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Aspects of Rehabilitation in Leprosy*

Leprosy (Greek *lepros*: scaly, scabby, rough) is a chronic, nonsuppurative inflammatory condition caused by infection with *Mycobacterium leprae*, also called Hansen's disease after the Norwegian physician who discovered the responsible bacillus in 1874.[1] Leprosy is notable for its propensity to produce disability and stigma, which makes rehabilitation a topic of key relevance to the disease.

Historical background

Egyptian archeological relics dating back to 4000 B.C. are probably the earliest existing evidence of leprosy,[2] with earliest written records dating from India (circa 1500 B.C.)[3] and China (circa 500 B.C.).[4] Despite this long history, rehabilitation in leprosy only became a viable possibility in recent years, and the first reference to rehabilitation in the leprosy literature was only made in 1929.[5]

Definitions of terms and concepts

A number of terms require definition before proceeding to a discussion of rehabilitation. These can conveniently be considered in the context of the "three-tier model" of the disability process:

Disease → Impairment → Disability → Handicap

Impairment may be defined as any loss of psychological, physiological or anatomical structure or function. When an impairment falls within the range considered normal for a human being, it constitutes a disability, but when fulfillment of a "normal" role is prevented, the term handicap is used. Related terms include deformity (deviation from the normal size or shape of a part of the body) and mutilation (partial or total absorption of a body part). Clearly, what is considered "normal" for a given individual will depend on a variety of social, economic and cultural factors, a point which shall be raised again later.

Scope of the essay

The importance of leprosy rehabilitation is reflected by the number of editorials and review articles written on the subject over many years,[6-10] during which time the scope and nature of rehabilitation has changed greatly. In this essay, the pathogenesis, nature and sequelae of disability in leprosy shall be considered, followed by aspects of leprosy rehabilitation, namely, its historical development, principles, nature, and impact where studied. Finally, prospects for the future will be discussed.

GLOBAL LEPROSY SITUATION

Leprosy remains a serious health problem in developing countries, and in 1988 was estimated by the World Health Organization (WHO) to affect some 10–12 million people worldwide, a figure which has changed little over the last 20 years.[11] The number of registered cases, however, which is based on more reliable data, has steadily increased over this period, from 2.85 mil-

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* This review, written by John Stephen Gilbody (B.Sc.Hons) a medical student at Guy's Hospital Medical School, London, shared 1991 first prize in the annual competition sponsored by the British Leprosy Relief Association (LEPRA) for essays on various aspects of leprosy. We take pleasure in publishing this review. The author's present address is: John S. Gilbody, Crombie, 78 Stopples Lane, Hordle Near Lymington, Hampshire SO41 0GL, U.K.

The JOURNAL has published the other essay sharing LEPRA's 1991 first prize in its September 1992 issue.

[1] Hansen, G. A. Spedalskhedens arsager (causes of leprosy), 1874. Reprinted in Int. J. Lepr. **23** (1955) 307–309.

[2] Weymouth, A. *Through the Leper Squint*. London: Sylwyn & Blount, London, 1938.

[3] Skinsnes, O. K. Notes from the history of leprosy. Int. J. Lepr. **41** (1973) 220–233.

[4] Skinsnes, O. K. Leprosy in society II. The pattern of concept and reaction to leprosy in Oriental antiquity. Lepr. Rev. **35** (1964) 105–122.

[5] Huizenga, L. S. Philippine Leprosy News. (Oct. 1929) 1–2.

[6] Bhowmick, A. Rehabilitation of leprosy patients. Indian J. Lepr. **59** (1987) 92–99.

[7] Davey, T. F. Rehabilitation today. (Editorial) Lepr. Rev. **47** (1976) 263–265.

[8] Hasselblad, O. W. The role of rehabilitation in the treatment of leprosy. Int. J. Lepr. **41** (1973) 372–381.

[9] Browne, S. G. The role of rehabilitation in leprosy control. Lepr. Rev. **41** (1970) 57–61.

[10] Karat, S. Preventive rehabilitation in leprosy. Lepr. Rev. **39** (1968) 39–44.

[11] WHO Expert Committee on Leprosy. Sixth Report. Geneva: World Health Organization, 1988. Tech. Rep. Ser. 768.

lion in 1966, to 3.6 million in 1976, and 5.4 million in 1985.[11] More than 70% of these registered leprosy cases reside in South-East Asia, most notably India, and it is in these countries that leprosy poses the greatest problems. Interestingly, since 1985 the number of registered cases has begun to decrease for the first time, from 5.4 million in 1985 to 5.1 million in 1987.[11, 12] Besides giving encouragement to leprosy workers, these figures have important implications regarding the allocation of resources for rehabilitation. The importance of rehabilitation becomes further apparent when one assesses the impact of leprosy in terms of disfigurement, disability, and its human, social and economic consequences.

PATHOLOGICAL CONSIDERATIONS

Leprosy results from infection with *M. leprae*, an acid-fast bacillus closely resembling the tubercle bacillus in appearance. *M. leprae* is an intracellular parasite, inhabiting macrophages, monocytes and Schwann cells, and has a relatively long doubling time of approximately 2 weeks. In general, leprosy has a low pathogenicity and is rarely fatal, tending instead to be chronic and progressively disfiguring in nature if left untreated. The classical feature of disfigurement in leprosy results from the predilection of *M. leprae* for the peripheral nerves and other relatively cool "surface" parts of the body, including the skin, anterior segment of the eye, mucosa of the nose and upper respiratory tract, and testis.[13, 14] Less commonly, the internal organs may be involved. From this information alone it becomes possible to build up a picture of what forms rehabilitation may take.

Classification of leprosy patients

Leprosy patients may be classified on a spectrum according to the level of host immunity, ranging from the lepromatous pole (LL), through borderline lepromatous (BL), borderline (BB), and borderline tuberculoid (BT), to the tuberculoid pole (TT).[15] The last group exhibits high levels of specific cell-mediated immunity (CMI) against *M. leprae*, which limits the number of bacilli present, so that lesions tend to be localized to the skin or peripheral nerves and spontaneous recovery may occur. Conversely, in lepromatous leprosy (LL), immunological resistance is low and bacilli numerous, resulting in a generalized multisystem infection which, if untreated, is likely to persist.

On the basis of the above classification, it is usual to divide patients into paucibacillary (PB) and multibacillary (MB) groups according to the following scheme:[16] PB patients = TT, BT and indeterminate leprosy with a bacterial index (BI) of < 2; MB patients = BB, BL and LL leprosy with a BI ≥ 2. Using this scheme, PB leprosy typically accounts for 70% or more of registered cases.[17]

Pathogenesis of nerve involvement

The high affinity of *M. leprae* for peripheral nerves is the key to the association between leprosy and disability. Possible reasons for this affinity include:[18, 19] a) protection from cell-mediated immunity within nerves; b) low temperature in nerves favoring proliferation; and c) vulnerability of superficial nerves to trauma.

Following the invasion of nerves by *M. leprae*, nerve inflammation (neuritis) may result, with the consequent possibility of nerve damage (neuropathy). The pathogenesis of neuropathy is incompletely understood but possible mechanisms include: [19-21] a) intraneural blood vessel changes; b)

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[12] Noordeen, S. K. A look at world leprosy. Lepr. Rev. **62** (1991) 72–86.

[13] Ramu, G. Clinical aspects of leprosy. Trop. Med. Parasitol. **41** (1990) 350–351.

[14] Binford, C. H. Comprehensive program for inoculation of human leprosy into laboratory animals. Public Health Rep. **71** (1956) 959–966.

[15] Ridley, D. S. and Jopling, W. H. Classification of leprosy according to immunity; a five-group system. Int. J. Lepr. **34** (1966) 255–273.

[16] WHO Study Group. Chemotherapy of leprosy for control programmes. Geneva: World Health Organization, 1982. Tech. Rep. Ser. 657

[17] Katoch, K., Ramu, G., Ramanathan, U. and Desikan, K. V. Comparison of three regimens containing rifampin for treatment of paucibacillary leprosy patients. Int. J. Lepr. **55** (1987) 1–8.

[18] Hastings, R. C., Brand, P. W., Mansfield, R. E. and Ebner, J. D. Bacterial density in the skin in lepromatous leprosy as related to temperature. Lepr. Rev. **39** (1968) 71–74.

[19] Guadagnini, M. Lepromatous neuritic lesions, their great incidence in certain sensory and motor branches, and their treatment. Lepr. Rev. **24** (1953) 147–155.

[20] Job, C. K. Nerve damage in leprosy. Int. J. Lepr. **57** (1989) 532–539.

mechanical internal compression due to epineural thickening and rigidity; c) increased intraneural pressure; and d) mechanical external compression and trauma from unyielding osteofibrous tunnels.

In general, nerve damage is more severe in tuberculoid (TT) than in lepromatous (LL) leprosy, while lepromatous disease is more extensive and involves more nerve trunks. Possible reasons for these differences include:[20, 22] a) autoimmune-mediated demyelination in TT, with early myelin exposure and immune sensitization; b) more marked ischemic/pressure changes and reactive episodes in TT; c) absence of granulomatous destruction in LL; and d) relation of damage in LL to rate of bacillary proliferation, which is low.

In borderline leprosy, nerve damage results from a mixture of tuberculoid reaction and lepromatous infiltration, combining the worst characteristics of each.[23] This makes it potentially the most widespread and crippling form of leprosy. A delicate "host-parasite" balance thus determines the degree of nerve involvement in leprosy, and although the factors responsible for this balance are unknown, age, genetic and nutritional factors have all been implicated. This emphasizes the importance of a generalist rehabilitative approach to leprosy care.

Leprosy reactions

The pathogenesis of nerve damage is closely linked with leprosy reactions and, indeed, most nerve destruction occurs during reaction, which may exacerbate any of the possible mechanisms of neuropathy considered above. Leprosy reactions are the clinical consequence of an acute inflammatory response to *M. leprae,* and may be divided into two types:[24] a) type 1 (lepra) reaction, due to unstable cell-mediated immunity in borderline leprosy, with either regression toward TT (reversal reaction) or progression toward LL (downgrading reaction); and b) type 2 (erythema nodosum leprosum, ENL) reaction, resulting from changes in humoral (antibody-mediated) immunity in MB patients.

In type 1 reaction, both the reversal and downgrading forms may accentuate nerve damage. In reversal, the most likely mechanism is raised intraneural pressure (requiring urgent relief), with a possible contribution from granulomatous destruction. In downgrading reaction, the mechanism is less clear. One possibility is decreased host immunity leading to the spread of infection, although Godal[25] proposed inflammatory damage mediated by a distinct population of T cells as the cause, the damage occurring despite a reduction in immunity systemically.

Type 2 reactions differ from type 1 in that they rarely result in serious or permanent loss of nerve function. Indeed, ENL foci when they occur tend to be found in previously damaged, heavily bacillated parts of a nerve.

Type 2 reactions, however, tend to result in painful, tender nerves. Immune complex formation has long been favored as the most likely cause of type 2 reaction,[26] which would be consistent with the propensity for reaction to occur during antileprosy chemotherapy which by leading to bacillary breakdown, may cause the release of antigen.

Pathogenesis of disability

Wayson and Badger in 1929[27] were among the first to describe how nerve damage in leprosy can lead to disability, and in 1958 Brand proposed that disability be divided into two types:[28] a) primary, due to direct tissue damage by *M. leprae*; and b) secondary, due to peripheral neuropathy. Primary deformities include flat nose, loss of eyebrows, gynecomastia, and iridocyclitis, and

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[21] Boddingius, J., Rees, R. J. W. and Weddell, A. G. M. Defects in blood nerve barrier in mice with leprosy neuropathy. Nature **237** (1972) 190–191.

[22] Mshana, R. N., Harboe, M., Stoner, G. L., Hughes, R. A. C., Kadlubowski, M. and Belehu, A. Immune responses to bovine neural antigens in leprosy patients. Int. J. Lepr. **51** (1983) 33–40.

[23] Vieregge, P., Reinhardt, V., Gershardt, L., Schlinwinski, V. and Jorg, J. R. Untreated borderline leprosy in the ulnar nerve. Lepr. Rev. **56** (1985) 5–15.

