Referral system: A vital link in the sustainability of leprosy services

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Introduction

Sustaining adequate and effective leprosy services in the light of low endemic situations and changing policies of health sector reforms is a challenging task.1–3 Disease Control Systems must be sustained as long as the need exists, until the disease and its complications are totally eliminated.4–5 Such sustainability depends not only on political wills but the administrative aspects of training and capacity building of service staff to provide quality care, as well as on the availability of necessary resources, especially drugs and other therapies.6 Beyond these grass root requirements, under the integrated health settings, successful sustainability requires a feasible, acceptable and efficient referral system that provides the necessary support to grass root staff in managing complex issues in patients as well as to provide education to the staff and the community.7 For developing countries, strategies that give greater focus on strengthening referral systems will assist better use of scarce resources.8

Establishing such a referral system seems acceptable and a good concept, but in many developing countries the health services have failed in its implementation.9–13 An effective referral system seems to be the weakest link in successful health delivery under the integrated setup, especially in rural areas.14–15 In India, referral systems planned for most urgent health problems such as maternal and child care, communicable diseases and many life-style diseases are dysfunctional, and leprosy services are no exception.16–17

In this paper observations and discussions focus on the need for a strong, efficient referral system if leprosy services are to be sustained in countries such as India, adopting contemporary and technological innovations and full community involvement. Components of a good referral system using public-private-people partnerships and methods of monitoring the functioning are given. Some background details of India’s National Leprosy Control Programmes and the involvement of international anti-leprosy organisations are provided.

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National Leprosy Eradication Programme (NLEP) of India

The predecessor of the present NLEP, initiated in 1982, was the National Leprosy Control Programme (NLCP) introduced in 1953 as an integral part of India’s first 5-year plan. Under the NLCP, the Government of India contracted with several leprosy NGOs to carry out Survey, Education and Treatment (SET) programmes throughout the country, thereby accelerating the control of leprosy. These arrangements continued even after the NLEP was established, and after MDT replaced DDS treatment. After the clarion call of WHO to eliminate leprosy as a public health problem by 2000, India also took up the challenge, but failed to reach elimination by the deadline, which was then extended to 2005. In December 2005, India declared elimination of leprosy. Even before that, several States started integrating leprosy services with general health systems, and formally the Government of India decided to integrate leprosy with the general health service, preparing guidelines for capacity building of staff at the periphery as well as at various upper levels with a logical referral system envisaged from the grass root level to the apex health facility. However, the system has failed, not just in making appropriate referrals for complex cases, but even in facilitating the correct diagnosis and classification of leprosy in simple cases, who then have to go to secondary or tertiary care centres for care. What then is required to make the referral system strong and effective?

Components and Functions of a good Referral System

As leprosy becomes less common, the ability of peripheral general health workers to suspect cases of leprosy and to make appropriate referrals, becomes the most important skill. The referral unit should not only be capable of dealing with such cases, but also handle patients with complex and complicated leprosy, providing the necessary feedback to the referring unit for education and follow-up. Thus, referral is a two-way process and must be facilitated by minimal, essential paperwork. New technologies provide innovative ways to assist in rapid communication using mobile telephones, text messaging, digital photographs, emails and telemedicine. As in any successful management protocols, periodical reviews on the working of the referral system, will enhance their effectiveness and efficiency. This is lacking at present. What is urgently needed is a clear directive to the health/medical personnel on what to refer, where and how, what directions should be given to the patient/family and the provision of both the upward and downward flow of information, as well as constantly reviewing the mechanism to ensure the system works to the benefit of the patient. Such a directive must include guidelines on: referring patients for diagnosis and classification of leprosy, prescription of the right type of MDT and additional drugs such as steroids where indicated, the referral for prosthetic and orthotic aids for reconstructive surgery, the referral in cases of superimposed infections such as tuberculosis, referrals for specialised services such as ophthalmology, occupational therapy, and counselling. Appropriate referrals for disability management and any laboratory investigations may also enhance medical care. Although the Operational Guidelines provide some details, professional staffs are not given sufficient orientation and training in making efficient referrals, and there are no proper systems for feedback that will improve the practice. In an extensive bibliographic search in the context of maternity referral systems in developing countries, the investigators conclude that the likely requisites for successful maternity
referral systems must include: a referral strategy informed by the assessment of population needs and health system capabilities, an adequately resourced referral centre, active collaboration between referral levels and across sectors; formalised communication and transport arrangements, agreed setting-specific protocols for referrer and receiver; supervision and accountability for providers’ performance, affordable service costs, the capacity to monitor effectiveness; and underpinning all of them, policy support. Such a comprehensive plan will no doubt yield good outcomes, and are applicable for leprosy referral systems as well, in a much simpler fashion. The essential functions of a referral unit at different levels in an integrated leprosy service critical in sustaining the quality and coverage as well as community support, so important in any public health programme are the following:

