Health Systems Research

Competition: winning article

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Bringing leprosy into the open

A study in Sarawak, Malaysia, revealed diverse opinions, prejudices and degrees of knowledge about leprosy among various ethnic groups. The information gathered was used as the base on which a health education package relating to the disease was established. It is intended that this will lead to the early detection and treatment of a higher proportion of cases than has previously been possible.

Although leprosy is not usually fatal, it can exact a high psychological and social toll on its victims, who are often shunned by other people. There may be a strong desire among sufferers to conceal the disease, thus forming a hidden reservoir of infection. Eventually, of course, deformities become obvious and concealment is no longer possible. Before the introduction of dapsone to combat leprosy, the isolation of patients was considered the only method of protecting other members of society against the disease. More recently, leprosy control programmes have involved surveys, education and treatment. None the less, case-finding and case-holding continue to present difficulties.

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Sarawak's leprosy control programme was started in 1974. By the end of 1986 there were 1180 registered patients and it was estimated that 1000–2000 additional cases remained undetected in the community. On average, just over 30 new cases were detected annually during the period 1975–86, making a total of 362 for the 12-year period. New cases were detected through contact-tracing, occasional expensive surveys, and self-referral. The rate of detection was low and victims were often not discovered until their deformities could no longer be concealed.

Case-detection has traditionally consisted of expensive epidemiological surveys covering the very small proportion of longhouses (communal habitations) where leprosy had previously been detected. There was a clear need to acquire information on people's views and assumptions about leprosy so that an appropriate health education package

aimed at early detection and self-referral could be designed. A study was therefore carried out to identify and quantitatively assess cultural beliefs, knowledge and prejudices in the Chinese, Malay, Iban,

The people's knowledge, fears and misconceptions were woven into the package so as to maximize the probability of winning acceptance for new ideas.

Bidayuh and Orang Ulu communities regarding leprosy, especially its nature, cause, transmission and curability. Informal open-ended talks were conducted with key persons from these ethnic groups, and this led to the formulation of a structured questionnaire and its use over 12 months to obtain quantitative data from 388 interviewees. The study covered rural Iban and Orang Ulu longhouse dwellers, rural Malay and Bidayuh communities comprising nuclear families, and urban and rural Chinese in linked shophouses or individual farmhouses.

Perceptions and attitudes

Of the ethnic communities studied, the Chinese had the greatest fear of the disease, largely because of deep-seated prejudices about its etiology and modes of transmission. The word "leprosy" often conjured up an image of rotten flesh and crooked fingers and toes. The disease was thus only recognized at an advanced stage. The lack of knowledge about the early signs of leprosy may be partly explained by the unwillingness of patients to show themselves to other people. It was thought by 41% of the Chinese respondents that leprosy resulted from contact with prostitutes, while 32.5% blamed heredity. The third most frequently mentioned cause, given by 10%, was the consumption of "wrong" food; for example, it was believed that eating goose or red-faced duck during an attack of measles could lead to leprosy. Almost all the Chinese respondents wanted to have absolutely nothing to do with lepers. Their prejudices and fears were so intense that they did not even want to have any direct or indirect contact with utensils, food, clothes, bedding or soap used by leprosy patients.

Having observed that leprosy seemed to run in families, 41.8% of Iban respondents believed that it was hereditary. Low resistance and "dirty" blood (17.7%) and germs (12.8%) were considered to be other major causes; "wrong" food (2.8%) and mosquitos or flies (1.4%) were also mentioned. The disease was considered curable by 82% of the interviewees, and 54% said they would visit a leper's house. However, 76% disapproved of the sharing of food, utensils or soap with lepers, and 69% also disapproved of the marriage of non-lepers to lepers.

Almost all the Bidayuh respondents (96%) had seen lepers and could identify someone in the advanced stages of the disease; 67% said that they did not know the causes of leprosy, although 8% attributed it to "wrong" foods and 15% blamed low resistance and "dirty" blood. In spite of the fact that 81% of the respondents said that leprosy was infectious, 52% were uncertain as to the mode of transmission. Thus, unlike the Chinese, the Bidayuhs did not have any definite views on leprosy. They had relatively low rates of disapproval of a man or woman marrying a leprosy patient or a relative of a leprosy patient.

The Orang Ulus had the least prejudice against lepers; 72% had not seen leprosy

and 53.5% did not know the cause; 15.5% attributed the disease to the consumption of the "wrong" type of food, while 11% blamed an evil curse. It was thought by 55% that proximity to lepers could result in transmission; 32% did not claim to know the mode of transmission.

A majority of Malay respondents did not claim to know the causes of leprosy and were not familiar with the disease. The principal supposed causes included evil curses, mosquitos, flies, and contact with lepers. Transmission was attributed to contact with lepers by 32% of the respondents, whereas 62% did not claim to know the mode of transmission. Leprosy was said to be curable by 70% of the interviewees.