[24] Pfaltzgraff, R. E. The management of reaction in leprosy. Int. J. Lepr. **57** (1989) 103–109.

[25] Godal, T. Immunological aspects of leprosy—present status. Progr. Allergy **25** (1978) 211–242.

[26] Waters, M. F. R., Turk, J. L. and Wemambu, S. Mechanisms of reactions in leprosy. Int. J. Lepr. **39** (1971) 417–428.

[27] Wayson, N. E. and Badger, L. F. Public Health Bull. **189** (1929) 16–42.

[28] Mallac, M. J. Onset and pattern of deformity in leprosy. Lepr. Rev. **37** (1966) 71–91.

they are usually seen in untreated, advanced lepromatous disease.[29] They are rare, however, and secondary deformities form the main focus of this discussion. Indeed, Brand described how the more closely he studied the natural history of deformity, the more he found that "secondary changes and sometimes almost incidental damage and infection have been the cause of most of the mutilation . . . patients suffer."

Peripheral nerve damage can lead to disability as a result of the loss of sensory, autonomic, or motor modalities. Within skin lesions, only autonomic and sensory modalities are usually lost, while nerve trunk damage can also affect motor nerve function.

Loss of sensation is usually the first sign of nerve deficit in leprosy, with pain and temperature loss (mediated by small myelineated fibers) occurring before loss of deep touch and pressure (mediated by large myelinated fibers).[30] Failure to feel pain due to trauma, burns, infection, and so forth, may cause wounds to go unnoticed and uncared for, resulting in ulcers and damage and infection of soft tissues, joints, and bones. Ultimately, this may lead to absorbance, in which gradual "spontaneous" amputation of the hands and feet occurs.[29]

In the foot, the sensation of pain protects not only against sharp objects, but also against the build up of excessive pressure under bony points in the sole. In a classic study in 1959, Price showed how plantar ulcers occur mainly in the weight-bearing parts of the foot and, using inked footprint impressions, demonstrated the greater pressures generated by anesthetic feet.[31] Similarly, a French study in 1960 of 1049 plantar ulcers found that 78% occurred under the metatarsal heads or tips of the toes, and 20% under the fifth metatarsal or great calcaneal tubercles.[32] Even with minimal anesthesia, therefore, pressure build-up in the sole of the foot may lead to aseptic fat necrosis, making the area increasingly susceptible to trauma, ulceration, and infection. Hence the importance of patient monitoring and the early recognition of anesthesia.

Autonomic nerve function loss usually follows sensory loss, and is associated with reduced sweating and sebaceous secretion, and loss of vasodilation and piloerection. The former results in dry, brittle skin which is susceptible to infection, fissures and ulcer formation.[33] The final modality to deteriorate is motor nerve function, which results in muscle weakness and wasting, joint stiffness and contracture, and in the anesthetic foot may predispose to ulceration by producing such deformities as claw toe.[34]

Interestingly, there is a delay of several months between the onset of nerve damage (as judged histologically) and clinically apparent nerve function loss, suggesting that a certain proportion of nerve fibers need first to be destroyed (30% in sensory nerves). The phenomena of receptive fields and fiber reserve are likely explanations.

Miscellaneous factors. Miscellaneous disabling effects of leprosy include associated anemia, malabsorption, endocrine disturbances, and morbidity due to ill health generally. One study in China, for instance, noted a poor nutritional status among leprosy inpatients, particularly those who were disabled, with 58% of all inpatients showing overt signs of malnutrition.[35] Blood levels of protein, vitamins, and hemoglobin were all found to be significantly below the population average ($p < 0.01$).

DISABILITY AND THE LEPROSY PATIENT

While disability is not an inevitable consequence of leprosy, it continues to pose major problems for rehabilitation pro-

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[29] Bourrel, P. Surgical rehabilitation. (Editorial) Lepr. Rev. **62** (1991) 241–254.

[30] Dastur, D. K. Cutaneous nerves in leprosy; relationship between histopathology and cutaneous sensibility. Brain **78** (1955) 615–633.

[31] Cochrane, R. G. (Editor). *Leprosy in Theory and Practice.* 2nd edn. Bristol: John Wright, 1964, p. 510.

[32] Languillon, J., Bourrel, P., Boissan, R. and Picard, P. Contributions à l'étude des maux perforants plantaires lépreux. Distribution, étiologie, pathogénie, complications traitement. Méd. Trop. **20** (1960) 219–255.

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[34] Srinivasan, H. Trophic ulcers in leprosy II—intrinsic muscles of the foot and trophic ulcers. Lepr. India **36** (1964) 110–118.

[35] Ma, H., Ye, G.-Y., Shu, H.-W., Jiang, C. and Zhou, D.-S. Studies on social medicine and leprosy in east China. Proc. CAMS and PUMC **4** (1989) 61–64.

grams,[36] and further studies of the nature and magnitude of disability, the reasons for its continuing high levels, and the best means for its reduction and amelioration, are needed. In this section, the grading, magnitude, nature, and sequelae of disability are discussed, together with factors which influence the occurrence of disability.

Grading of disabilities

Some form of a standardized grading system is essential for the consistent and reliable assessment of disability. In particular, disability grading enables: a) determination of the number and proportion of patients with disabilities; b) consistent periodic assessment to observe changes with time; and c) comparison of disability status between different individuals, areas and countries. It can also be used to judge the effectiveness of service allocation, and the level of program care generally.

In 1960, the WHO Expert Committee on Leprosy recommended a five-grade disability grading system which, being the oldest classification available, is probably the best known and most often used.[37] Briefly, it comprises assessment of: a) the hands and feet for anesthesia, deformity and damage; b) the eyes for visual impairment; and c) overall disability status, representing the highest grading for any part of the body. It has been criticized, however, for difficulty in data analysis, for not considering such deformities as wrist drop and fixed contractures of the fingers and ankle joint, and for making no distinction between contracture of the fingers secondary to paralytic clawing and that secondary to fibrosis of the hand.[38, 39] The latter is important, as fibrosis of the hand, unlike clawing, is not easily amenable to surgical correction. Suggested modifications have included increasing the number of grades to allow more detailed and accurate recording, and alternative schemes have been proposed.[36, 38, 40, 41]

The WHO itself modified its grading system in 1969 and 1988, the latest formulation being a relatively simple three-grade classification.[11] Of these, the 1969 classification was probably overly complex, and the WHO Expert Committee recognized in 1977 that it was "rather beyond the comprehension of primary health workers," being best suited to use by well-trained workers for identifying patients needing special attention.[42] The variety of available disability grading systems has posed problems regarding the standardization and comparability of data,[36] and even where the WHO scales have been used, validation has been limited.

Indeed, it has been proposed that disability grading alone is neither appropriate nor adequate for evaluating disability control since significant changes in severity can occur without any change in the disability grade.[41] Other modes of assessment of disability therefore deserve consideration, one important example being the disability index (DI). This was first proposed by Bechelli and Dominguez in 1971,[39] with the aims of: a) providing an overall picture of disability severity within leprosy programs; b) enabling easy comparison between different communities and countries; and c) assisting in service planning. A Tamil Nadu-based study in India validated the DI, and found that paramedical personnel could assess and record it accurately in 98.8% of the patients with the same interpretation of results irrespective of whether DI(1), DI(2), or DI(3) was used.[43]

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[41] Watson, J. M. WHO disability grading. (Letter) Lepr. Rev. **56** (1985) 172–175.

[42] WHO Expert Committee on Leprosy. Fifth Report. Geneva: World Health Organization, 1977. Tech. Rep. Ser. 607.

[43] Reddy, B. N., Sekar, B. and Neelan, P. N. Use of disability index to assess the extent and severity of disabilities in leprosy. Indian J. Med. Res. **83** (1986) 355–359.

Other important modes of assessment include sensation testing (ST) and voluntary muscle testing (VMT), authoritative accounts of which have been published.[44] The aim of ST is to quantitatively evaluate alterations in protective sensation, and this has been proposed as the best means of assessing the progress of nerve damage.[24] ST is usually performed on the eyes, hands and feet, using the tip of a ballpoint pen for the latter, although to assist standardization some authors advise the use of monofilaments applying particular forces.[45] In VMT, muscle strength is usually graded as strong, weak or paralyzed.[45]

Regular repetition of disability grading, ST and VMT is advisable, one recommendation being at the time of diagnosis, during chemotherapy (every month, or up to every 3 months), and following the cessation of chemotherapy.[46] Those most at risk and in need of regular examination include new BT and BL patients, and women throughout pregnancy and for the first few months postparturition.

Magnitude of disability problem in leprosy

The epidemiology of disability remains poorly understood, as illustrated by the apparent associations between disability and regular clinic attendance[47] and extended regular use of dapsone.[48] Moreover, data where it exists is usually in the form of disability prevalence or incidence, and the WHO Expert Committee on Disability Prevention and Rehabilitation has proposed that it would be better to assess disability from the point of view of need for rehabilitation. As an example, while the disabled from all causes make up some 10% of the world's population, it is estimated that only 1.5% are in need of rehabilitation. Such an approach could prevent care of the disabled becoming an insurmountable proposition.

Other limitations of studies of disability have included: a) disability data seldom related to population denominators; b) leprosy seldom related to other causes of disability; and c) estimates of the frequency of leprosy-attributable disabilities vary widely, making them difficult to interpret. The variability may result from variation in the definitions of leprosy and disability, grading system used, or how representative the sample studied is to leprosy patients as a whole. Nevertheless, despite these limitations, valuable data concerning disability prevalence and incidence have accumulated.

Disability prevalence. In 1960, the WHO estimated that 25% of leprosy patients had some form of disability.[37] At the time, it was accepted that this was likely to be an underestimate since, for instance, many programs do not record anesthesia except when accompanied by deformity.[49] This has subsequently been shown to be the case, and reported disability rates in India in the 1970s and 1980s ranged between 16% and 44%,[50–59] being highest in eastern Uttar Pradesh

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[44] Watson, J. M. Essential action to minimise disability in leprosy patients. London: The Leprosy Mission International, 1986.

[45] Pearson, J. M. H. The evaluation of nerve damage in leprosy. Lepr. Rev. **53** (1982) 119–130.

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[57] Hasan, S. A survey of leprosy deformities among the patients of Hyderabad City. Lepr. India **49** (1977) 393–399.

(44.6%)[51] and lowest in Pondicherry (16.2%).[54] Recent rates in other countries have included 45% in eastern China,[35] 39%[60] and 50%[61] in Nigeria, 17% in Malawi,[62] and 38% in Ethiopia.[46]

Thus, worldwide disability rates in leprosy patients in recent years have ranged between 16% and 50%. This compares with rates in the 1950s and 1960s of 7.5%–31.6%,[28] and it is tempting to speculate that improvements in the reporting of disabilities and in leprosy control generally may have been at least partly responsible.

Disability incidence. Few studies of disability incidence have been performed, although reported rates include 2.9 to 8 per 1000 person-years in Malawi,[63] 14 per 1000 person-years in Polambakkam, southern India,[48] and 0.6% (2/335) in Trinidad and Tobago.[64]

Disability rate as measure of leprosy control. It has long been accepted that leprosy control by secondary prevention (early detection and treatment) is unlikely to eradicate leprosy on its own,[65] and, indeed, with only a few exceptions,[66, 67] leprosy incidence has been unaffected by improvements in the quality of leprosy control. Similarly, changes in prevalence are variable, depending on a wide range of factors. This is not only bad for field worker morale, but is of little help to program planners.

A more appropriate objective of leprosy control has been said to be the reduction of leprosy morbidity, such as the disability rate among new patients, to a level at which it no longer poses a significant health problem.[56, 68, 69] This is well illustrated by one Indian study which found leprosy prevalence to remain static between 1979 and 1983, despite a reduction in the disability rate from 91.4 to 62.3/100,000 over the same time period.[68]

Even in one of the only two studies to have demonstrated a reduction in leprosy incidence, it was necessary to validate the case detection rate as an appropriate measure of incidence by assessing the proportion of disabled new patients (which should tend toward zero).[67] Finally, since disability is widely perceived by both patients and society as the main problem in leprosy, people will find it hard to believe that leprosy can be cured until disability rates have been shown to be decreasing and at a low level.

