

Leprosy and the community

COMMUNITY PARTICIPATION IN LEPROSY CONTROL AND OTHER HEALTH PROGRAMMES: AN ANTHROPOLOGIST'S VIEWPOINT

During recent years ever-increasing interest has developed in encouraging community participation in public health programmes. As far as leprosy control is concerned, it seems likely to me that such interest has arisen because other approaches have proven to be so disappointing. We must look for something new. Neither isolation of leprosy patients in leprosy hospitals, nor out-patient care at special clinics or integrated health centres has stopped the spread of the disease. Perhaps if we involve people from the daily surroundings of leprosy patients, some experts argue, if community members will participate in case-finding and case-holding activities, then leprosy patients will prove more coöperative with medical services. After all, any community has its own ways of keeping its members in line, it can put pressure – soft or hard – on difficult patients. True enough, at first hearing this line of reasoning sounds promising. Before we become overly optimistic, however, I want to raise some questions about what we can hope to achieve with community participation in leprosy control.

To begin with, is *active* community involvement a feasible goal at present? Or is the *stigma* attached to leprosy still so strong that we should content ourselves with trying to reduce public fear of the disease? Experience and study have made it clear to me that from culture to culture and community to community the nature and intensity of leprosy stigma will vary considerably. In the past I have worked among leprosy patients in Kenya and Northern Nigeria. At present I am beginning similar research in Indonesia. In these three research settings, the steps necessary to reduce leprosy stigma and to enlist the help of the community in leprosy control will be different indeed.

If you wish to change certain attitudes in a community, you must first know that community thoroughly. You must understand the *value patterns* which determine the choices and decisions that people make in their daily lives. With reference to leprosy, you must know how members of the community expect

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a leprosy patient to behave. What are the many rules that people know, unwritten rules handed down from the past to keep the danger of leprosy infection as far as possible from healthy people? What, moreover, does a new leprosy patient, or someone who suspects he might have leprosy, think about the kind of life he will have to lead in the future? What attitudes do members of the community share towards burned-out cases, towards mutilated but cured patients with whom they are familiar?

The social sciences provide a number of useful ways to study the *value patterns* of a community. In this way they can potentially serve leprosy control programmes wishing to achieve community participation. A number of leprosy control programmes have in fact already made attempts to carry out social scientific research. In most instances the people performing the research have not had enough training. Such research has also often relied far too heavily on questionnaires. A group of persons, more or less representative of the community as a whole, is asked to answer a prepared list of questions about leprosy and leprosy patients. Any such study can only help us learn – in a crude way – about the stereotypical ways in which the members of a certain community think about leprosy.

Collecting data in this fashion is not very satisfactory. Even worse is interpreting these data, as too often occurs, as if people's stock answers actually told us anything about how they *act* when coming into contact with a leprosy patient. We all know that what a man says is not always what he thinks, and what a man thinks is not always the same as how he behaves. We must not forget these simple truths when evaluating how much the questionnaire method can teach us about value patterns in relation to leprosy. A man who is asked, for example, whether he would work together with a leprosy patient at the time of harvest is likely, for a variety of reasons, to say no. No is the answer that a healthy member of the community is perhaps *expected* to give. But if this same man's relative or friend or neighbour contracts leprosy and asks for help bringing in his crop, such help may very well be given without hesitation. We must be careful to distinguish *rule* from *reality*, the rule of the leprosy patient stereotype as outcast, the reality of flesh and blood patients who, despite the rule, lead rather ordinary lives. The gap between rule and reality can often be explained by pointing out how the rule reflects the situation of the past when leprosy patients were subject to severe discrimination; reality may since have changed whereas values of the past still remain in the community's thoughts in the form of inherited prejudices.

