

AN EVALUATION OF THE FUTURE ROLE OF NON-GOVERNMENTAL ORGANIZATIONS CURRENTLY ENGAGED IN LEPROSY CONTROL IN INDIA

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Abstract. The mass implementation of short term multi-drug therapy in India, has led to dramatic falls in the prevalence of leprosy. This paper addresses the future role of non-governmental organizations currently involved in leprosy control. This evaluation is based on current trends in leprosy control, projected health needs in the future and the necessity to maximize health care outputs in the face of limited resources.

INTRODUCTION

The WHO in 1981 estimated that the world prevalence of leprosy was 12 million (WHO, 1988), of which 4 million patients were believed to be in India (Mittal, 1991). One of the major advances in leprosy control has been the introduction of the mass use of short term multidrug therapy (MDT). In many countries MDT is administered as part of an integrated health care system. Where leprosy endemicity is high however, and the development of health services inadequate to meet the demands of MDT control, specialized vertical programs form a rational approach to the control of leprosy. In India, the National Leprosy Eradication Program provides the guidelines for the entire country. Under this program, MDT was introduced on a mass basis in 1987, in a phased manner, covering highly endemic districts with a prevalence of greater than 5 per 1,000. MDT has since been sanctioned for all the 201 districts that come under this category. The non-governmental sector is an integral part of the national program, covering a general population of approximately 60 million and with over a quarter of the total leprosy patients detected, under its care (0.84 out of 3.34 million) (Rao and Mittal, 1987).

The introduction of MDT is characterised by a dramatic reduction in prevalence rates (Rao, 1988), and merits discussion about the alternative use of agencies currently engaged in leprosy control (Wheate and Harris, 1987). The Government of India has already begun to address the future role of the public health sector currently involved in leprosy control

(Dharmshaktu, 1990). The need to optimise human and financial resources in the health sector is clearly a necessity, given the lacunae in health staffing patterns currently existent, particularly in rural India (Anonymous, 1992).

The non-governmental organizations (NGOs) working in leprosy control have to a large extent been unresponsive to the rapidly changing situation, brought about by the introduction of MDT, and have yet to objectively evaluate their future role in health care. This paper attempts to provide a rational argument for the need for NGOs currently involved in leprosy control, to undertake additional health care responsibilities. This is based on an evaluation of current trends in leprosy control, projected health needs in the future and the necessity to maximize health care outputs in the face of limited resources.

CURRENT TRENDS IN LEPROSY CONTROL

The marked reduction in the prevalence of leprosy following the implementation of MDT is essentially reflective of two factors. The most important of these is the shorter duration of treatment; a minimum of 6 months for paucibacillary and 2 years for multibacillary leprosy. A second factor is the concerted effort made to screen all registered patients prior to the implementation of MDT. It has been estimated that upto 35% of these patients may be clinically inactive and can be deleted from the register (Rao and Sirumban, 1990). This is in keeping with the natural history of the disease process, where a large number of patients towards the tuberculoid end of the spectrum are known to heal spontaneously.

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The fall in prevalence, denotes a reduction in the reservoir of infection and is associated with a gradual increase in the age of onset of leprosy, as well as a shift from paucibacillary to multibacillary leprosy among new cases (Irgens, 1985). The fall in prevalence rates are not however accompanied by an equivalent fall in incidence; this is related to the large range in the incubation period of leprosy.

While the fall in prevalence, is associated with a reduced work load for leprosy field-workers, particularly in relation to case-holding, it is important to note that there is the need to provide continuing medical care for the leprosy patient, particularly with regards to ophthalmic care, treatment of trophic ulcers and provision of protective footwear. There is also a need to continue efforts towards the social and vocational rehabilitation of leprosy patients. Similarly, there is also a need to maintain a high standard of case detection, in order to ensure that all incident cases are registered and treated, and that relapses following cessation of therapy are detected early. This is particularly important since relapse rates reported following MDT appear to be highly variable (WHO, 1988; Grugni *et al*, 1990). An analysis of the future role of health workers currently engaged in leprosy control, must therefore recognize that the dramatic reduction in the prevalence of leprosy does not imply the cessation of leprosy services. It is our contention however, that there is a need for NGOs currently engaged in leprosy control to undertake additional responsibilities, while ensuring the continuation of leprosy control services.