Disability index. Reported levels of disability index have been in the range 0.9–1.25.[51, 54, 56, 70] Like the disability rate, the DI shows a degree of variation between studies.

Nature of disabilities in leprosy

Site. The hands are the commonest site of disability in leprosy, perhaps due to their relatively active functional role, followed by the feet and the face.[28, 60, 71, 72] One Nigerian

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[65] Meade, T. W. Epidemiology and leprosy control. Lepr. Rev. **42** (1971) 14–25.

[66] Crawford, C. L. The effect of outpatient dapsone in an area of endemic leprosy. Lepr. Rev. **40** (1969) 159–163.

[67] Rose, P. Changes in epidemiological indices following the introduction of WHO MDT into the Guyana leprosy control programme. Lepr. Rev. **60** (1989) 151–156.

[68] Smith, W. C. S. and Parkhe, S. M. Disability assessment as a measure of progress in leprosy control. Lepr. Rev. **57** (1986) 251–259.

[69] Bechelli, L. M. Evaluation of leprosy control programmes—some suggestions for operational and epidemiological assessments. Bull. WHO **42** (1970) 631–634.

[70] Lopez-Bravo, L. and Ratard, R. C. Leprosy disabilities in the New Hebrides. Lepr. Rev. **48** (1977) 247–260.

[71] Chaturvedi, R. M. Epidemiological study of leprosy in the Malwani suburb of Bombay. Lepr. Rev. **59** (1988) 113–120.

study quantified the site of deformities as hands 49%, feet 40%, and face 11%, with claw hand (12.9%) and finger absorption (3.3%) the commonest hand deformities.[60] This compares with an Indian study which observed hand involvement in 86% of disabled patients, face in 51%, and feet in 49%.[53] Other Indian studies have found hand problems to comprise 29% of all deformities,[57] and claw hand and finger absorption to occur in 19.7% and 8%, and 8.3% and 19.8% of deformed patients, respectively.[73, 74]

Mallac was one of the first workers to show how deformity is seldom restricted to one site, observing a ratio of involvement of both limbs to one limb of 3:1 for the hands and 2½:1 for the feet.[28] Subsequent studies have confirmed these findings.[53] As regards the development of disabilities, Mallac found that in 8% of patients (59/700) the disease began and persisted with neural disorders, and 89% of patients with deformity of the extremities notice skin signs before neural disorders. In addition, 97% had a disturbance of sensation prior to developing motor or trophic symptoms. Similarly, Bresani-Silva found that 54.7% of deformities started with neural symptoms, and disturbance of sensation was present in 85% of patients subsequently developing motor or trophic signs.[75] Such observations give useful insights into where best to target clinical attention to prevent disabilities going unnoticed.

Ocular lesions. Worldwide rates of blindness and severe visual impairment in leprosy patients are currently estimated at 4%–7% and 6%–10%, respectively,[76] with approximately 25% of all leprosy cases destined to ultimately develop eye involvement.[77] Indian rates of visual impairment vary widely between 2.6% and 80%,[78-81] many studies being limited by their anecdotal nature,[82] or by having been conducted by non-ophthalmologists.[83] Nevertheless, it is clear that leprosy contributes significantly to world blindness.

A more reliable large-scale field study of ocular lesions in leprosy, conducted in Andhra Pradesh, India (the first of its kind), observed rates of 4.7% (38/806) in MB and 1.2% (92/7997) in PB leprosy patients.[84] In addition, a recently reported worldwide survey of ocular complications in 3500 patients, organized by LEPRA since 1983, found that 24.3% (86/354) of patients completing multidrug therapy (MDT) had sight-threatening conditions, compared with 32.9% (56/170) of post-dapsone patients.[85] Of these, 37.2% (41.1%) had lid problems [MDT (dapsone)], 39.5% (42.8%) corneal disease, and 23.3% (16.1%) iridocyclitis-related complications. Blindness and severe visual impairment were commoner in the post-MDT group; 6.8% (4.7%) and 8.8% (5.9%), respectively, perhaps reflecting the greater number of MB patients in the MDT group. These findings are consistent with those of other studies.[78] Interestingly, a higher prevalence of cataracts was observed in MB compared with PB patients, which could reopen debate about the possibility of leprosy-induced cataracts.[86] Of other ocular

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[76] Courtright, P. and Johnson, G. F. Prevention of blindness in leprosy. London: International Centre for Eye Health, 1988.

[77] Somerset, E. J. and Dharmendra. Eye complications in leprosy. In: *Leprosy. Vol. 1.* Bombay: Kothari Medical Publishing House, 1978, pp. 142–164.

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[79] Lamba, P. A., Santoshkumar, D. and Arthanariswaran, R. Ocular leprosy—a new perspective. Lepr. India **55** (1983) 490–494.

[80] Saxena, R. C. and Dwivedi, M. P. Ocular manifestations in Hansen's disease. Lepr. India **43** (1971) 7–10.

[82] Spaide, R., Nattis, R., Lipka, A. and D'Amico, R. Ocular findings in leprosy in the United States. Am. J. Ophthalmal. **100** (1985) 411–416.

[83] Dutta, R. K. A study of patients with ENL syndrome. Lepr. India **51** (1979) 209–212.

[84] Reddy, S. C., Raju, B. D. and Achary, N. R. S. B. Survey of eye complications in leprosy in Prakasam district (Andhra Pradesh). Lepr. India **53** (1981) 231–239.

[85] ffytche, T. J. Residual sight-threatening lesions in leprosy patients completing multidrug therapy and sulphone monotherapy. Lepr. Rev. **62** (1991) 35–43.

[86] Choyce, D. P. The diagnosis and management of ocular leprosy. Br. J. Ophthalmal. **53** (1961) 217–223.

problems, it is interesting that while glaucoma is widely considered to be rare in leprosy, a 20.5% rate (39/190) has been reported in a United States' hospital population.[87]

What is most notable about the above findings is the frequency with which ocular lesions develop after "cure," when many patients have been released from control. This is clearly of concern, and would strongly support continued ophthalmic supervision after the cessation of chemotherapy. What are now needed to supplement the cross-sectional studies conducted to date are follow-up studies of ocular complications in leprosy to gain further insights into their epidemiology and pathogenesis.

Onset. One key question regarding disability in leprosy concerns its latent period (time to appear following diagnosis). Mallac's classic 1966 study of 700 patients in northern Burma found that deformity occurred on an average of 2.8 years postdiagnosis in tuberculoid cases, 4½ years in borderline, 5¼ years in indeterminate, and 9 years in lepromatous cases.[28] Moreover, deformity took an average of 2 years to spread from one hand to the other, 2½ years from foot to foot, and 3 years from hand to foot or foot to hand. These findings emphasize the great potential for preventive care in leprosy, and it is an indication of how neglected a disease leprosy has been that disabilities have nevertheless occurred. Mallac also found that deformity developed on the average 2½ years earlier in men than in women, which may reflect the greater tendency for men to engage in rough manual work. In addition, a consistent increase in the latent period of deformity with age was observed, the two extremes being 2.6 years in the 11–20 age group and 9 years for those aged 51 years or over. Such findings might support targeting preventive activities at children and young adults. Subsequent studies have corroborated Mallac's findings.[53]

Severity. Most disabled patients present with moderate disability,[51, 52] milder disability being either not noticed or ignored. Whether this is because of poverty, ignorance, or a lack of knowledge about leprosy is clearly of great importance to primary prevention.

Factors influencing occurrence of disability

The occurrence of disability depends on many factors, only one of which is leprosy. These factors may at least partly account for the variation in reported levels of disability, and include: a) definition of disability; b) quality of leprosy control; c) geographical factors; d) environmental factors such as urbanization; and e) patient and disease factors. The latter factors include leprosy type, patient age and disease duration, sex, presence of nerve thickening and reaction, and socioeconomic factors.

Type of leprosy. Disabilities are generally more common in MB than PB leprosy,[51–53, 55–57, 70, 88, 89] including ocular problems.[78] In addition, disability tends to be more severe in MB leprosy, as indicated by higher DI levels.[54, 70, 90] Against this trend, Mallac observed the greatest frequency of disability in borderline leprosy followed by tuberculoid, lepromatous and indeterminate types.[28] The reasons for these differences may include geographical variation or the asymptomatic nature of borderline leprosy, such that patients only become aware of the disease when disability has set in.

Patient age and disease duration. The frequency of disability is well known to increase with patient age.[51, 52, 54, 55, 57, 70, 88, 89] This association appears to be independent of the leprosy type,[56] although it is most marked in lepromatous disease followed by borderline types. The lower frequency of disability in children is likely to reflect a number of factors, including the: a) preponderance of the milder forms of leprosy; b) shorter duration of disease; c) increased tendency for self-healing; and d) lower incidence of reaction in this age group. In ad-

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[87] Joffrion, V. C. Eye lesions in leprosy—glaucoma and tension. (Letter) Lepr. Rev. **60** (1989) 328.

[88] Srinivasan, H. Changes in epidemiology of deformity in leprosy in a rural area of south India. Indian J. Med. Res. **76** (1982) 795–803.

[89] Noordeen, S. K. and Srinivasan, H. Epidemiology of disability in leprosy. Int. J. Lepr. **34** (1966) 159–174.

[90] Thappa, D. M., Kaur, S. and Sharma, V. K. Disability index of hands and feet in patients attending an urban leprosy clinic. Indian J. Lepr. **62** (1990) 328–337.

dition, the cumulative effect of many years of permanent disability is an important factor in adults.

Similarly, the disability rate has been positively associated with the duration of leprosy (both MB and PB) and, in particular, the disease duration prior to treatment.[53] Finally, the severity of disability, as measured by the DI, appears to increase with both patient age and disease duration.[51, 70, 90]

Sex. Male leprosy patients are more prone than females to develop disabilities,[51-56, 70, 89, 91] including ocular problems.[78] This has been partly attributed to a lower lepromatous rate in females,[92] since the disability rate in lepromatous patients is the same in both sexes.[51] Other responsible factors may include the greater tendency for males to smoke and to have hazardous occupations or outdoor habits. A higher DI level has also been found in males compared with females,[51, 54, 56] although exceptions exist.[70]

Nerve thickening and reactional states. The occurrence of disability in leprosy has been positively associated with both nerve thickening[51, 52, 73] and reaction,[47, 70] with reactive neuritis probably accounting for the association with nerve thickening.

Socioeconomic factors. The geographic distribution of leprosy in the tropical and subtropical regions of the world is more likely to reflect socioeconomic factors than any climatic effects, since leprosy was found throughout the temperate climates of Europe in the first half of this millenium, and in Norway until as recently as the beginning of this century.[93] Similarly, leprosy disappeared from parts of the Far East during this century,[94] most probably because of favorable social and economic changes leading to improved living conditions and health status, better health systems, and reduced disease transmission.[95]

Increased rates of disability have also been associated with illiteracy, hazardous occupations such as manual labor or farming, and low social class,[51-55, 90, 97] low social class itself being associated with illiteracy, poor working conditions, social hardship and economic deprivation.[54, 96] Mechanisms by which these factors may predispose to disability include trauma, poor self-care, infection, and poor compliance with treatment. Nevertheless, exceptions to these findings exist, such as a relatively low disability rate in agricultural laborers,[89] and a high DI in housewives second only to beggars,[90] which suggests that further work in this area is needed.

Sequelae of disability in leprosy. Despite the low global morbidity of leprosy compared with other communicable diseases, it has marked social, economic and psychological effects, principally as a result of physical disability.

Social sequelae. Leprosy is associated in many countries with a high level of public prejudice and discrimination. Reported levels of "social disability" vary widely, ranging between 2.9% and 26%.[54, 89, 97] In addition, one case-control study from eastern China found that leprosy patients were significantly ($p < 0.01$) more likely to be unmarried, divorced, or have broken homes.[35] Many social problems in leprosy, such as family upsets and break up, undoubtedly cause considerable distress and unhappiness, but they are difficult to quantify and have only infrequently been assessed. It is therefore likely that studies to date have underestimated the scale of the problem.