Health education package

The survey showed that the main differences in perception and attitudes lay between the Chinese and the other ethnic groups. The health education package that was developed focused only on a few key elements, namely the cause, mode of transmission, and curability of leprosy, its early signs and symptoms, the importance of early treatment, and the consequences of delayed treatment. The people's knowledge, fears and misconceptions, as revealed by the study, were carefully woven into the package so as to maximize the probability of winning acceptance for new ideas.

Prototype materials were tested in the field, then modified in response to suggestions from medical staff and the people at large. Copies of the revised versions were distributed throughout Sarawak. Staff in the *klinik desa* (health centres) were trained in the use of these materials. The package was produced in versions for adults in longhouses and villages, and children in primary schools. The different interests and concerns of adults and children were thus taken into consideration.

A cartoon tape-slide show is being used in longhouses and villages. After preliminary tests, it was decided that a tape-slide show would be appropriate as it would be inexpensive to produce and could easily be taken to remote places. Included in the script are elements of the people's misconceptions and fears concerning leprosy, which are shown to be unfounded. Before each showing, a health education talk is given, with the aid of slides, and both early and late signs of leprosy are indicated. This package is available in Bahasa Malaysia, Iban, Bidayuh and Kayan.

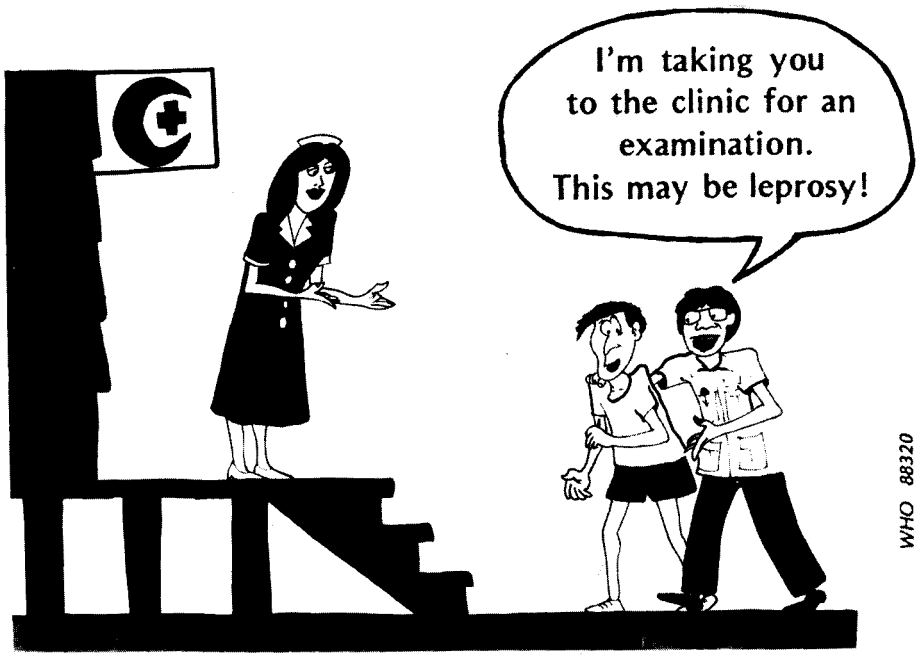
Two posters were designed and subjected to a simple field trial in order to assess their suitability for use in rural areas with high rates of adult illiteracy. The more effective one was produced in Bahasa Malaysia, Iban, Kayan, Chinese and English (see figure) and distributed to all hospitals, dispensaries and rural clinics.

The press was felt to be the most effective medium for reaching the Chinese public in Sarawak, and articles with the following titles were published.

- What is leprosy?
- The cause of leprosy.
- The incubation period, clinical manifestations and diagnosis of leprosy.
- The prevention and treatment of leprosy.
- Leprosy in Malaysia.
- The problems of leprosy in the world.

The health education package for children consists of a book containing a cartoon story set in a rural boarding school of the kind found throughout Sarawak. The book, in Bahasa Malaysia, Iban and Chinese, has been distributed to all primary schools.

Part of a poster distributed to hospitals, dispensaries and rural clinics.



Evaluation and follow-up

Studies on the knowledge and perception of *klinik desa* staff and the identification of case-finding problems have led to the development of task-orientated training workshops. Initial success can be measured by the:

- enthusiasm of *klinik desa* staff;
- establishment of a regular health education programme aimed at increasing case-finding through self-referral;
- reorganization of some aspects of the leprosy programme to increase case-holding, e.g., provision of travel allowances for patients where necessary;
- adoption of the project by the Sarawak Medical Department and the sending of monthly reports to the University;
- request from the Medical Department for a similar project to assist the tuberculosis programme;
- commitment of the Medical Department to meeting approximately half the cost of the workshops;
- strengthened educational activities in respect of other health matters, such as immunization and child care. □

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