

SPECIAL ARTICLE

Health education to aid leprosy control in Nepal: Lepra Elective Study*

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Introduction

Leprosy is curable, but remains one of the most feared diseases of the Third World. This is not surprising, because the handicaps caused by untreated leprosy reduce sufferers' abilities to perform physical work and thereby to earn enough money to survive in developing countries.

Unfortunately, the potentially disastrous effects of leprosy have increased stigmatization of the disease and isolation of its victims. This means that sufferers in the early stages of the disease, suspicious of the diagnosis but fearing social isolation, are reluctant to seek help. This is a serious problem since effective management of leprosy, using multidrug therapy and techniques to help prevent disability, must be started as early as possible to prevent progression of the disease.¹

In endemic areas, where the majority of cases are detected by self-reporting, it has been shown that earlier presentation of sufferers is encouraged by raising public awareness about leprosy.^{2,3} Such health education schemes are designed to develop a high index of suspicion about leprosy among health workers and the general population and tend to concentrate on leprosy's existence as a transmissible disease, its symptoms, the need for prompt medical treatment and its amenability to cure.

In this report the authors, both final year medical students at Oxford University, have made use of an eight-week period spent on elective in Nepal to study health education and social attitudes towards the leprosy in that country.

Leprosy is a serious public health concern in Nepal and has a prevalence of over 12 per 10,000 in 19 of the country's 75 districts.⁴ (WHO target for leprosy elimination is 1 per 10,000 by the year 2000.)

Unfortunately, the combination of tight socioeconomic limitations and unforgiving hilly terrain means that government capital available for effective public health measures and widespread health education is very limited. Resources available for leprosy control are no exception and the disease remains a major public health and social problem.

Numerous international voluntary organizations play a vital role in leprosy work in Nepal and in recent years have worked increasingly in close cooperation with the Nepali Ministry of Health and its Leprosy Control Programme. At present, Nepali policy is aimed at reducing the

* This study was undertaken during an 8-week period as a Lepra Elective Student.

prevalence of leprosy by training local health workers about the disease and instituting widespread health education about the disease's features and the importance of early treatment.⁴

This report reviews current opinion about the place of health education in the control of leprosy and draws specifically from the authors experiences in Nepal.

Information gathering in Nepal

Information was obtained by interviewing doctors in leprosy mission hospitals, volunteer workers at the headquarters of two leprosy relief charities and health workers in tuberculosis/leprosy health posts in three villages in the Eastern region of the country. Seven interviews were conducted by the two authors and were between 25 and 50 minutes in total duration.

The interviewing style was deliberately informal. The interviewees were asked open questions and encouraged to voice their own opinions. The interviews were designed to allow the respondents to express their ideas and to have as much free speech as possible and not to constrain them to answering set questions. The interviewees opinions on certain issues were sought in each case, as follows; How well does the local population comprehend the disease of leprosy? What are the population's attitudes towards leprosy sufferers? Has health education perceptibly changed local attitudes? and Are any local health education initiatives especially effective?

The interviewees were: Dr Mark McKenzie; Anandaban Leprosy Hospital; Dr Dhundi Raj Paudel, Chainpur Health Centre; Mr Harka Bdr Gurung, BNMT Khandbari; Mr Kirtiman Grl, BNMT Ditel; Mr DK Chapagain; Netherland Leprosy Control Project; Mr Shir Narayan Chaudhary; BNMT Bojpur; and The Director, BNMT Headquarters (East Nepal), Biratnagar.

In an attempt to provide a semiquantitative indication of social attitudes towards leprosy, a questionnaire was used whilst the authors worked with the Gurkha Welfare Trust in the Eastern Region of the country. Subjects were retired Gurkha soldiers and their families who attended Gurkha Area Welfare Centres as patients. The aims of questioning were: to establish the extent of the subjects' contact with the disease either through experience or education; to establish the understanding of leprosy as a transmissible, curable disease; and to explore attitudes towards sufferers of leprosy.

Each patient seen at the health centres was asked to help the authors by answering a few questions when their medical consultation had finished. The eight simple questions were devised in conjunction with Dr Mark MacKenzie of the Anandaban Leprosy Hospital and the authors' Nepali language teacher Mr B. Devkota. Questions were in the Nepali language and were designed to prompt simple 'yes' or 'no' answers (Table 1).