As regards the nature and determinants of social prejudice, a detailed study in Gwalior found that when present it took the form of restriction of touch in 63% of patients,

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[91] Rao, N. M. S., Shankar, S. V., Murthy, N. D. P., Vomstein, E. and Meermeir, H. Problems of leprosy in Karnataka. Lepr. India **52** (1980) 236–244.

[92] Fine, P. E. M. Leprosy: the epidemiology of a slow bacterium. Epidemiol. Rev. **4** (1982) 161–188.

[93] Fine, P. E. M. Leprosy and tuberculosis—an epidemiological comparison. Tubercle **65** (1984) 137–153.

[94] Saikawa, K. The effect of rapid socioeconomic development on the frequency of leprosy in a population. Lepr. Rev. **52** Suppl. 1 (1981) 167–175.

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[96] Vyas, G. K., Dudani, I. U. and Chaudhary, R. C. A sociological study of leprosy in Gandhi Kusht Ashram, Jodhpur (Rajasthan). Lepr. India **54** (1982) 324–331.

[97] Kushwah, S. S., Govila, A. K., Upadhyay, S. and Kushwah, J. A study of social stigma among leprosy patients attending a leprosy clinic in Gwalior. Lepr. India **53** (1981a) 221–225.

hatred in 56%, limitation of movement around the home in 30% and surroundings in 12%, and restriction of speech in 9%.[97] The source of this prejudice was mainly neighbors (57%), followed by relatives (43%), and members of the immediate family (20%). Patients aged 45–54 years were most affected, followed by the 35–44, 6–14, and over 65 age groups, the lower levels of stigma in the latter two groups probably reflecting their relatively low mobility. In addition, males were more stigmatized than females (63% vs 37%), perhaps related to the greater mobility and lesser covering by clothes of males. Stigma was also linked to social status, being most prevalent in illiterates (56%) and those in social class V (65%), in agreement with earlier American findings.[98] Exceptions exist, however, such as a Tamil Nadu-based study which observed high levels of stigma even among the better educated and more affluent sections of society.[99]

Finally, perhaps the ultimate symbol of socioeconomic decline among leprosy patients is when they begin begging. Begging is of particular concern since it is associated with a low rehabilitation success rate and perpetuates public prejudice concerning leprosy. Regarding the latter, an illuminating recent Indian study of 41 beggars in Aska questioned two popular prejudices concerning leprosy beggars—their indifference to treatment and infectivity.[100] They found that not only were all those questioned taking treatment, but that all but two were skin-smear negative, and thus no infection risk.

Economic sequelae. Disability affects the economic status of patients principally as a result of unemployment (vocational displacement), which may arise either directly through a reduced ability to work (patient factors), or indirectly as a result of adverse social customs, attitudes, or restrictive laws (society factors). In a wider sense, the socioeconomic development of some endemic countries may have been hampered by a loss of manpower due to leprosy.

One Indian longitudinal study of 116 agricultural laborers with leprosy, of whom 63% had physical disabilities, found that only 62% retained the same job after 4 years.[101] Disability was the main reason for losing or changing job, and those changing jobs were found on the average to have worse disabilities than those keeping the same job. As in so many studies, disability was predominantly found in older patients (average 51 years) in whom vocational rehabilitation would be relatively difficult, thus emphasizing the importance of a preventive approach to rehabilitation. Other studies have observed increases in the level of unemployment before and after the appearance of deformities from 46% to 92%,[50] and 42% to 78%.[102] It was notable that in the former of these two studies, employment where retained was found to aggravate deformities, apparently because adverse financial circumstances forced patients to take any type of work.

As regards the financial implications of disability, one Indian study observed a reduced income in only 19% of disabled patients,[54] while in a Chinese study a 64% "loss of productivity" was reported.[35] A further study of 550 patients in Tamil Nadu, India, concluded that the elimination of disability in leprosy would double the patients' average annual earnings, and by extrapolating these figures to the whole of India, estimated the annual productivity loss due to disability in leprosy patients to be over US$130 million.[102]

Clearly, the economic impact of leprosy is substantial, despite the variation in reported levels between studies. This variation is likely to reflect differences in such factors as disability severity and initial economic status. If a patient is poor to begin with, for example, disability will make little if any difference to their economic status. It

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[99] Ramu, G., Divedi, M. P. and Iyer, C. G. S. Social reaction to leprosy in a rural population in Chingleput district, Tamil Nadu. Lepr. India **47** (1975) 156–169.

[100] Krishnamurthy, K. V. and Prabhakara Rao, S. A study of leprosy affected beggars in Aska. Indian J. Lepr. **62** (1990) 113–115.

[101] Kuppusamy, P., Richard, J. and Selvapandian, A. J. A study of causes of unemployment among agricultural labourers afflicted by leprosy. Lepr. India **51** (1979) 369–375.

[102] Max, E. and Shepard, D. S. Productivity loss due to deformity from leprosy in India. Int. J. Lepr. **57** (1989) 476–482.

is also likely that reports underestimate the economic impact of leprosy, when one considers disability occurring in unreported cases, and productivity losses resulting from premature mortality. In addition, estimates often only consider the indirect costs of leprosy, and not the direct costs in terms of medical care and so forth.[103] Further studies of the economic sequelae of leprosy and disability are needed, therefore, not least to aid policy decisions and justify expenditure on rehabilitation services such as physiotherapy, which, despite being highly effective in limiting disability when administered early, requires a substantial initial input of resources.[102]

Psychological sequelae. Leprosy is so much associated with sin, punishment, physical disfigurement, isolation and public prejudice, it is perhaps not surprising that psychological sequelae pose major problems for leprosy rehabilitation. It is well known, for example, that many leprosy patients make poor use of available rehabilitation services, and instead of rejecting these patients as "difficult," reasons for their poor cooperation, aggressiveness and so forth could be determined. Particular concerns of leprosy patients include the outcome of the disease, insecurity about the future, and loss or change of job. In addition, patients face loss of confidence and a sense of inadequacy.

Early studies of the nature of psychiatric morbidity in leprosy patients were confined to institutionalized patients. These hallmarks included Henderson's study in 1964 of 11 chronic leprosy patients in whom signs of institutional neurosis (passivity, depression and apathy) were observed,[104] Weigand and Dawson's findings in 1967 of increased levels of depression, neuroticism and paranoia in 85 patients compared with a control group,[105] and Flynn and Harvey's observations in 1968 that leprosy patients tend to handle emotional problems in a neurotic manner, or by means of somatization.[106] In 1976, Dharmendra reported an 11% rate of psychiatric disturbance among 494 patients, with depression by far the commonest finding.[58] These levels were significantly higher than the general population, and increased with the duration of disease. No association was found with leprosy type, however. Finally, in 1983, Mhasawade reported high mean scores of anxiety and depression in 120 institutionalized patients.[107] Ultimately, a "deformed personality" may result, making re-entry into society difficult and producing further isolation.

These studies were valuable in identifying high levels of psychiatric morbidity in leprosy patients, but were limited in being confined to institutionalized patients. Thus, it is difficult to extrapolate their results to the community at large, or to rule out the effects of institutionalization *per se*. Nevertheless, community-based studies have made similar observations. One such Chinese investigation, which administered the Eysenck Personality Questionnaire to 100 leprosy patients, observed a marked 83.8% rate of psychological disorders, including anxiety, tension, anger and depression.[35] Moreover, 69% of the patients had thoughts of suicide, and a retrospective analysis by the same workers revealed a higher suicide rate in leprosy patients (1484/100,000) compared with the general population (13.6/100,000). Community surveys in Gudiyattam Taluk and Vellore in India have reported psychiatric morbidity rates of 99/1000[108] and 63/1000,[109] respectively, both higher than the population average. In the Gudiyattam Taluk study, depression was by far the commonest finding (84%), with psychiatric disturbance more common in males (61%), the poorly educated (78% illiterate), chronic patients (61% having leprosy for over 10 years),

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[103] Wardekar, R. V. Sulphone treatment and deformity in leprosy. Lepr. India **40** (1968) 161–171.

[104] Henderson, A. S. Psychiatric sequels of leprosy in New South Wales. Med. J. Aust. **2** (1964) 632–634.

[105] Weigand, E. L. and Dawson, J. G. Response patterns of Hansen's disease patients on the perceptual reaction test. J. Clin. Psychol. **23** (1967) 452–454.

[106] Flynn, P. E. and Harvey, H. Investigation of the psychological world of the Hansen's disease outpatient. (Abstract) Int. J. Lepr. **36** (1968) 633–634.

[107] Mhasawade, B. C. Leprosy—a case for mental health care. Lepr. India **55** (1983) 310–313.

[108] Kumar, J. H. R. and Verghese, A. Psychiatric disturbances among leprosy patients; an epidemiological study. Int. J. Lepr. **48** (1980) 431–434.

[109] Verghese, A., Beig, A., Senseman, L. A., Sundar Rao, P. S. S. and Benjamin, V. A social and psychiatric study of a representative group of families in Vellore town. Indian J. Med. Res. **61** (1973) 608–620.

and those with physical handicaps (63%).[108] The latter finding supports the widely held assumption that physical disability is the root cause of much of the social stigma and psychiatric morbidity associated with leprosy. The observed influence of disease chronicity on psychiatric morbidity is both supported[108] and refuted[109] by other studies, and it would be interesting to conduct a longitudinal study to see if there is any pattern of change with the different stages of the disease process.

In other studies, patients with gross deformities have been shown to be relatively "adventurous" and "paranoid," with a high neuroticism score,[110] and in 91 Bombay patients with grade 2 and 3 deformities, over 70% were found to feel either worry, shame or embarrassment.[111] It is ironic that in the latter study the proportion experiencing physical difficulties due to deformity (53%) was actually less than the proportion with psychological problems. Interestingly, only half of those who were psychologically affected attributed it to a fear of stigma, suggesting that the importance of leprosy stigma *per se* may be overestimated.

REACTIONS AND THE LEPROSY PATIENT

Reactions are widely accepted as responsible for much of the physical disability associated with leprosy, which they seem to accelerate. Since over half of leprosy patients experience reaction at some time during the course of their illness (the most frequent medical complication of leprosy), increased attention to reactions as part of rehabilitative care would seem to be indicated. Studies of the frequency of leprosy reactions have been few and small-scale, but findings to date are as follows.

Paucibacillary leprosy

PB patients (and BT patients in particular) are generally accepted as more prone to reaction than MB patients, accentuated by the relatively short duration of chemotherapy in this group. Reported rates of reversal (type 1) reactions in PB patients during 6-month MDT fall in the range 1.5%–29%,[112–117] with most below 5%. These levels seem fairly low and acceptable, and have been attributed to an immunosuppressive action of rifampin and dapsone, independent of their antibacterial effects. Nevertheless, it is of concern that the ALERT program in Ethopia found that up to half of the reversal reactions diagnosed in BT patients developed after the discontinuation of MDT. Indeed, the same workers found new nerve function loss to occur more than 1 year post-MDT,[46] raising the possibility that many patients developing reaction go unrecognized. It is possible, therefore, that the 2-year post-MDT follow-up period recommended by the WHO may need to be extended, but carefully controlled larger-scale corroborative studies would be needed before implementing such a proposal.

Multibacillary leprosy

Data concerning type 2 reactions in MB leprosy are more scarce than those for PB leprosy, but in one well-known Indian study no worsening of existing reactions or development of fresh reactions was observed after 2 years of MDT.[116] In the Tamil Nadu program in India, which has a coverage of some 98,000 patients (both MB and PB), only 90 type 2 reactions were observed over

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[111] Price, J. E. A study of leprosy patients with deformities, and the implications for the treatment of all leprosy patients. Lepr. Rev. **54** (1983) 129–137.

[112] Reddy, P. K. and Mohinuddin, S. K. Pattern of relapses in paucibacillary leprosy patients treated with MDT (WHO 1982). Indian J. Lepr. **60** (1988) 581–588.

[113] Reddy, P. K. Occurrence of reversal reactions in BT patients during WHO paucibacillary leprosy MDT 1982. Indian J. Lepr. **60** (1988) 453–456.