Given our goal of improving community-patient relations, we need research techniques to help us determine how the rule and the reality of leprosy stigma are interconnected. Clearly more than prepared questionnaires are necessary. Here, I think, the anthropologist can make a contribution. There seems to be a common, widespread misconception about what anthropologists do, or can do. Really, we are not eccentrics out to record the dying customs of out-of-date

cultures. Often in my work I am called upon to explain that anthropology just like other social sciences, can be contemporary and practical in its objectives. Take for instance problem identification in leprosy control. Where sociology, however, makes use of surveys and other kinds of extensive tests, anthropology works *in depth*. Anthropologists use the intensive techniques of open-ended interviews and observation. Both approaches – the quantitative one of sociology, the qualitative one of anthropology – have advantages and disadvantages. In-depth interviews and observation, however, seem particularly well-suited to the study of problems related to leprosy control. We are, surely, interested in doing more than measuring the stereotypical responses of members of the community to ‘the leprosy patient’. We want to learn about behaviour. Before a research can hope to understand the subtle social processes related to leprosy, he must build up close and confidential relations with patients and members of the community. For this purpose open-ended interviews are essential. Such interviews, of course, cover certain set topics preselected by the anthropologist but, if well managed, the interviews seem to develop as informally as any conversation.

If we want to involve members of a certain community in leprosy control, as I have already stated, we must first become thoroughly acquainted with social processes related to leprosy. The research necessary, and later the preparation of suitable health education for the public, costs money, time and expertise. Is there any reasonable security that such expenditure will produce the desired result? There is nothing more difficult than changing people’s minds so that they will change their actions.

In leprosy control programmes I am not at all sure, moreover, that we define our principal problems accurately enough. The proposal to involve the community in leprosy control seems to suggest rather strongly that the failure of control up to now is primarily the patient’s fault. He is to blame for poor case-finding and case-holding. The patient reports late for treatment. The patient is erratic in attendance. To offer an excuse for the patient’s shortcomings, stigma is brought forward. In 1975 I began research in Kenya with just such a view of matters: leprosy control was not succeeding because negative attitudes in the environment of the patient discouraged him from using available services fully. What I found was something altogether different. There was stigma, true, yet nevertheless in communities where the leprosy control services functioned well, there were virtually no defaulters and no large number of ‘hidiers’ fearing to report for diagnosis. An analysis of the DDS content of patients’ urine established that they swallowed their medicine at home as instructed! Where leprosy control services did not function well, on the other hand, where the health worker at the base was himself irregular in holding his clinics and was not particularly concerned about the health of his patients, in these communities we found ‘defaulters’ and new cases slow to come for modern treatment.

Without saying anything negative about the goals of community involvement and community health education – for I do believe both of these can help reduce stigma beneficially – still I must ask whether it isn't more important for the medical services to take a penetrating, critical look at themselves first. Are leprosy control services functioning well? Will they indeed be able to live up to the promises that health education will make to the community about what modern medicine can achieve against leprosy? Or are there major problems that must first be solved: organizational problems, financial ones, problems of staff motivation, of staff mentality.

Before we attempt to involve the community in leprosy control, the medical services must be in good working order. To end on a blunt note: in the interests of better public health, members of the community may need to exercise social control not merely over patients, but over the functioning of the health services as well.

IMAN BIJLEVELD

Manado

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**COURSE 941: TUBERCULOSIS; THE BRITISH COUNCIL, LONDON,
9–21, MARCH, 1980.**

This course was attended by 21 specialists, mainly in the fields of medicine or tuberculosis, from – Nigeria, Norway, the Yemen, Denmark, Egypt, Ethiopia, Finland, Germany, Hong Kong, Indonesia, Lesotho and Malaysia. The whole subject of tuberculosis was covered by invited speakers, and an entire day was devoted to leprosy, with short lectures on epidemiology, vaccination, experimental chemotherapy, drug-resistance and persistence, chemotherapy in man and reactions. The speakers were invited to submit summaries of their talks in advance and these were printed by the British Council in a compendium, which makes interesting reading for those seeking the views, in compact form, of experts in both these diseases.