Unfortunately, despite early successes using the questionnaire in a pilot study in Kathmandu, the method did not work well in rural East Nepal where dialects are different. Out of 13 East Nepali subjects that were initially interviewed, only one was able to understand the verbal questions and give answers that the authors could confidently translate. The remaining 12 were only able to complete the questionnaire with assistance from local health workers fluent in Nepali. This requirement is a potential source of bias as there was no way to verify that their translations were accurate. In addition, the authors found that the process of asking patients several questions after their medical appointments was very time consuming and caused the clinics to run unacceptably late. This became a particular

Table 1. The interviews with Gurkha Welfare Centre patients proceeded as follows.*Introduction*

ma student doctor hu, mero desh belaayat ho
[I am a student doctor, I am from the United Kingdom]

ma kustarogko/maharogko baaremaa anusandhaau gardaichhu
[I am doing some research into leprosy]

ma tapaailaai kehprasua sodhna chaahanchhu
[I would like to ask you some questions]

tapaailaai kustarog/maharog bhaeko chaina
[You do not have leprosy]

Questions

maharogko/kustarogko baaremaa sunnubhaeko chha?
[Have you heard of leprosy?]

kasailaai maharog/kustarog bhaeko thaahaa paanubhaeko chha? (pariwaar ki saathi)
[Do you know anybody who has had leprosy? (family or friends)]

kasailaai tapaailaai maharogko/kustarogko baaremaa sikaeeeko chha?
[Had anybody ever taught you about leprosy?]

Maharog/kustarog purnaruple niko huna sakchha?
[Can people with leprosy be completely cured?]

Maharog/kustarog bhaeko/laageko maanchhelaai aru maanchhebhandaa taadhaa rakhnuparcha?
[Is it important to keep people with leprosy away from other people?]

Maharog/kustarog bhaeko maanche, baseko gaaumaa, basna khatraa huncha?

Maharog/kustarog bhaeko maanche, baseko gaarmaa, basna khatraa huncha?

Maharog/kustarog bhaeko maanchelaai chhuna khatawaa huncha?

[Is it dangerous to —live in the same house as someone with leprosy?
—live in the same village as someone with leprosy?
—touch someone with leprosy?]

Tapaaailaai kustharogiko samparkabata kustarog lagchha ki lagdina?
[Could you catch leprosy from someone with leprosy?]

kustarog sarab ho?
[Is leprosy a punishment from God?]

problem on days when the welfare centres payed pensions as the medical cells were already busy.

Discussion

THE IMPORTANCE OF HEALTH EDUCATION IN LEPROSY CONTROL

It is now widely recognized that health education is an essential component of leprosy control:

In 1982, the International Federation of Anti-Leprosy Associations (ILEP) summarized the aims of health education as:

- to correct by dissemination of the truth in simple terms popular conceptions about leprosy and the stigma that these engender;
- to increase the index of suspicion about leprosy in first, the patient himself, so that he

seeks advice early, and second, in all medical workers, so that they consider the possibility of leprosy at an early stage in the disease;

- to create public support for leprosy patients in their efforts to obtain treatment for the disease;
- to ensure that leprosy patients maintain their place within the family and the community; and
- to show a realistic appreciation of the benefits of antileprosy treatment in preventing progress of the disease and deformity, so that patients will continue their treatment as long as is necessary.⁵

Lennon has argued that the first step in any successful leprosy control programme should be to overcome the stigma of the disease. He suggests that there should be an emphasis on leprosy case-finding, but that if the problem of stigma has not been addressed before leprosy sufferers are identified then results of any programme might be disastrous:

‘People will often avoid detection until their leprosy has developed into a more advanced stage, making treatment and cure more difficult’.

He suggests that if the social basis of stigma is not tackled then leprosy sufferers may become socially isolated.⁶

This concept is consistent with the authors’ own experiences: It is frequently the case that young Nepali women who are diagnosed as leprosy sufferers have great difficulty in finding a marriage partner. Such a woman may often only be able to marry another sufferer. The problem is made worse in Nepali society because the younger members of the typical extended family are expected not only to become self-sufficient as in the developed world, but also to support the older generations. The potential loss of earning capacity of a daughter diagnosed as having leprosy, who is unable to wed, may place considerable strain on her family. In addition, stigmas such as the misconception that leprosy is hereditary may also cause isolation of the family unit.

Thus, the social and family consequences of the disease are potentially great on the young Nepali woman and her family, and pressures on her to avoid the diagnosis are huge.

This problem is not confined to Nepal. Valencia mentions that the stigma leprosy engenders in Indonesia can result in the loss of job and family, whilst in India, female sufferers are often unable to marry.⁷

Sandhu has suggested that health education should become a high priority against diseases where sufferers have become a prey to social prejudices. Such prejudices are deeply engrained in culture and require education programmes to be sustained indefinitely to have a significant impact.⁸

Health workers interviewed in Nepal also referred to the widespread idea that leprosy is viewed as a curse or punishment from God.

Mr D. K. Chapagain, a health assistant at the Netherland East Nepal Leprosy Control Project (ELCP) in the city of Biratnagar on the Nepali–Indian border, drew a distinction between Indian and Nepali attitudes. He suggested that Hindu Indians passing through the clinic were more likely to regard leprosy as a punishment for evil acts committed in a previous life, whereas an increasing proportion of the Nepali patients regarded the disease as a medical problem. Followers of Hinduism would often avoid social contact with sufferers of leprosy, he said, not through fear of contracting the disease, but because of a belief that it was best to avoid people that had done so much wrong in a previous incarnation.