[114] Bhate, R. D., Gupta, C. M., Chattopadhay, S. P. and Singh, I. P. Experience with multidrug therapy in paucibacillary leprosy. Indian J. Lepr. **58** (1986) 244–250.

[115] Becx-Bleumink, M. Implementation of multidrug therapy in the ALERT leprosy control programme in the Shoa region of Ethiopia. First results with paucibacillary patients. Lepr. Rev. **57** (1986) 111–119.

[116] Kaur, S., Sharma, V. K., Kumar, E., Singh, M. and Kaur, I. Multidrug therapy in bacilliferous leprosy—two years experience. Indian J. Lepr. **57** (1985) 483–490.

[117] Rose, P. Short course multidrug therapy of paucibacillary leprosy in Guyana: preliminary communication. Lepr. Rev. **55** (1984) 143–147.

5 years,[119] while in another study type 2 reactions occurred in 29% of patients (9/31 patients) over the same time period.

Antileprosy chemotherapy and reaction

As the period of greatest risk of reaction appears to be in the first 6 to 12 months of treatment, it has long been thought that chemotherapy may have a causal role. Chemotherapy provides only a partial explanation of reaction, however, since: a) reversal reactions often occur in untreated patients; b) patients may initially present in reaction; c) drug therapy may be a coincident finding; and d) clofazimine[120] and high doses of dapsone[121] may have a protective effect.

Apart from lepra reactions, despite the rarity of reports of drug hypersensitivity reactions up to the late 1970s, an increasing trend has more recently been reported.[122] One Thailand study of 7300 treated leprosy patients, for instance, noted an increase in the incidence of drug reactions from 0.3% over the period 1970–1982 of 3.6% for 1982–1988. The proposed reasons for this increase included:[123] a) increased awareness; b) low doses of dapsone prior to 1976; c) altered quality of dapsone; and d) introduction of multidrug therapy from 1982 onward.

Interestingly, dapsone toxicity seems to affect only motor nerve fibers, which may be a useful differentiating factor.[20]

It has been proposed that the low frequency of ENL reactions in treated patients with WHO-MDT may be partly attributable to an antiinflammatory action of clofazimine, although reactions have previously been observed after clofazimine therapy.[124] Another proposal is that rifampin may sensitize some patients to dapsone.[123] Indeed, the latter authors suggested that in MDT dapsone be given for 8 weeks prior to starting rifampin, although there is little evidence to support this view. Other possible precipitants of reaction besides chemotherapy include intercurrent infection (especially tuberculosis), physical and mental stress, vaccination, and pregnancy. As regards the latter, the puerperium appears to be the time of greatest risk, while CMI is returning to normal from a depressed state. Mechanisms for most of these precipitants remain unclear, however.

RELAPSE AND THE LEPROSY PATIENT

Relapse may be defined as the reappearance of active disease in patients who have completed the prescribed course of treatment.[125] In leprosy, its most likely cause is *M. leprae* persistence, which is defined as the ability of some bacilli to survive treatment by effective drug doses despite being fully susceptible to their effects. Patient compliance is also likely to have a role. Relapse is usually diagnosed by a positive skin smear, or an increase in antibody titer in spite of a negative smear, and it is proving to be an increasingly important concept. Indeed, some workers have proposed the absence of relapse as the best measure of cure.[126]

Reported relapse rates can be divided into those for MB and PB leprosy combined and those for PB and MB patients separately. In the former group, rates for dapsone monotherapy have included 11.6% after 12 months of therapy,[127] 14% after 18 months,

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[122] Smith, W. C. S. Are hypersensitivity reactions to dapsone becoming more frequent? Lepr. Rev. **59** (1988) 53–58.

[123] Richardus, J. H. and Smith, T. C. Increased incidence in leprosy of hypersensitivity reactions to dapsone after introduction of multidrug therapy. Lepr. Rev. **60** (1989) 267–273.

[124] Mahapatra, S. B. and Ramu, G. Transformation from lepromatous to borderline leprosy with clofazimine therapy. Lepr. India **48** (1976) 172–176.

[125] Van Brakel, W., Kist, P., Noble, S. and O'Toole, L. Relapses after multidrug therapy for leprosy: a preliminary report of 22 cases in west Nepal. Lepr. Rev. **60** (1989) 45–50.

[126] Georgiev, G. D. and McDougall, A. C. A re-appraisal of clinical and bacteriological criteria in the implementation of multiple drug therapy for leprosy control programmes and proposals for their better use. Lepr. Rev. **64** (1990) 64–72.

[127] Lowe, J. The late results of sulphone treatment of leprosy in east Nigeria. Lepr. Rev. **25** (1954) 113–124.

and 28% for treatment lasting up to 5 years.[128]

Paucibacillary leprosy

During the era of dapsone monotherapy, observed relapse rates in PB patients included: 1.8% in patients followed up for 5–6 years (73.5% in the first 3 years of follow up),[129] 3% after 4 years,[130] 4.4% in borderline cases treated for 3–9 years after subsidence,[131] and 9.4% after 6–18 months.[132]

With a few exceptions,[133] lower relapse rates have been reported following 6-month WHO-MDT, including 2.2% (2/92),[112] 2.3% (1/44),[134] and 2.9% (16/555).[125] In the last study, 92% of the relapses occurred within 3 years of stopping MDT. Finally, an excellent, recent large-scale study in the Baroda District of India, which confirmed all relapses histologically, reported a mean relapse rate of 0.19% (21/11,050), with all relapses occurring within 3 years of stopping MDT (76.2% in the first 2 years).[135] These findings not only suggest that MDT has reduced the occurrence of relapse, compared with dapsone monotherapy, but also that the WHO-recommended follow-up period of 2 years after stopping MDT is reasonable. Firm conclusions will not be possible until corroborative larger-scale studies have been conducted, however.

Multibacillary leprosy

Even fewer follow-up studies of relapse have been conducted in MB than in PB patients, probably because MB patients are less numerous and less readily released from control than PB patients. Nevertheless, a recent study from Nepal reported a relapse rate of 1.6% (6/372) after 2 years of MDT,[125] and it has been a consistent finding that fewer than 50% of relapses occur within 2 years of stopping MDT,[136, 137] suggesting that the 5-year follow-up period recommended by the WHO may be too short.

This being said, an Indian study utilizing a modified MDT regimen of just 3 months observed no relapses in 64 patients followed up over 3 years, despite all patients being bacteriologically positive at the end of therapy.[138] Moreover, skin biopsies over this period yielded no viable bacilli, and the conclusion was reached that MDT should be stopped in MB patients after 2 years, even in the presence of a positive BI. Thus, the absence of relapse, rather than bacterial inactivity, would serve as the measure of cure. Pattyn's study raised important questions regarding the value of skin smears and, indeed, it is true that reliance on the reappearance of morphologically intact bacilli in skin smears as proof of relapse is peculiar to MB leprosy.[139] One should appreciate that skin smears have some major limitations, particularly regarding their accuracy, reliability, and the choice of appropriate sampling sites.[125] There is a need for standard criteria for the diagnosis of relapse, and a simple tool, such as a urine dipstick, capable of reliably detecting a rise in the level of *M. leprae* antigens, for instance, would be invaluable.

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[128] Touw-Langendijk, E. M. J. and Naafs, B. Relapses in leprosy after release from control. Lepr. Rev. **50** (1979) 123–127.

[129] Ekambaram, V. Duration of treatment for disease arrest of non-lepromatous cases and relapse rate in these patients. Lepr. Rev. **50** (1979) 297–302.

[130] Jesudasan, K., Christian, M. and Bradley, D. Relapse rates among non-lepromatous patients released from control. Int. J. Lepr. **53** (1984) 304–310.

[131] Ramu, G. and Ramanujam, K. Relapse in borderline leprosy. Lepr. India **46** (1974) 19–25.

[132] Girdhar, B. K., Girdhar, A., Ramu, G. and Desikan, K. V. Short course treatment of paucibacillary (TT/BT) leprosy cases. Indian J. Lepr. **57** (1985) 491–498.

[133] Central JALMA Institute for Leprosy. Annual Report, Agra, India, 1983.

[134] Puavilai, S. and Timpatanapong, P. Short-course multi-drug therapy for leprosy patients. J. Med. Assoc. Thai. **72** (1989) 33–36.

[135] Chopra, N. K., Agarwal, J. S. and Pandya, P. G. A study of relapse in paucibacillary leprosy in a multidrug therapy project, Baroda district, India. Lepr. Rev. **61** (1990) 157–162.

[136] Nollet, E., Janssens, L., Groenen, G., Bourland, J. and Pattyn, S. R. Incubation time for relapse in multibacillary leprosy. (Abstract) Int. J. Lepr. **52** (1984) 686.

[137] Pattyn, S. R. Incubation times of relapses after treatment of paucibacillary leprosy. Lepr. Rev. **55** (1984) 115–120.

[138] Pattyn, S. R. Efficacy of different regimens in multibacillary leprosy. Lepr. Rev. **57** Suppl. 3 (1986) 265–271.

[139] Waters, M. F. R., Ridley, D. S. and Ridley, M. J. Clinical problems in the initiation and assessment of multidrug therapy. Lepr. Rev. **57** Suppl. 3 (1986) 92–100.

Finally, despite the apparent potential of using relapse in leprosy control and rehabilitation, it is of concern that aspects of its diagnosis remain problematic. Thus, while diagnosis is usually straightforward in MB leprosy, in PB leprosy relapse may be confused with reversal reaction. Indeed, clinically, reversal reaction may be the first sign of relapse in PB patients, and can produce almost all of the signs of relapse.[139, 140] Even histologically, reaction and relapse may be difficult to differentiate.[141, 142] One proposal to aid differentiation is careful observation of the timing of onset, since signs developing within 1 year of diagnosis are usually due to reversal reaction, while those occurring beyond 18 months suggest relapse.[16] Nevertheless, early relapse can still be difficult to distinguish from late reaction, and in order to overcome this dilemma, adoption of the worse diagnosis of relapse in all uncertain cases has been proposed by some.[137]

STIGMA AND THE LEPROSY PATIENT

G. Armauer Hansen observed over a century ago that leprosy is "a disease like any other," and yet public prejudice still abounds. The term stigma (derived from the mark used to brand a slave) has been defined as any deeply discrediting attribute preventing acceptance, respect or regard from the community.[143]

The predilection of *M. leprae* for the skin and nerves, and the resultant tendency for skin lesions and disfigurement together with the incurability and chronic nature of leprosy, meant that stigma arose almost as an instinctive reaction to the disease. It is thus not surprising that leprosy became a metaphor for highly stigmatized and feared conditions; a symbol not only of the horrible and hopeless, but also of the sinful.[144] Indeed, in the Old Testament leprosy is described as a divinely ordained punishment for sin (Leviticus, 13:45): "The leper in whom the plague is, his clothes shall be rent, and his head bare, and he shall put a covering upon his upper lip, and shall cry, Unclean, unclean."

In Western Europe, leprosy stigma reached its peak in the Middle Ages, with sufferers denied civil rights and required by Levitical law to "live apart" in lazar houses or hospitals outside the city walls. They were considered dead to the world, without rights to marriage or property,[145] and in some cases were even killed.[146] Interestingly, isolation of leprosy patients seemed to be more out of fear of moral or spiritual contagion than of disease transmission *per se,* and cases of leprosy sufferers being let out from colonies for farmwork and begging, or expelled as a punishment for misdemeanors, have been recorded.[144] Moreover, as recently as 1867 the U.K. Royal College of Physicians published the view that leprosy was inherited and not infectious.[147]

With the decline of leprosy in Western Europe toward the end of the 15th century, leprosy stigma also diminished, although a resurgence ("retainting") occurred at the end of the 19th century, coinciding with the discovery by the Western nations of leprosy hyperendemicity in their colonies and scientific breakthroughs, such as the germ theory of disease and Hansen's discovery of the leprosy bacillus.[148] This led to the view that leprosy was highly contagious, and was partly responsible for the persistence of associations of leprosy with incurability, in-

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[140] Pandian, T. D., Sithambaram, M., Bharathi, R. and Ramu, G. A study of relapse in non-lepromatous and intermediate groups of leprosy. Indian J. Lepr. **57** (1985) 149–158.