IMPEDIMENTS TO NON-GOVERNMENTAL LEPROSY PROJECTS UNDERTAKING GENERAL HEALTH SERVICES

It would be simplistic to assume that the process of integrating other health care programs with leprosy services could proceed without any problems. Among these are:

- 1) the need to generate funding for the additional health programs envisaged. Donor agencies prefer to support vertical programs with autonomous infrastructures. Thus voluntary agencies which have received relatively unquestioned funding in the past for leprosy work might find their donor agencies more reluctant to fund integrated health services. This problem has been highlighted by other workers who have pointed out that while funding can be obtained

for specific programs, it is more difficult to generate funds for primary health care (Anonymous, 1990).

- 2) the problems of acceptance by the public, when general health services are provided by projects previously engaged in leprosy work. This was reported earlier for tuberculosis, when sanatoria were converted to general hospitals (Prem Kumar, 1988). This is more likely to be a transient problem. At Palamaner for instance, despite the emphasis on leprosy, the outpatient statistics reveal an increasing attendance of patients with general health problems. In-patients with general problems are now being admitted at their own request.

- 3) the need to provide appropriate training for leprosy field workers, to ensure that they can meet wider health needs.

The need to generate financial resources is clearly a very real problem, and potentially, a major limiting factor to the success of any proposed programs. There appear to be only a few options open in the face of this problem:

- 1) there must be a greater commitment to self-financing, including a major re-evaluation of spending patterns, drug prescribing and the need to promote community contributions to the cost of health care. This has been tried with some success in other developing countries (Pangu and Van Lerberghe, 1990).

- 2) non-governmental organizations can take up government health programs and bear part of the cost, *eg* staff salaries, while eliciting contributions from government for the running costs of the program. This compromise represents a saving for both sides and has been successfully implemented in an integrated leprosy-tuberculosis control program, now running at the Emmaus-Swiss Leprosy Project in Palamaner.

HEALTH PROJECTIONS FOR DEVELOPING COUNTRIES -THE BASIS OF FUTURE HEALTH STRATEGIES FOR NGOS CURRENTLY ENGAGED IN LEPROSY CONTROL

The future public health problems in developing countries, appear to be linked to two major factors:

- 1) the demographic transition, brought about by gradually declining fertility rates and a lowered infant mortality, resulting in an enhanced life span and a

slowly expanding adult population (Mosley *et al*, 1990).

2) the success of public health programs focused on infectious and 'tropical' diseases.

With regard to the first factor, public health policy makers will be under greater pressure in the future to address diseases of the elderly, including diabetes, cardiovascular disease and cancer. In India for instance, 1 in 66 males in the 1960s who lived to their expected life span of 46.4 years were affected with cancer, the projection for the year 2,000 is 1 in 18 for a life-span of 60 years (Jayanth, 1989). On the other hand, developing countries are likely to have fewer lifestyle risk factors for many of the diseases of the elderly in comparison with their western counterparts (Rose, 1985).

Infectious diseases continue to be the prime focus of current health programs in developing countries. The efficiency of these programs is frequently less than desirable, and it is conceivable that our health systems will be considerably overburdened with the continuing problems of infectious diseases, in addition to the emerging problems of the elderly. It has been estimated for instance, that if there is no change in the present trends of decline and no improvements in case detection and treatment, there will be as many as 2.4 million deaths from tuberculosis in the year 2015, a decline of only 12% from 1990. Other infectious diseases which will assume major importance will be that of sexually transmitted diseases and AIDS (De Schryver and Meheus, 1990).

MEETING FUTURE HEALTH NEEDS - POSSIBLE STRATEGIES FOR NGOS CURRENTLY WORKING IN LEPROSY

The future health roles of the NGOs must clearly be linked to their proven capabilities, if they are to have a significant impact. In terms of their location, NGOs are frequently in a position to meet the wider demands of relatively underserved communities. The hospital infrastructure of NGOs currently involved in leprosy work, frequently includes physiotherapy and reconstructive surgical facilities. This provides an excellent base for the extension of these facilities to other medical conditions. In terms of their peripheral field infrastructure, the NGOs are particularly suited to the conduct of surveys, public health education and the follow-up of chronic diseases or diseases with social implications.

Possible health care strategies for the future, therefore include the following:

1) Utilization of hospital facilities:

- the outpatient department should be converted from predominantly skin and leprosy OPD to a general OPD, geared towards meeting a wider spectrum of the health needs of the community.

- in-patient facilities can be opened for general health problems, but only after evaluating the in-patient requirements for continuing medical care of leprosy patients.

- reconstructive surgery and physiotherapy sections should increasingly begin to meet the needs of patients disabled from causes other than that of leprosy.

2) Utilization of field infrastructure:

- at a local level, promoting health awareness through health education, as a means of supplementing programs that are already running, and which may be under the control of other agencies, including the government health sector. The areas that could be covered include immunization, prevention and treatment of common diseases eg childhood diarrheas, antenatal and postnatal care, feeding practices, family welfare etc.