**HEALTH FOR ALL BY THE YEAR 2000; THE ROLE OF HEALTH
EDUCATION. INTERNATIONAL JOURNAL OF HEALTH EDUCATION.
SUPPLEMENT TO VOL XXII. ISSUE NUMBER 1. JANUARY–MARCH,
1980. BY V.T.H. GUNARATNE.**

This interesting article begins –

The 1979 World Health Assembly considered the report of the International Conference on Primary Health Care which was held at Alma-Ata, USSR, in

1978, and reaffirmed that the main social target of governments and of WHO in the coming decades should be attainment by all citizens of the world of a level health that will permit them to lead a socially and economically productive life by the year 2000. Active continuing participation of the community in health education plays a major role in attaining this goal. It is therefore necessary, in the first instance, to briefly review emerging trends in health care in the developed and the developing world and the demands made upon health education in the light of these trends.

and goes on to discuss health education under headings which include 'Health education in the developing world'; 'Relevance to needs; the key issue'; 'Consumer learning'; 'The danger of over-reliance on mass media'; 'Health education training for health workers'. The bibliography has 12 publications, all essential reading in this field. The author, Dr V.T. Herat Gunaratne, has been Regional Director of the South East Asia Region of the World Health Organization since 1968. Prior to taking this appointment, he was a leading figure in the health services of his country, Sri Lanka, first as Acting Deputy Director of the Public Health Services, then as Deputy Director of the Medical Services, and finally as Director of Health Services. He led his country's delegation at the World Health Assembly in 1965 and 1966, and was President of the WHA in 1967.

THE WORLD DIRECTORY OF MEDICAL SCHOOLS. WHO, GENEVA, 1979

This is a 5th edition, 358 pages long, and full of information about medical schools across the world. Under each country, there is a valuable short introduction. India, one learns, has a population of 589,097,000, with 106 medical schools, which produce now fewer than 11,364 graduates per year. Information of this kind has already prompted a number of people to wonder if adequate attention has ever been given to ensuring that leprosy is adequately taught in the medical schools of leprosy endemic areas. In a recent editorial in the *International Journal of Leprosy* (Vol 47, Numer 4, December 1979), Roger K. Ackley drew attention to a recent survey of the medical schools in India indicating that the average time spent on leprosy is 4½ hours. This Directory should be consulted by all who are concerned with the distribution of teaching material in leprosy, particularly by those who are convinced that the attack on leprosy would be much improved by up-dating the attitudes of medical students, and those who teach them.

WHO: REPORT OF THE SIXTH MEETING OF THE STEERING COMMITTEE OF THE SWG ON THE CHEMOTHERAPY OF LEPROSY, GENEVA, 16–17, 1979.

The summary of this meeting reads as follows –

A draft protocol, produced by an *ad hoc* subcommittee to design a protocol for a field trial of leprosy chemotherapy, was reviewed intensively. Because of the complexity of the issues, it was decided to consider alternative protocols. Prevalence surveys of dapsone resistance are to be undertaken in Burma, South India and Upper Volta. Steps have been taken to increase the rate at which patients are recruited into the two THELEP-sponsored clinical trials in Chingleput and Bamako. Planning for a survey of anti-rifampicin antibodies among these patients is to be completed, and a protocol for short-term trials of several antileprosy drugs and regimens is to be drafted. A programme of screening combinations of drugs in mice for evidence of antagonism and unexpected toxicity has been completed. A number of new compounds are being screened in mice for evidence of activity against *Mycobacterium leprae*, and finally, preparations have been completed for the Mouse Foot Pad Technique Standardization and Application Workshop, to be held in Chingleput from 19 November to 14 December 1979.

WHO: REPORT OF THE SECOND MEETING OF THE SCIENTIFIC WORKING GROUP (SWG) ON THE CHEMOTHERAPY OF LEPROSY (THELEP) GENEVA 27–29, MARCH, 1979

The summary of this meeting reads as follows –

The second meeting of the Scientific Working Group (SWG) on the Chemotherapy of Leprosy (THELEP) was held in Geneva, 27–29 March 1979, to review current activities and proposed plans, most of which were endorsed by the Group. The immediate planning and undertaking of field trials of leprosy chemotherapy was recommended as a matter of highest priority. These trials, involving large numbers of lepromatous patients who have already responded to dapsone monotherapy, are to study one- or two-year intensive combined regimens by stopping therapy and observing subsequent relapses. Greater resources for the years 1980–1982 will be required for undertaking these trials.

The two ongoing formal clinical trials, which involve small numbers of patients, and seek to determine the presence of persisting *Mycobacterium leprae*, are to be continued as a high priority, but no new trials are to be undertaken in the immediate future.