(a) Correctly diagnose and classify leprosy, through clinical and laboratory tests, in order to prescribe the appropriate MDT;
(b) Decide on release from treatment, especially those on MB-MDT, who may have reported with a high BI, but unknown at the periphery;
(c) Initiate appropriate management for complications, especially for Type 1 and Type 2 reactions or even neuritis or ocular morbidity;
(d) Management of superimposed diseases, especially serious infections such as tuberculosis, HIV, diabetes, severe malnutrition, etc.;
(e) Counselling for patient and family, reduction of social restrictions and rehabilitation;
(f) Advice and provision of prosthetic and orthotic aids and disability prevention/management, including reconstructive surgery;
(g) Relevant, need-based training to peripheral staff;
(h) Operational research on delays, defaulting, drug resistance, relapses, community awareness and attitudes, health service enhancements, management issues and drug logistics.

ILEP and NLEP

The International Federation of Anti-leprosy Associations, popularly known as ILEP, was founded in 1966 to support governments in their leprosy control activities, and also to work together towards a world without leprosy.29 In India, there are 10 such autonomous international NGOs, who have been involved for decades in supporting leprosy control, through medical, social and humanitarian activities, with their presence spread throughout the country. The support given to the National Leprosy Eradication Programme has been substantial and significant. While there are a few formal memorandums of understanding (MOU), between the government and ILEP agencies, such as in the training of health professionals, developing district technical support teams or the recent preventive and medical rehabilitation programmes including the provision of reconstructive surgery or footwear, there has been no proper understanding in establishing a solid, feasible, effective referral system covering all the essential aspects listed above. In fact most of ILEP’s activities are rather individualistic, although through a mutual understanding there are no serious overlaps in the services provided. The Government has not actively partnered with ILEP, but rather suggested areas where ILEP could supplement governmental programmes. Thus, an excellent opportunity for an effective partnership between NLEP and ILEP is lost or
inadequately utilised. Each ILEP member agency has competent staff and resources with an adequate infrastructure to be able partner to the government, and to deliver essential services, in particular to act as the competent referral body, in the development, implementation and evaluation of specific referral systems, as required in different parts of the country. In fact NLEP-ILEP could be a model for an effective public-private-people partnership (PPPP) described in the next section.

Public-Private-People Partnership (PPPP) in building a feasible, efficient referral System

Health care in the majority of low- and middle-income countries is delivered by a mixed health system – defined as a health system in which out-of-pocket payments and market provision of services predominate as a means of financing and providing services in an environment where publicly financed government health delivery coexists with privately-financed market delivery.30

