure 1.** Verses from the Holy Koran written on wood (Loah) in ink. When the ink is dry, the verses are washed with water and the fluid is used as a drink and for bathing the affected skin.
In the early part of this century, some workers in the Sudan believed that badly cooked fish was a vehicle for transmission of the leprosy bacillus. Anderson supported this in 1908 in Kordofan province of Western Sudan, where he observed that there was a close relation between leprosy and localities where fish eating was common, while the disease was unknown in areas where there was no fish consumption.

Traditional medicine is widely used in the Sudan for the treatment of many diseases, including leprosy. Among the Muslim tribes, Mihaya is usually used as described under results. In Kordofan Province, a special method of preparing Mihaya for leprosy was used. A verse from the ‘Surat El Ekhlas’, (Chapter of Sanctity), is written 1000 times on Garad (fruit pods of Sunt tree, Acacia arabica, or on small pieces of paper. A decoction from this is then brewed, drunk in large quantities and rubbed over the entire body. This practice was generally due to their strong belief of the healing powers of the Quran and not to their belief in evil eye as a cause of the disease. Among the Nuba of Kordofan who are mostly pagans, scarring of the skin is practised, after which decoction from the roots of the Buda plant or the bark of El Talih El Hamra (Acacia seyal) or a mixture of both is administered in large doses and a course of warm baths or fumigation is indulged in. Apparently, these remedies are still practised. Many, if not all of our patients use Mihaya and some admit to using roots. We suspect that roots are used more frequently than the patients admit.

In conclusion, the communities in this area were well aware of the clinical manifestations of leprosy. Although they knew that the disease was infectious, they did not know about the causative agent. The stigma of leprosy is not strong. Patients who were cured by MDT were re-integrated into society. The community is now realizing that leprosy can be treated medically and many of the patients are now reporting to our clinics in a comparatively early stage of disease.

References