

## Will you change as you were taught?

*\*Le Le Win, \*\*Than Tun Sein, \*\*\*Kyaw Nyunt Sein & \*\*\*\*Khin Maung Lay*

\*Health Systems Research Division

\*\*Department of Medical Research (Lower Myanmar)

\*\*\*Department of Health

\*\*\*\*Leprosy Control Programme, Department of Health

An intervention study was conducted in *Padaung* Township during 1999–2000 to examine whether health intervention was successful in changing the behaviour of leprosy patients. A random sample of 50 patients was interviewed and observed regarding leprosy-related practices before and after intervention, which were eight months apart. They were taught multiple self-care prevention practices after the first time interview. During the intervention period, their practices were observed and case histories were taken two-monthly for four times. The research team interviewed with pre-tested questionnaire, guidelines and observed with a checklist, and the trained midwives disseminated about self-care. While most of the non-stigmatizing practices had changed to some extent, some stigmatizing practices had not changed. Patients who adopted stigmatizing practices were more likely to relapse than patients who adopted non-stigmatizing practices. However, we found a limited success in behavioural change due to constraints in culture, beliefs, stigmatization, and impractical techniques.

## INTRODUCTION

In a society, once a person has contracted leprosy disease, and especially after deformity has developed, that person is labelled as a “leper”, even if the disease is cured. Though some physical disfigurements can be corrected by reconstructive surgery, a patient’s psychological problems cannot be solved easily. Thus, supporting patients to live again normally as a full member of society is important. Surgery is expensive and not accessible to everyone. The World Health Organization (WHO) thus encourages helping patients to practise prevention of disability (POD) through self-care.

In Myanmar, leprosy, ranked 8<sup>th</sup> as a public health problem, was eliminated in 2003. Although the incidence of new cases may be very low beyond that, in addition to the disabled cured cases; there will still be patients with deformities among new patients. There is, thus, a need for continued

health education (HE) and care to reduce the occurrence and severity of disability. However, providing patients with health messages alone is not enough. Patients need to change specific behaviours posing risks to disability. The patient’s decision to change or not to change behaviour is said to rely upon or at least be related to effective HE as well as motivation, coping skills, beliefs, and environmental support. As the human nature, some people are always quick to try something new, while others are very slow to change. Not every one is ready to change simultaneously [1].

The present study addressed multiple practices, which needed to be appropriate for physical disabilities and circumstances of individual leprosy patients. Hence, changing behaviour of leprosy patients requires a more complicated change process. The objective was to examine whether the health intervention was successful in changing behaviour.

## MATERIALS AND METHODS

The study was conducted during 1999-2000 in *Padaung Township, Pyay District, Bago Division*, which had a high leprosy prevalence rate (4.8 per 10,000 population in 1998) [2]. The study was a “before-and-after-test design”, with an introduction of an intervention – dissemination about prevention of disability by self-care to patients by health workers. Health education material about POD by self-care was developed and tested basing on the existing preventive methods used by leprosy control programme of Myanmar at the time of study and WHO [3-7]. Out of five rural health centers (RHCs), two RHCs – *Kyaunt-phu* and *Htone-bo* were considered as the study site due to their easy accessibility for frequent visits at two-month intervals.

Fifty patients were chosen at random from the selected two RHCs for cohort observation. All patients in this study were over 18 years of age. They were interviewed and observed regarding leprosy-related practices before intervention. They were taught about more than one type of self-care prevention to be adopted. Six months later they were interviewed and observed again. During the intervention period, their practices were observed and case histories were taken two-monthly, resulting in four times. The study took for one year. While the research team interviewed with a pre-tested questionnaire and guideline, and observed with a checklist, trained midwives disseminated about self-care.

This paper is based on the findings from the observation and case histories regarding the changes of multiple risk behaviors of an individual of a cohort of 50 patients.