[141] Waters, M. F. R. and Ridley, D. S. Tuberculoid relapse in lepromatous leprosy. (Abstract) Int. J. Lepr. **47** (1979) 350.

[142] Pearson, J. M. H. and Ross, W. F. Nerve involvement in leprosy—pathology, differential diagnosis and principles of management. Lepr. Rev. **46** (1975) 199–212.

[143] Goffman, E. *Stigma: Notes on the Management of Spoiled Identity.* London: Penguin Books, 1968.

[144] Richards, P. *The Medieval Leper and His Northern Heirs.* Cambridge: DS Brewer Ltd., 1977.

[145] Browne, S. G. Some aspects of the history of leprosy: the leprosie of yesterday. Proc. R. Soc. Med. **68** (1975) 485–493.

[146] Brody, S. *The Disease of the Soul: Leprosy in Medieval Literature.* New York: Cornell University Press, 1974.

[147] Report on Leprosy by the Royal College of Physicians, 1867.

[148] Gussow, Z. *Leprosy, Racism, and Public Health: Social Policy in Chronic Disease Control.* San Francisco & London: Westview Press, 1989.

fectiousness, and divine punishment in contemporary Western cultures.[149] This is well illustrated by the portrayal of leprosy in films such as "Papillon" (RCA-Columbia, 1973) and a recent study's remarkable finding that people in the West would prefer to contract AIDS than leprosy.[20] It is also notable that active leprosy remains one of only two nonvenereal diseases excluding potential immigrants to the United States.[150] The persisting mythology concerning the body and disease, despite unprecedented developments in medicine, was recently discussed by Cecil Hellman in his book "Body Myths" (Chatto and Windus, London, 1991).

As regards endemic countries, possible reasons for the persistence of leprosy stigma include:[151] a) public misconceptions; b) compulsory segregation and isolation of patients in leprosaria; c) low profile of clinically normal and cured leprosy patients (concealment); d) high profile of deformed, burnt-out patients engaged in begging; e) discriminatory laws, such as India's Leprosy Act of 1898, which restricts the activities of leprosy sufferers and various marriage acts permitting divorce if a spouse has leprosy; f) use of leprosy by writers and politicians as symbolism for evil, degradation or immorality; and g) portrayal by charities of the "horrors" of leprosy. The low priority given to leprosy research and control programs and the lack of initiative or resources to inform the general public and medical profession, are also likely to have played a role.

Despite the daunting prospect of tackling stigma, it is encouraging that leprosy programs are now giving greater consideration to operational and public health issues, in particular health education. Moreover, Jopling has predicted that when active leprosy is eradicated, as many hope, the stigma should also vanish, just as it did from Western Europe in the 15th century.[151]

REHABILITATION—GENERAL CONSIDERATIONS

Traditionally, death has been the antithesis of success in medicine, with extravagant resources consequently devoted to the prolongation of life. The absence of death does not ensure health, however, and slowly the concept of quality of life has emerged. The preceding discussion clearly supports a role for rehabilitation in the prevention and reversal of disability and its sequelae, and the WHO Expert Committee on Disability and Prevention has recommended that governments make a firm committment to include disability prevention and rehabilitation in their plans for primary health care development. Moreover, with the escalating number of patients completing relatively short-duration MDT, and the recognition that completion of therapy holds no guarantee of total cure or safeguard against relapse, together with the problem of residual disability, many centers are evolving "care after cure" policies. It is of concern, however, that in many others with less resources, deregistration and release from control remain the accepted policy after the completion of therapy.

Rehabilitation (Latin *rehabilitare*: restore) was defined by the National Council on Rehabilitation in 1942 as "the restoration of the handicapped to the fullest physical, mental, social, vocational and economic usefulness of which they are capable." The WHO Expert Committee on Leprosy expanded on this definition in 1960 to include all treated patients, restoring them "to normal activity [to] resume their place in the home, society and industry. To achieve this, treatment of the physical disability would obviously be necessary, accompanied by education of the patient, his family and the public, so that not only could he take his normal place in society, but society would also be willing to accept him and assist in his complete rehabilitation."[37] The main objectives of rehabilitation therefore are:[11] a) improvement or prevention of deterioration of physical disabilities; b) improvement of social and economic status; and c) assurance of a positive attitude and cooperation from the community at large.

Local variations in the demography of disability and the availability of funds,

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[149] Abel, G. and van Soest, A. H. Psychologic difficulties in the treatment of leprosy patients in a nonendemic country. Int. J. Lepr. **39** (1971) 429–432.

[150] Gostin, L., Cleary, P., Mayer, K., Brandt, A. and Chittenden, E. Screening immigrants and international travellers for the human immunodeficiency virus. N. Engl. J. Med. **322** (1990) 1743–1746.

[151] Jopling, W. H. Leprosy stigma. (Editorial) Lepr. Rev. **62** (1991) 1–12.

equipment, and personnel, make it difficult to define a standardized general strategy for rehabilitation, although key elements can be identified. An ideal leprosy "team," for instance, would comprise a reconstructive surgeon, physician, social worker, physiotherapist, occupational therapist, shoemaker, and other prosthetists. Similarly, resources permitting, rehabilitation services would include the prevention of disability, health education, suitable training and prevocational help, simple treatments such as plaster casts, physiotherapy, inpatient treatment including reconstructive surgery, the provision of protective devices, and counselling.

Despite the excellent definitions and associated guidelines for rehabilitation considered above, however, the Seven Nations Consultation on Leprosy in South-East Asia concluded in 1976 that "the prevention and treatment of deformities are rather neglected areas in the management of leprosy."[152] Reasons for the poor implementation of leprosy rehabilitation, together with aspects of its principles and development, are considered in the following section.

Historical considerations

The first recorded reference to leprosy rehabilitation was made by Huizenga in the *Philippine Leprosy News* of October 1929, who stated that "no higher type of relief work could be done."[5] In the same year, the British Empire Leprosy Relief Association (precursor to LEPRA) included "preventive propaganda" among its objectives,[153] and in the first issue of *Leprosy Review* in 1930, Cochrane stated that "something more than a mere eradication of the disease should be our aim."[154] The Fourth International Congress of Leprosy in Cairo in 1938 was probably the first conference to refer to leprosy rehabilitation.[155]

Despite these references, however, rehabilitation did not become a viable proposition until the introduction of sulfone drug therapy in the 1940s, which for the first time could prevent mutilation and death. The demonstration by Brand and others from 1947 of the value of reconstructive surgery also helped to bring rehabilitation to the fore, and heighten recognition of the contribution of anesthesia and misuse to trophic ulceration and deformity.[8]

By 1960, rehabilitation was firmly accepted as an integral component of leprosy control,[37] but as early as 1963 concern was expressed by the Eighth International Congress of Leprology that "deformity and blindness are being allowed to develop which could be prevented by simple advice and inexpensive treatment."[156] In 1970, Browne stressed the importance of evaluating the efficacy of rehabilitation to prevent program planners considering it "too expensive" for developing countries.[9] This latter view partly resulted from experiences with reconstructive surgery which, despite its success, was expensive and only available to a small number of patients. Indeed, Brand himself stated that "the greatest danger now is that we, who previously did nothing because we thought nothing could be done, will now do nothing because the little we can do seems so small compared with the size of the problem."[157]

In 1976, the Director-General of the WHO stated that "disease-oriented medicine needs to be complemented by disability-oriented medicine," with the objectives "not only [of] the prevention and cure of disease, but also . . . restoration of the individual to normal social function."[152] This reiteration of what had first been proposed almost 50 years earlier is a sad reminder of how poorly implemented rehabilitation has been.

Community-based versus institution-based rehabilitation

In recent decades, the emphasis of leprosy rehabilitation has shifted away from insti-

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[152] World Health Organization. Report of the Director-General to the Thirtieth World Health Assembly on the work of WHO in 1976. WHO Chronicle **31** (1977) 207–238.

[153] Indian Council of BELRA. Lepr. India **1** (1929) 4, 18.

[154] Cochrane, R. G. Prognosis in leprosy. Lepr. Rev. **1** (1930) 3–5.

[155] *Proceedings of the Fourth International Congress of Leprology.* Cairo: Fourth International Congress Leprology, 1938.

[156] Eighth International Congress of Leprology, Rio de Janeiro. Report of the Technical Panels approved by the Plenary Session. Int. J. Lepr. **31** (1963) 437–514.

[157] Brand, P. W. Life after leprosy through rehabilitation. Rehabil. Lit. **21** (1960) 239–245.

tutional leprosarial care toward a more primary health care-oriented, community-based approach. It is useful to consider why. Proposed advantages of community-based over institution-based rehabilitation include:[12] a) greater cost-effectiveness; b) participation of families as well as patients; c) techniques more appropriate to the local setting; d) service delivery via local infrastructure; and e) diminishes rather than increases leprosy stigma.

The maintenance of costly segregated leprosy institutions for the few has been to the detriment of the vast majority of patients living in the community, who often have inadequate health care. A redistribution of resources has been proposed with "every effort and cluster of resources . . . divided by the total number of people."[158] Another criticism of institution-based rehabilitation is that even the simplest service is provided by highly trained professionals with deleterious consequences for lay community-care and self-care. It is also difficult for "leprosy hospitals" to provide all of the services their patients may require. Finally, institutionalization has its own dangers, including the perpetuation of public prejudice and "institutional neurosis" among inmates in which apathy and dependence develops, thus reducing their ability and desire to return to the outside world.

One study of 40 patients in a leprosy colony in Mysore observed a 93% illiteracy and 73% deformity rate, and found that, while all of the patients had been employed prior to settlement in the colony, following settlement 65% had resorted to begging, significantly reducing their income.[159] Moreover, even some healthy male relatives were found to leave their jobs so that they could transport patients to places of begging. Similar negative observations have been made in other studies.[160]

Value of integration

The rationale of integration of leprosy services into the general health care system is to make them more comprehensive and accessible, with consequent benefits for patient care and compliance.[161] Indeed, this approach to leprosy care is necessitated by the increasing complexity of modern rehabilitation, such that programs are unable to provide all of the services themselves. Another consideration is that leprosy patients may concomitantly have other diseases, for instance, a significantly higher prevalence of HIV infection has been observed in some leprosy patients, with leprosy a presenting feature in some cases.[162, 163] An association between leprosy and tuberculosis has also been observed,[13] and although there are insufficient data at present to determine if tuberculosis is a major cause of death in leprosy patients, the possibility deserves investigation.

Other arguments in favor of integration include the absenteeism and poor compliance associated with specialized leprosy centers, which can have serious social consequences for the patients. This could be greatly reduced by having facilities open to both leprosy patients and those disabled from other causes. Nor would the benefits of integration be one-way, and the general health services would benefit from the organizational structure and expertise of leprosy programs. Finally, the adverse consequences on personnel training and general interest in leprosy of declining numbers of patients as leprosy control measures take hold should be anticipated[164] and, indeed, this problem has already been experienced in Zimbabwe.[165] Only if leprosy workers are integrated into the health service structure will they be able to influence policy deci-

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[158] Bryant, J. *Health and the Developing World.* Ithaca, NY: Cornell University Press, 1969, pp. 1–52.

[159] Vasundhra, M. K., Siddalingappa, A. S. and Srinivasan, B. S. A study of medico-social problems of the inmates of a leprosy colony in Mysore. Lepr. India **55** (1983) 553–559.

[160] Dwivedi, M. P. A study of medico-social problems of cured leprosy cases in Pandri Village of Raipur District, M. P. Lepr. India. **46** (1974) 245–252.

[161] Feenstra, P. and Tedla, T. A broader scope for leprosy control. WHO Forum **9** (1988) 53–58.

[162] Meeran, K. Prevalence of HIV infection among patients with leprosy and tuberculosis in rural Zambia. Br. Med. J. **298** (1989) 364–365.

[163] Nunn, P. P. and McAdam, K. P. Mycobacterial infections and AIDS in tuberculosis and leprosy. Br. Med. Bull. **44** (1988) 801–813.

[164] Lechat, M. F. Leprosy: the long hard road. WHO Forum **9** (1988) 69–71.