The perceived low status of leprosy sufferers in the Hindu religion is perhaps exemplified

by the fact that sufferers are not allowed to be cremated on the burning ghats on the River Ganges at Varanasi, the most holy site in the Hindu religion.

This type of religious stigmatization is well documented elsewhere: Bijleveld reports that in Indonesia, leprosy is regarded as a curse from God but points out that when challenged, no one is able to cite a passage from the Bible or Koran to support the notion of leprosy as a curse. He goes on to suggest that, religious teachings may be able to be used, with the help of local spiritual leaders, to overcome notions about health that are unfounded in the respective faith.⁹

Health workers interviewed at BNMT posts in Khadbari and Bojpur, two towns in the rural east of Nepal, reported that leprosy sufferers were still becoming ostracized from the community to some extent, but thought that there had been a perceptible change in attitude, with the extensive education campaign, in the last 5 years.

Their impression was that whilst the more elderly people often still regarded leprosy as a punishment from God, the younger generations had a better concept of the disease as a transmissible and curable condition. This impression is based purely on the health workers' own anecdotal experiences, but is consistent with studies in Nepal that have shown a change in attitudes and an increase in case-finding since the introduction of widespread health education schemes.¹⁰

Mr Chapagain, suggested that another explanation for what he saw as the recent destigmatization of leprosy was the recent twinning of the medical care of leprosy with tuberculosis, a disease which he feels more widely acknowledged as a medical condition. These two conditions are soon to be managed at district level by the new government employed leprosy/tuberculosis/sexually-transmitted disease (L/TB/STD) assistants supported and trained by supervisors from The Leprosy Mission.¹¹

While reducing the stigma attached to leprosy is designed to encourage earlier presentation, education must also inform susceptible individuals about the symptoms of the early stages of the disease.

Studies to establish the level of awareness about the condition should be carried out before health education programmes begin, so that resources can be most efficiently allocated, and should be repeated to help establish the education programmes' efficacy. The vast majority of such studies relate to India, which is better resourced than Nepal, and which has a population of 928 million with the highest national incidence of leprosy of any nation in the world.

In Mangalore, Shetty *et al.*¹² used a survey of community knowledge and attitudes about leprosy as a basis for a health education programme there. When asked the cause of leprosy, only 8% of people (who had never suffered from leprosy) answered correctly, with 15% of those surveyed able to describe the common symptoms. A relatively high proportion (54%) believed that the disease could be spread to others, although only 19% believed that spread was 'due to close proximity with a case'. The authors of the study concluded that there was an overall lack of knowledge in the basic ideas of leprosy and the health education programme was then designed to address these points.¹²

A similar survey of nine villages and six urban slums in Tamil Nadu State, India carried out by the Indian Leprosy Control Programme showed that there was a high lack of knowledge about the cause of leprosy. It found that 81% of the community (non-patients) and 75% of leprosy patients had 'insignificant-to-little awareness of disease causation'. It was also found that 73% of people surveyed were against social contact with leprosy patients.¹³

A study of attitudes of leprosy patients done in Agra, India indicated that over 80% did

not understand the cause of the disease, and believed it to be due to past sin, fate, curse of God or other causes. The authors of the study emphasized the need for health education, saying that the low level of understanding among leprosy patients about their own condition suggested that the community's understanding would be even poorer.¹⁴

Matthews & Jesudasan surveyed the leprosy knowledge, attitudes and practices (KAP) of a community in South India before and after a leprosy health education project. The evaluation of the project showed a favourable attitude change in both the public and leprosy patient groups with the 'mean attitude score' increasing from 12% to 43% in the public and from 3% to 50% in the leprosy patients.¹⁵

Methods of health education

The Nepali Leprosy Control Programme has three stated aims. The first is to reduce the incidence of leprosy to below 1 per 10,000 by the year 2000, the second to integrate leprosy care into the existing health setup, and the third to use appropriate health education media to encourage the early detection of cases.⁴

Health education media can be classified into basic and extended types:¹⁶ Basic media are those which communicate ideas from person-to-person and person-to-group, for example, in classroom discussions and meetings. Extended media, on the other hand include books, printed matter, films, radio and the television. In the basic media setting, extended media such as posters, flashcards, pictures etc. may be a useful way of strengthening the impact of the message.