## RESULT

Study patients considered ‘disability’ as the stigmatisation and considered any change in behaviour that drew attention to the disability as further stigmatisation. Additionally, the patients were rooted with

their innate rural culture - very conservative. This, together with their customs or habits and their economic problems constituted barriers to frequent communication with health staff and to adoption of recommended practices. Consequently, the majority of patients did not adopt all of the recommended preventive measures. While a particular practice could be easy to adopt for some patients, the corresponding one would be difficult for other patients.

To protect their eyes, the majority of patients covered their heads and eyes with a hat or a piece of cloth when out of doors and in a sunny or windy place, which were conformed to local practice. Most had already recognised the risk of burns to the hands by using a pad to move a hot pot or to lift the lid of the hot pot or padding the handles of cooking pots, cups, and kettles. Only 2 patients were in the habit of cooking without padding and 2 patients of moving hot materials with their bare hands before the intervention. They corrected their behaviour during the period of observation so that none practised heat-related harmful behaviours at the end of the study. Obvious problems with hands were that they needed to maintain a good grip on the agricultural tools and equipment. At the beginning of the intervention, protection of feet was inadequate. Half did not wear recommended footwear and nearly all refused to wear footwear all of the time. Most walked long distances without taking rest to relieve the pressure on their feet. Only two checked their feet for injury. Wound care was poor. They did not keep first-aid kits and did not clean, dress or bandage wounds. Out of the specific risk practices, which changed during the study period, most relapsed practices were the type of stigmatising practices such as protecting hands against injury, caring of damaged hands and feet, and doing hand and foot exercise.

We will illustrate the different types of behaviour changes of 50 cohort patients with the following extracts.

Having immediate and frequent injury driven the patients to prevent their body parts. U A1, who had deformities in hands and feet, used to get injuries to his palms and soles while cooking, chopping and carrying water buckets. At each observation visit, I saw him having one kind or another of injury. At the first visit, he had sores on soles, but did not bandage them. During the second visit, when I saw him in the morning, his right palm ( he got burns while cooking ) was bandaged with a piece of cloth. At the evening, when he went out to carry water, he unfastened it, but bandaged it with a new cloth after finishing the task. A similar pattern was observed during the third visit. At the last visit, I saw him bandaging both his palms and right sole the whole day indicating he could maintain his changed behaviour.

Among those who changed their risk practices, one man (U L) with deformed hands said why and how he had changed his digging practice when planting banana trees in his back yard:

*When I made a hole to plant a tree, I always dug the earth with my hands and got bruises. Then I thought about using a coconut shell, which would make fewer abrasions.*

I asked him what made him change, and he said,

*... in the booklet, I saw a picture of a man striking with a padded mattock. If I wrapped my hand [with a cloth] when digging, it wouldn't work. So I used a coconut - shell for digging.*

Some changes were not as simple as the patients mentioned above. An example is that of U B, a poor elderly patient who lived alone. He had difficulty holding nails when hammering with his claw hands. He developed his own technique of grasping the nail between the teeth of a comb and thus avoiding injury to himself. In addition, he succeeded in changing of cooking practices

but he had a couple of things to consider. He needed to compare the efficiency of draining water with wooden sticks when the rice is cooked and using an old shirt to hold a small pot for boiling water two to three times a day. If he had had a bigger pot he would not have needed to boil water so often to fill his flasks with a zinc mug but he had to consider the cost of the pot and ease of handling it. He needed to replace a zinc mug that conducted heat easily with something safer. He thought, perhaps, he should have been ordering his meals from a shop than cooking. But that too would cost him. This was much more complicated than changing a single behaviour in order to protect his hands.

Sometimes, progression of changes was less clear-cut. Patients would often move backwards and forwards throughout the changing process. For instance, U A, who had no extremities, used two different knives for daily activities. The first knife was used to split bamboo slats. He started to wrap a blade of this knife between times 2 and 3. Because of getting fewer injuries he continued to split the slats with this padded knife to the end of study. He used a second knife, or machete, to clear grass and weeds. He started to wrap the handle of this knife in cloth between times 3 and 4, at the time towards the end of study. He also started doing foot exercises between times 2 and 3 but relapsed between times 3 and 4 because of pain. He was thus involved in a quite complicated process of changes during six months of intervention period.