[165] Warndorff, D. K. and Warndorff, J. A. Leprosy control in Zimbabwe: from a vertical to a horizontal programme. Lepr. Rev. **61** (1990) 183–187.

sions and ensure that the need for rehabilitation and health education services, long after "active" leprosy has disappeared, is appreciated.

The government of India has recognized the value of integrating leprosy patients into vocational training and sheltered work programs for the physically handicapped (Report of the Working Group on the Eradication of Leprosy, 1982), and the Bombay Leprosy Project recently opened a clinic for the integrated training and rehabilitation of leprosy patients (News and Notes, Int. J. Lepr., Sept. 1991). This is the first clinic of its kind, and should provide many important lessons in such areas as the elimination of stigma. In China, integration of disability management and eradication programs for leprosy is often organized through dermatology institutes.[166]

It is significant that the public already views leprosy care in an integrated fashion, as exemplified by the adverse influence on leprosy patients' compliance of failure to treat an unrelated condition in a family member.[167] Thus, no one will believe that leprosy is "a disease like any other," until those suffering from it are admitted to general hospitals.

Operational factors and compliance

The introduction of MDT by many leprosy programs was associated with marked operational changes, and an increased appreciation of how poor utilization of services by patients, regardless of service efficacy, may result in poor overall care.[16, 168] Indeed, poor compliance to dapsone monotherapy was a major argument in favor of the introduction of MDT, and there is good evidence that MDT has indeed increased patient compliance.[117, 118, 169–174] Likely reasons for this observed increase include the relatively short duration of MDT, and the favorable associated operational changes, including:[169, 175] a) better health education leading to increased self-reporting by patients of problems; b) better surveillance by health staff; c) more convenient location of clinic sites; d) better defaulter retrieval; and e) discouragement of treatment by proxy. Common operational problems experienced by leprosy control programs include:[12] a) poor health infrastructure; b) inadequate resources; c) no proper plan of action; d) poor referral facilities; e) insufficient patient education; f) low priority of leprosy in some countries; and g) inadequate training of health workers.

The need for improvements in leprosy teaching at medical and paramedical schools has received particular attention.[176] Many of these factors can influence patient compliance, and one Indian study found the main reasons for noncompliance in 500 patients to be:[177] a) inconvenient clinic times (40%) or location (19%); b) belief that they are cured, or do not care (22%); and c) dissatisfaction with treatment or fear of reaction (18%). A previous study made similar observations, with fear of social stigma found to be a further patient factor.[178] Another study of rural leprosy patients found

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[166] Ryan, T. J. Ma He (1910–1988); a dermatologist to emulate. Int. J. Dermatol. **28** (1989) 413–414.

[167] Hogerzeil, L. M. and Kesava Reddy, P. General education as the main approach to leprosy control, Dichpalli, India. Lepr. Rev. **53** (1982) 195–199.

[168] Becx-Bleumink, M. Operational aspects of multidrug therapy. Int. J. Lepr. **57** (1989) 540–551.

[169] Balakrishnan, S., Kumar, A., Rao, B. R. and Patro, T. P. Implementation of tests for monitoring drug compliance of leprosy out-patients under multi-drug therapy. Indian J. Lepr. **58** (1986) 555–559.

[170] Revankar, C. R., Ganapati, R. and Naik, D. D. Multidrug therapy for paucibacillary leprosy; experience in Bombay. Indian J. Lepr. **57** (1985) 773–779.

[171] Keeler, R. F. Multidrug therapy in leprosy in Trinidad and Tobago; a preliminary report. Lepr. Rev. **55** (1984) 391–396.

[172] Hagan, K. J., Smith, S. E., Gyi, K. M., Lwin, M. M., Myaing, Y. Y., Oo, K. M., Shwe, T., Tin, K. M., Than, K. N., Hla, T. and Kywe, W. W. The reliability of self-administration of dapsone in leprosy patients in Burma. Lepr. Rev. **50** (1979) 201–211.

[173] Low, S. J. M. and Pearson, J. M. H. Do leprosy patients take dapsone regularly? Lepr. Rev. **45** (1974) 218–223.

[174] Hertroijs, A. R. A study of some factors affecting the attendance of patients in a leprosy control scheme. Int. J. Lepr. **42** (1974) 419–427.

[175] Ellard, G. A. Drug compliance in the treatment of leprosy. Lepr. Rev. **52** (1981) 419–427.

[176] McDougall, A. C. The medical student and leprosy. Lepr. Rev. **57** (1986) 97–100.

[177] Kumar, A., Thangavel, N., Durgambal, K. and Sirumban, P. Medical care delivery through leprosy clinics—consumer's perception, experiences and suggestions. Indian J. Lepr. **57** (1985) 845–861.

[178] Kumar, A., Sivaprasad, N., Anbalagan, M., Thangavel, N. and Durgambal, K. Utilization of medical agencies and treatment compliance by urban (Madras) leprosy patients. Lepr. India **55** (1983) 322–332.

that 65% preferred home delivery of drugs to collection at a clinic since it saved time, avoided loss of wages, and allowed treatment to be given to those unable to get to a clinic. The latter has clear implications regarding the promotion of self-care. Good compliance is also observed when leprosy workers show a personal interest in their patients,[179] and it is tempting to speculate that some of the past "failures" of rehabilitation resulted from failure to consider social, psychological and other felt needs of leprosy patients.

PHYSICAL REHABILITATION

Physical rehabilitation may be defined as the physical restoration of an individual to the best possible function, and in some countries where leprosy is not associated with much stigma, particularly in Africa, may be all that is required for a moderately disabled patient to return to a normal life. Key topics in physical rehabilitation include the roles of physiotherapy and corrective surgery, management of plantar ulceration and ocular problems, and the use of protective devices.

Role of physiotherapy

Robert Cochrane's *Practical Textbook of Leprosy*, published in 1947, was the first account in an English textbook of physiotherapy in leprosy, and Alderson, in the following year, laid down principles of physiotherapy and occupational therapy in the prevention and treatment of deformity.[180] Key roles of physiotherapy include:[181] a) recording of deformity status; b) application and teaching of methods of care; c) recognition and prevention of complications; d) discouragement of unnecessary attempts at rehabilitation of established deformities; e) pre-operative preparation of patients (isolation and strengthening of muscles, measurement of angles of contracture and so forth); and f) post-operative education and care.

For example, it is well known that nerve function loss is at least partly reversible, and physiotherapy has an important role to play in maintaining muscle bulk and activity during the period of paralysis, together with strengthening them during recovery.[182] This cannot only aid recovery but also prevent joint stiffness and contractures. Little data is available on the efficacy of physiotherapy, although an improvement in the status of 70% of disabled patients has been reported.[111]

Role of corrective surgery

Over its 40-year history, the emphasis of surgery in leprosy rehabilitation has shifted from purely corrective procedures toward the understanding of derangements, associated with the development of various preventive interventions.[29, 183] The pathology of nerve damage is now much better understood, as is the etiology of plantar ulcers and paralytic deformities. The objectives of surgery are thus: a) the prevention of handicap by disability reversal and return to normal appearance; and b) the prevention of the onset and worsening of disabilities. To this end, leprosy surgery can be divided into five types: a) reconstruction in cases of motor paralysis and hand and foot deformity; b) care of ulcers and infection; c) therapeutic surgery such as nerve decompression; d) cosmetic surgery; and e) restoration of sensation.

Despite this apparent complexity, a dozen or so surgical procedures typically meet the requirements of most leprosy patients, with the remainder a continuing source of new developments. Examples of corrective procedures for deformities due to motor paralysis include the many-tailed graft of Brand using plantaris tendon for paralyzed fingers, transfer of tibialis posterior muscle for drop foot, and various procedures for clawed fingers/toes. Ideally, surgery should only be performed when patterns of paralysis are stable, reactions are absent, and the patient has been taking MDT for at least 6 months.[29]

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[179] Emmanuel, F. When can a patient stop treatment? The Star **37** (1978) 10.

[180] Alderson, S. Physical therapy in leprosy. Lepr. Rev. **19** (1948) 119–129.

[181] Hasan, S. The aims and methods of physiotherapy in field conditions in the national leprosy control programme. Lepr. India **53** (1981) 608–619.

[182] Kulkarni, V. N. and Mehta, J. M. Special features of physical therapy in the claw hand of leprosy. Lepr. India **55** (1983) 694–696.

[183] Malaviya, G. N. Recent advances in restorative surgery of extremities in leprosy. Acta Leprol. (Genève) 7 (1990) 239–245.

For reconstructive surgery to be complete, patients should be absorbed back into society post-operatively, which necessitates the integration of surgery with physiotherapy and occupational therapy services. Moreover, surgical rehabilitation facilities need not and should not be limited to leprosy patients since they may be the only such facilities in the area, and could be integrated into the general health services.

As regards plantar ulceration, surgery would be considered when chronic ulceration does not respond to conservative measures, or is complicated by infection.[184] The rationale of ulcer surgery is to prevent ulcer recurrence, principally by reducing the mechanical factor involved. This may be achieved by the correction of deformities or removal of bony prominences.[29] Removal of a damaged or infected metatarsal combined with ulcer excision, for example, may provide a permanent cure. Otherwise, incision, drainage, metatarsophalangeal joint excision, or amputation may be considered. Skin grafting also has a role, and the removal of underlying abnormalities, such as a bone spur, is occasionally of value. Finally, prophylactic tibial nerve decompression, first published by Reginato and colleagues in 1962,[182] may have some value.

The principle of therapeutic nerve surgery is to relieve mechanical compression of a nerve, either by surgical decompression (neurolysis) or transposition, usually of the ulnar nerve. Neurolysis has had encouraging results,[186] although a recent study demonstrated for the first time an additional benefit of perineural corticosteroid injection, with 83.3% improvement in the combined treatment group compared with 57.1% in a group receiving neurolysis only.[187]

Cosmetic surgery is most often used to correct gynecomastia, facial palsy, nasal deformity, loss of eyebrows, lagophthalmos, or facial disfigurement, although it may be considered for any disfiguring deformity. Cosmetic procedures are often done for social and vocational reasons, to minimize rejection by society or family and/or increase the likelihood of obtaining a job.

Finally, procedures for the restoration of sensory loss, though seldom possible, offer exciting possibilities for the future, since sensory loss is the root cause of most disabilities in leprosy. One technique involves the grafting of a neurovascular skin island pedicle from a relatively "unimportant" part of the hand to an insensitive area in an attempt to transfer sensation.[188] One study grafted skin from the central fingers to the little finger or thumb in 20 patients with partially anesthetic hands, and reported excellent results in 90% over a 6-year period of follow up.[58] Patients were carefully selected, however, and in practice the procedure is rarely possible due to widespread sensory loss. A related method uses cutaneous nerve autografts, but these too are often involved in leprosy. Nerve grafts from fresh cadavers have been utilized in an attempt to overcome this problem, but with only limited success.[189]

While there is no doubt that surgery can be dramatically successful, it has been argued that this overstates the role of surgery, which is resource-inefficient, has limited impact on a population basis, and de-emphasizes other aspects of rehabilitation. For surgery to "survive," it has been proposed that procedures will need to be simple and quick, and not require general anesthesia, prolonged hospitalization, or significant post-operative education.[190] In this way, not only would surgery be made more cost-effective, but procedures could be performed by nonspecialized district surgeons, thus increasing the availability of surgery. Indeed,

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[184] Srinivasan, H. Nerve damage, surgery and rehabilitation in leprosy. Trop. Med. Parasitol. **41** (1990) 347–351.

[185] Reginato, L. E., Belda, W., Canton, P., Faggin, J. E., Cruz, E., Almeida, N. G. and de Mendes, F. C. A epineurectomia do tibial posterior no tratamento do mal perforante plantar de origen leprosa. Rev. Bras. Lepr. **5** (1962) 103–110.

[186] Palande, D. D. Surgery of the ulnar nerve in leprosy. Lepr. India **52** (1980) 74–88.

[187] Dandapat, M. C., Sahu, D. M., Mukherjee, L. M., Panda, C. and Baliarsing, A. A. Treatment of leprous neuritis by neurolysis combined with perineural corticosteroid injection. Lepr. Rev. **62** (1991) 27–34.