Successful health education borrows many of the principles and techniques used by commercial advertising in which a so-called multimedia approach has been found to be particularly effective. This approach aims to bombard the general public with key messages on billboards, buses, posters, magazines, television and on radio and thereby to pass on information whether the public likes it or not.¹⁷

An example of an effective multimedia approach to health education in Nepal is the Nun Chini Pani (literally 'salt sugar water') oral rehydration campaign. Radio, television, and practical demonstrations in village squares and schools throughout the country were used. In addition, posters, memory cards and leaflets giving directions on how to make the solution were distributed to households throughout the country.

The potential effectiveness of this type of multimedia approach in Nepal is suggested by the fact that at the end of the 3-year campaign, 85% of the population had heard the message, 57% could repeat the ingredients and 25% had actually used it. Also 60% reported that they had heard the message on the radio. This highly effective health education campaign was thought to be due to the continuous, rather than sporadic repetition of simple messages over a long period of time using all available media.

Crucially, it was based on well-conducted research studies into the local beliefs, attitudes and customs. It was concluded that interpersonal means of communication using practical demonstrations were by far the most effective way of transmitting the message, whilst posters, radio and television were good for creating awareness and lending authority to the health terms.¹⁸

The success of the Nun Chini Pani programme has provided an excellent model for other health education programmes in Nepal. The Leprosy Control Programme has made much use of the extended media to reach as wide a possible audience and to continuously repeat three

simple messages: leprosy can be caused . . . ; the early signs of leprosy are . . . ; and treatment can be found at . . .

The messages are reinforced by health workers in the field, by street plays performed by travelling drama groups, by printed materials distributed among literate community leaders and by being repeated again and again on the radio. It has been found that leprosy case-finding significantly increases during and after the periods of radio broadcasting of these messages.¹⁹

Interestingly, the widespread use of printed materials has not proven effective in Nepal. This is thought to be due partly to the difficulty of carrying and distributing the material and partly due to low literacy rates in rural areas. McBean has shown that visual literacy is limited to those who are already literate, thereby limiting the effectiveness of visual aids and posters.²⁰

This is an important finding; previously, many education schemes have exclusively relied on the basic media so that a health worker might have felt his educational obligation met by simply sticking a poster on his wall. Friedericks suggests that health workers should be trained in communication skills so that they can effectively pass on information, use initiative to meet the needs of a local population and be able to effectively use extended media.¹⁷

The ELCP educates volunteer village health workers and holds workshops for village leaders. By using a combination of oral teaching with visual aids, the health workers and village leaders are taught new skills so that they become able to identify new cases and also pass on information about leprosy to village dwellers.

BNMT village health workers interviewed by the authors operate a number of interesting health education schemes at district level. Workers at Bojpur train traditional faith healers to be able to recognize the symptoms and signs of leprosy in the hope that the traditional healers will refer leprosy cases to them. Such an approach is important since traditional healers constitute a vast reservoir of healthcare manpower. In Nepal, the ratio of qualified doctors to population is 1 : 50,000, whilst the ratio of traditional healers to population in India (probably similar to the Nepali figure) is 3550 : 50,000.²¹

The education of traditional healers in Varanasi, India was studied in 1983 by Kaur *et al.*²⁰ Kaur's team selected 20 traditional healers using defined criteria and subjected them to five days of training about the causation, transmission, cardinal signs and curability of leprosy. In particular, the trainees were told about the misconceptions prevalent in the local community regarding leprosy. They were taught that patients with any one of the cardinal signs should be referred to the nearest leprosy clinic, but were not advised to stop any other form of treatment that they had been practising.

The researchers showed, using questionnaires, that the knowledge level of the traditional healers had significantly increased 3 months after training and that most of the new leprosy cases presenting to the clinics had been referred by the traditional healers.²¹

Another approach at Bojpur and in Diktel BNMT health posts is to spend time in local schools teaching children about leprosy in the expectation that they will subsequently pass on health education information to their parents. The efficacy of such an approach was studied in Tamil Nadu, India by Kumar *et al.* in 1991.²¹ They showed that although significant improvement in the knowledge about leprosy was detectable in a leprosy-educated group of children compared to controls, no transmission of information to family members was detected in either group. The authors speculated that this failure may be explained by the fact that in the usual family hierarchy in India, the direction of knowledge flow is from elders to their offspring and not vice versa. Despite their results, they suggest that a potential for

knowledge transfer from schoolchildren to their families does exist and propose that actively encouraging the children to discuss leprosy with their parents may be effective.²¹

Conclusions

Leprosy remains a serious public health concern in Nepal, where sufferers continue to be victims of social stigmatization and consequently are reluctant to be identified. Effective health education is important to encourage earlier presentation of sufferers, to educate about the disease and to create public support for the patients. Education schemes need to be well planned to suit the particular requirements of the local population and their effectiveness should be checked at intervals. Current policy in Nepal is to use a multimedia approach as well as more basic interpersonal techniques to reinforce the messages at a local level. Local initiatives encountered include interesting techniques such as teaching parents by educating their children and involvement of traditional healers.

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