Public-Private partnerships have shown to be useful in many health settings. Based on a study in Pune, India,31 the authors concluded that public-private partnerships can enhance the continuity of care for patients with TB and HIV/AIDS, and argue that interventions to involve private medical providers (PMP) must be supported by appropriate research along with political commitment and leadership from both public and private sectors. A study in Brazil32 presented results from a public-private partnership (PPP) in successful hospital reform in Sao Paulo. On the basis of a search of international data bases such as Cochrane Central Register of Controlled Trials, MEDLINE, EMBASE etc., Lagarde and Palmer33 concluded that contracting out by the government might be an appropriate response to scale up service delivery in particular settings, such as post-conflict or fragile states, but were not sure if this would work in other settings, as there were no controls in many reports. They, however, cautioned that introduction of non-state providers in some settings and not others might bring in potentially confounding variables such as the presence of additional management expertise or expatriate doctors, which may improve drug supply or increase utilisation. When a public and private mix of health care delivery shows symptoms of compromised quality and equity, it can be ‘diagnosed’ as having a mixed health systems syndrome.34 While there are many ways of treating this malady, ensuring that the people or the community one serves is given an equally important role as a third partner in the public – private partnership, thereby forming a PPP partnership would in most instances bring about a more satisfying solution. This is likely to be true in setting up an effective referral system for sustainability of leprosy services.

There is no doubt that the Government alone cannot handle any public health programme without the full cooperation of the public as well as the active collaboration of various like-minded non-governmental and private enterprises. In the case of National Leprosy Eradication Programme of the Government of India(NLEP), there are many instances of such Public-Private collaborations during the pre-MDT era in terms of case-detections, case management and provisions of IEC or other supporting services such as provision of footwear, etc.3 Although they don’t strictly qualify as partnership, such collaborations continued during the MDT era as well, but after integration, the Government decided that they can manage the bulk of NLEP activities, leaving only some marginal issues and covering of unreachable areas to leprosy NGOs.35 The identification of some
institutions for Reconstructive Surgery and offering monetary benefits do not by themselves become successful in managing the grade 2 disabilities, unless, the process and paperwork for proper feedback is in position. At present, there are no authentic records of how many were referred for RCS, how many responded, and how many were operated. Details on how the operated patient was facilitated to resume his occupation and re-settled economically and socially are essential for further progress and sustainability of RCS services. Today there are many community based activities, and reports of successful outcomes through such ventures, but not part of a public-private partnership. After all, the health must become the responsibility of the people for a programme to be successful, with necessary inputs from the government and nongovernmental agencies. Therefore, the need of the hour is to establish PPPP for provision of an effective referral system. The initiative for such partnerships must come from the government in a big way, and the bureaucratic tangles eliminated, to get the programme on the way. This is an urgent and strategic issue for the government if it has to continue its progress towards eradication, removing all biomedical and social obstacles.

Need for an Innovative Partnership for developing a referral system to sustain Leprosy services

There are a few basic principles in forming and nurturing partnerships for achieving common benefits for people affected by leprosy through a successful Referral system. These include:

(a) Sincere commitment of the Government and the proposed partners
(b) Geographic areas, preferably the size of a District, population not less than 1,000,000 and no more than 2,000,000, be defined for purposes of referral
(c) Building of technical, professional and administrative capacities at each level of care
(d) Minimal, simplified paperwork for onward referral and feedback to the original professional who made the referral
(e) Community partnership and ideally ownership of the referral system
(f) Enhanced public awareness of the process and increased motivation to follow the process
(g) Sufficient incentives and funding to ensure compliance
(h) Periodic reviews to fine tune and refine the Referral system, identifying the weaknesses, problems, and failures. The organisation of such reviews will vary according to local circumstances.

There are less difficulties in developing such a Referral system for a single disease such as Leprosy, if the Government makes up its mind to act urgently and seriously. The referral system in a rural setup will need to be modified for an Urban area, where the private practitioners will have to be part of the system as well as multiple stakeholders.

Any public system established to achieve certain goals is bound to have some flaws; Periodical and regular reviews will help in improving and strengthening the system. The Government should start first with one or two major private organizations such as TLM, develop a memorandum of understanding (MOU), and with full community support initiate the referral network, which is bound to help the national interests if the basic principles are kept in mind.
Conclusion

A strong PPPP for developing and implementing a referral system is the urgent need of the hour to sustain a cost-effective and acceptable leprosy service. This is practical and feasible.

References

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