Some patients did not change their risk practices. When asked why they had not changed to a new behaviour, patients gave multiple reasons for not changing their behaviour. They frequently just said: 'We are not accustomed to doing it'. This terse response seemed to cover a number of issues that were preventing them from adopting new behaviours: if a cultural practice was entrenched (for example, wearing footwear in a house or the farm), unconvinced in prevention (for example,

believed that the deformities could not be prevented because of atonement for past sins and misdeeds (ဝဲတူဝဲ) afraid of being stigmatised by the recommended practices (for example, wearing sunglasses, soaking calluses on palms and soles, and doing hand and foot exercises), if it was against their religious beliefs (for example, walking with footwear in religious places even if the person suffered from a plantar ulcer), not recognising the risk by holding tools and equipment with bare hands (e.g., they did not see common materials such as ropes, bamboo, wood and cane could harm to them) or if it was not feasible (e.g., using mirrors to check eyes was not possible for people who left the house while it was still dark and who worked in the fields all day).

When we examined changing pattern of individuals, patients were more likely to change practices if they could see an immediate benefit and they discontinued their changed behaviour, which drew more stigmatisation to themselves and negative reactions from other people. They were less likely to change because they themselves were not conditioned to change.

It was important to note that the number of new behaviours that patients adopted tapered off over successive two-month periods. It appeared that by the end of the study, the limits of this particular intervention had been reached.

## DISCUSSION

This study finds that changes in practices were not fully determined by knowledge. Not one patient reported changing all his or her risk practices, since the patients had to adopt multiple new practices, which need to be appropriate for physical disabilities and circumstances of individual patients. Most of the non-stigmatising practices had changed to some extent (for example, heat-related practices). Some stigmatising practices also changed but the most stigmatising behaviours did not change at all

(for example, wearing footwear at all times). Negative reinforcement from the community was also a factor. Patients who adopted stigmatising practices were more likely to relapse than were patients who adopted non-stigmatising practices. Since the duration of the study was relatively short, it was not able to evaluate the patients who could establish to sustain the changes for six months or longer.

This study also makes us aware of many important issues that should be considered when conducting research on human behaviour. In spite of the great care we took in preparing the educational material, we were successful in changing behaviour of a limited number of patients only. It is not easy for people to change deeply rooted behaviours and beliefs, when the effects of stigma and religion are so strong. The findings highlight the needs to focus on reinforcements of targeting the individuals with minimum and essential prevention of disability, and working together among patients, community and health staff by trying to change beliefs and attitudes of all responsible persons.

## ACKNOWLEDGEMENTS

The authors wish to thank Director Generals of Department of Medical Research (Lower Myanmar) and Department of Health to allow for conducting this study. Thanks are due to WHO / TDR for providing with the grant. Last, but not the least, we are grateful to the patients, because without them, this study would not be accomplished.

## REFERENCES

1. World Health Organization. *Education for Health: a manual on health education in primary health care*. World Health Organization. Geneva, 1988.
2. Department of Health. *Health Profile of Leprosy Control Project, Padaung Township*. Ministry of Health, Myanmar. Padaung, 1998.
3. Watson, J.M. Essential action to minimise

- disability in leprosy patients. The Leprosy Mission International. Brentford, 1986.
4. World Health Organization. *A guide to leprosy control*. World Health Organization. Geneva, 1988.
  5. World Health Organization. *Training package for a family member of a person who has no feeling in the hands or feet: information about the disability and what you can do about it*. World Health Organization. Geneva, 1989.
  6. World Health Organization. *Training package for a family member of a person who has no feeling in the hands and feet: how to prevent injuries and deformities of the hands and feet*. World Health Organization. Geneva, 1989.
  7. World Health Organization. *Training package for a family member of a person with a disability: household activities*. World Health Organization. Geneva, 1989.