- functioning as peripheral screening units for tertiary centres; the survey capabilities of the NGOs can be used for the screening of diseases which may not be treatable in a peripheral institution. This can include cancer detection with referral to regional cancer centers, screening for mental disorders, epilepsy, etc. with referral to the appropriate centers. In these situations the NGOs can undertake a vital role, while recognizing that they are incapable of meeting the entire requirements of patient care in these situations. After confirmation and initiation of treatment, the NGOs can be involved in the follow-up of patients in the field.

- development of comprehensive health programs in situations where they are currently underdeveloped or non-existent. This includes particular areas of health care which have not had a priority rating in the past, but which are likely to be larger determinants of health policy in the future. Relevant areas include diabetes, cardiovascular disease, STDs and AIDs among others.

There are several issues which should govern the

functioning of NGOs in the future:

1) There should be no attempt to duplicate programs already existing. This is an economic luxury we can ill-afford. Rather, an attempt should be made to liaise with already functioning organizations in an attempt to optimise their programs, by providing them inputs they are deficient in eg health education, survey, etc. In so doing, there will be a need for closer cooperation between governmental and non-governmental organizations. There will also be a need for these organizations to see themselves as inter-dependent rather than parallel units within the health system.

2) NGOs should particularly focus their interests in those situations where health programs are currently underdeveloped or non-existent. The development of successful field programs is a long drawn-out process with many revisions as previously unforeseen problems are identified and tackled. The government with its major economic and structural constraints may not be able to take the lead in devising new field programs. The NGOs with their greater flexibility can, and in the process will provide valuable information to the government for the formulation of its future health strategies.

3) It is imperative that the concern for continuing effective care of leprosy patients is always kept in mind. We believe that it is important that any new programs undertaken by NGOs are initiated in a phased manner. This will allow for a concurrent evaluation of the new programs and their effects on pre-existing leprosy programs.

REFERENCES

- Bulletin on Rural Health Statistics. Rural Health Division. Directorate of health Services, New Delhi, 1992.
- De Schryver A, Meheus A. Epidemiology of sexually transmitted diseases: the global picture. *Bull WHO* 1990; 68 : 639-54.
- Dharmshaktu NS. A project model for attempting integration of leprosy services with general health care services after the prevalence of the disease is reduced in the endemic districts on multi drug therapy for over five years. *Indian J Lepr* 1990; 64 : 349-57.
- Grugni A, Nadkarni NJ, Kini MS, Mehta VR. Relapses in Paucibacillary leprosy after MDT: a clinical study. *Int J Lepr* 1990; 58 : 19-24.
- Irgens LM. Secular trends in leprosy: Increase in age at onset associated with declining rates and long incubation periods. *Int J Lepr* 1985; 53 : 610-7.
- Jayanth K. An index for assigning priority for cancer control within the health care delivery system in developing countries. *Bull WHO* 1989; 67 : 565-6.
- Mittal BN. The National Leprosy Eradication Programme in India. *World Health Stats Q* 1991; 44 : 23-9.
- Mosley WH, Jamison DT, Henderson DA. The health sector in developing countries: Problems for the 1990's and beyond. *Ann Rev Public Health* 1990; 11 : 335-58.
- Pangu KA, Van Lerberghe W. Self-financing and self-management of basic health services. *World Health Forum* 1990; 11 : 451-4.
- Prem Kumar R. A lesson from the decline to tuberculosis around the world (letter). *Lepr Rev* 1988; 9 : 266-7.
- Primary Health Care - what still needs to be done? - Round Table. *World Health Forum* 1990; 10 : 359-66.
- Rao CK, Mittal BN, Dharmshaktu NS, Chaudhury SBR, Kumar S. Voluntary agencies and leprosy control in India (editorial). *Lepr Rev* 1987; 58 : 97-103.
- Rao CK. Drugs against leprosy. *World Health Forum* 1988; 9 : 63-7.
- Rao PS, Sirumban P. Screening of registered leprosy cases and its effects on prevalence rate. *Indian J Lepr* 1990; 62 : 180-5.
- Rose G. Sick individuals and sick populations. *Int J Epidemiol* 1985; 14 : 32-8.
- Wheate HW, Harris GF. Operational problems in leprosy programmes when the endemicity declines (editorial). *Lepr Rev* 1987; 58 : 1-5.
- WHO Expert Committee on Leprosy (Sixth Report). *WHO Tech Rep Ser* 1988; 768.