[188] Lennox, W. M. Use of a neurovascular skin island pedicle graft in the management of the anaesthetic hand in leprosy. J. Bone Joint Surg. **48B** (1966) 198.

[189] McLeod, J. G., Hargrave, J. C., Gye, R. S., Pollard, J. D., Walsh, J. C., Little, J. M. and Booth, G. C. Nerve grafting in leprosy. Brain **98** (1975) 203–212.

[190] Chevallard, A. J. Simplified surgical technique for flexible clawed hand rehabilitation. Int. J. Lepr. **55** (1987) 160–162.

Bourrel has claimed that a surgeon able to carry out some neurolyses and just four different palliative interventions could prevent or cure deformity in over 90% of leprosy patients.[29]

Care of plantar ulceration

Plantar ulceration has been said to pose the greatest single threat to leprosy rehabilitation.[191] Conservative management includes covering any skin break to prevent secondary infection, and splinting to allow healing to take place.[58, 192] Infection should be treated, if present, and any dead tissue or callus removed by debridement. Following this, the limb should be immobilized by means of a plaster cast, crutches, or bed rest. Once complete healing has occurred, suitable protective footwear is often of value.

Numerous agents have been proposed to improve the healing of plantar ulcers, including acriflavin, cod liver oil, amniotic membrane, hydrogen peroxide, hyperbaric oxygen, vitamins, and zinc, among many others, but their value has been questioned.[193] One cause for concern, for example, is the subjective nature of evaluative trials, as exemplified by a classic Canadian study in which exposure to a nonfunctioning device apparently led to better healing of bed sores; attendants believed it to emit an invisible healthy ray.[194] It is important that reliance on "wonder cures" does not detract from basic care and education.

Finally, one series but seldom discussed potential sequel of trophic ulceration, squamous cell carcinoma (SCC), deserves consideration. This form of SCC was first observed by Job and Riedel in 1964,[195] and at the time was considered "extremely rare." Subsequent reports suggest that its importance may be understated, however.[196] When it occurs, SCC is usually found in the heel area,[197] which notably is a relatively uncommon site for neuropathic ulceration.[198]

Role of footwear and other protective devices

Valuable protective aids for leprosy patients include spectacles for eyes with inefficient blink, thick towelling bags to protect insensitive hands from cooking burns, modified tools, toespring shoe supports for foot drop, and footwear. Of these, footwear is the most frequently discussed, owing to its role in the management of plantar ulceration. Nevertheless, using the example of footwear many important insights can be gained into the principles and problems of the use of protective devices in general.

The aim of protective footwear is to distribute a patient's weight over the maximum possible area of plantar skin. Microcellular rubber and plastazote are two good materials for this purpose since they have good shock-absorbing and moulding qualities. When making provisions for protective aids, local factors first need to be assessed, such as, in the case of footwear, the frequency of sole sensory loss, availability of suitable footwear, and average life of shoes once provided.[199]

Ideal protective footwear, like any appliance, should be cheap, capable of being produced in large numbers, and not associated with its own stigma. As regards cost, suitable footwear has been described costing just US$10 and US$3.50 per pair[200] and developments, such as a rapid method for cutting out sandal components with a steel strip and

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[191] Antia, N. H. Plastic footwear for leprosy. Lepr. Rev. **61** (1990) 73–78.

[192] Bryceson, A. and Pfaltzgraff, R. E. *Leprosy*. London: Churchill Livingstone, 1979.

[193] Srinivasan, H. Do we need trials of agents alleged to improve healing of plantar ulcers? Lepr. Rev. **60** (1989) 278–282.

[194] Fernie, G. R. and Dornan, J. The problems with clinical trials with new systems for preventing or healing decubiti. In: *Bed Sore Biomechanics*. Kenedi, R. M. and Cowden, J. M., eds. London: Macmillan, 1976.

[195] Job, C. K. and Riedel, R. G. Squamous cell carcinoma arising in plantar ulcers in leprosy. Int. J. Lepr. **32** (1964) 37–44.

[196] Arora, S. K. and Mukhija, R. D. Squamous cell carcinoma in trophic ulcer cases. Indian J. Lepr. **59** (1987) 100–102.

[197] Bhoopalraj, J. M. and Muthusami, T. C. Squamous cell carcinoma arising from trophic ulcers. Lepr. India **51** (1979) 74–77.

[198] Srinivasan, H. Trophic ulcers in leprosy. I—Pattern of distribution of trophic ulcers. Lepr. India **35** (1963) 119–127.

[199] Watson, J. M. Disability control in a leprosy control programme. (Editorial) Lepr. Rev. **60** (1989) 169–177.

[200] Wiseman, L. A. Protective footwear for leprosy patients with loss of sole sensation: locally made canvas shoes, deepened for a 10-MM rubber insert. (Letter) Lepr. Rev. **61** (1990) 291–292.

hammer,[201] may enable further cost reductions. The costs of footwear should not prevent its provision, however, since they are far lower than those of the disability and human suffering resulting from plantar ulceration.

As regards stigma, this may result from sandals exposing deformed feet, or an association of particular types of footwear with leprosy. Proposed ways of avoiding stigma have included employing a local shoemaker to modify shoes available to all people in the market,[29] and making shoes which resemble those in the market.[202] Indeed, there is much ongoing research into the development of appropriate, fashionable and acceptable footwear. Besides design changes, another solution might be to integrate leprosy services into those for handicapped patients generally. Finally, shoes should be readily obtainable, preferably at a local center, and if patients find it inconvenient to reach a center, encouragement in the form of subsidized travel and/or footwear could be considered.[203]

Once shoes or other aids have been administered, it is important to check that they are being used, and to identify and rectify any problems which arise. In the case of footwear, for instance, patients should be instructed to wear it at all times, and not only on special occasions such as a visit to the leprosy clinic! To this end, it is essential that patients have a good understanding of problems, such as anesthesia, which can only be achieved by appropriate education and training. In this respect, it is possible that lessons could be learned from such bodies as the British Arthritis and Rheumatism Council, which produces an excellent series of patient booklets on such subjects as the best choice of footwear.

As regards the efficacy of footwear, one Indian study of 101 patients found that immobilization with plaster of Paris followed by the issue of microcellular rubber footwear resulted in a 65% reduction in ulcer incidence within 2 years, and an associated drop in unemployment from 66% to 9%.[10] Notably, 90% of the patients who regained employment attributed it to use of the footwear. A later study in Swaziland distributed canvas shoes to 90 patients, of whom 36 initially had open ulcers, and after 6 months found that 15 were completely healed, 13 much improved, and only 6 were worse.[200] After 12 months, a further 25 were completely healed and 6 much improved, with 3 developing new ulcers. It was notable that deterioration, when it occurred, was associated with inconsistent shoe use.

Care of ocular problems

The care of ocular problems has a special importance in leprosy rehabilitation, since it is so instrumental in maintaining the quality of self-care. Examples of remediable ocular problems include lagophthalmos, helped by daily eyelid exercises; dry eye, prevented using a bland oil; iridocyclitis, treated by pupil dilatation and antiinflammatory medication; and the prevention and early treatment of infection. If corneal sensation is impaired, or exposure keratitis or glaucoma present, referral to an eye specialist is advisable. As regards the latter, Joffrion has proposed increasing the level of specialist referral for regular ophthalmic examination and care in light of such findings as a high level of glaucoma among his patients, and the apparent inaccuracy of digital compared with tonoscopic assessment of intraocular pressure.[87] In practice, it is likely that this would pose untenable logistical problems, but greater integration of ophthalmic care into the general management of the leprosy patient could be a realistic alternative. Increased specialist involvement in staff training would also be of value.

In the worst case of blindness, the leprosy patient is at a disadvantage compared with other blind people, since he lacks fingertip and other sensation. This results in a propensity to injuries, and an inability to communicate by means of braille or touch typing. Rehabilitation includes training patients to compensate through their remaining

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[201] Butsch, R. Protective footwear for leprosy patients: a rapid method for the cutting out of sandal components. (Letter) Lepr. Rev. **61** (1990) 290–291.

[202] Kulkarni, V. N., Antia, N. H. and Mehta, J. M. Newer designs in footwear for leprosy patients. Indian J. Lepr. **62** (1990) 483–487.

[203] Naganur, V. L., Bald, J. and Hopkins, M. An analysis of causes of injuries in workers with leprosy and suggestions for preventive measures. Lepr. India **48** (1976) 756–762.

senses, such as hearing, smell, proprioception, and tactile sensation in the lips and hand, and using any remaining light perception to teach a sense of direction.[204, 205] Other useful advice includes eating with a spoon instead of fingers, using utensils in a certain order to know where they are, having larger than normal shirts with buttons replaced by Velcro, and using cut-out X-ray films for writing.

One Indian study found that the average time to train a blind leprosy patient in this was about 100 hours, at a rate of two sessions per day over 8–10 weeks.[204] A break in training of more than 1 month, however, resulted in a loss of acquired skills. Thus, despite great potential, training remains highly resource-inefficient, and further research is needed to determine its long-term efficacy and the key elements of value.

Finally, among developments in the ocular care of leprosy has been the use of xenon arc photocoagulation to improve vision by reshaping the pupil.[206] This has been proposed as a useful, noninvasive and cheap outpatient procedure, which could be transported easily to field locations, for patients unsuitable for keratoplasty or unable to reach specialized centers.

PSYCHOLOGICAL REHABILITATION

There is an increasing recognition of the importance of psychological problems in leprosy and their detrimental influence on rehabilitation. What is less clear is how to ameliorate them. Psychological rehabilitation may be divided into two types; primary (prevention of deformity and dehabilitation) and secondary (supportive psychotherapy and counselling). The former is synonymous with preventive rehabilitation. As regards the latter, the aims of secondary psychological rehabilitation can be divided into: a) minimization of development of psychiatric problems; b) easing of recovery from problems; and c) restoration of confidence and ability to cope.

Patients and their families need to be reassured, both to allay fears concerning disease transmission and so forth and to try to solicit the help and cooperation of families, and encourage support at home. In order to help prevent family break up and rejection of the patient, it has been proposed that families be given psychological support together with health education and counselling if necessary.[207] Among the special issues emerging in psychological rehabilitation is the counselling of HIV-positive leprosy patients,[208] with whom leprosy workers may increasingly be faced, particularly in Africa. Guidelines are needed for this and other areas.

Little evaluative data are available concerning psychological rehabilitation, not least because it is not generally practiced. The viability of many proposals thus remains to be assessed. Nevertheless, one study in Kondhawa of 120 institutionalized patients found that combined psychotherapy and drug therapy significantly reduced levels of anxiety and depression, although levels remained much higher than in the general population, but the possibility of relapse after the cessation of therapy was not explored.[107] Further studies of psychological rehabilitation in leprosy are therefore needed to assess not only its efficacy but also its cost-effectiveness, since counselling tends to be rather labor-intensive. In addition, the psychological benefits of reconstructive surgery and other rehabilitative procedures should be considered and, indeed, psychological rehabilitation *per se* could prove to be unnecessary in programs providing good overall care and health education.

SOCIAL AND ECONOMIC REHABILITATION

There is an increasing awareness of the ways in which social, cultural and economic factors can influence leprosy rehabilitation,

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[204] Kumar, R. P. Blindness in leprosy: a report on evaluation and physical rehabilitation methods. Lepr. Rev. **55** (1984) 11–18.

[205] Parry, C. B. and Salter, M. Sensory re-education after median nerve lesions. Hand **8** (1976) 250–257.

[206] Lamba, P. A. and Santoshkumar, D. Repositioning of pupil for visual disability. Indian J. Lepr. **56** (1984) 4–9.

[207] Kumar, R. K., Ramanaiah, T. B. B. S. V., Jessie, F. S. N. K. B. and Sabhesan, S. Level of knowledge of leprosy patients towards their ailment. Lepr. India **55** (1983) 107–110.

[208] Ponnighaus, J. M. and Oxborrow, S. M. Counselling HIV positive leprosy patients. (Letter) Lepr. Rev. **62** (1991) 105–106.

and how these may be modified. Indeed, efforts to improve the socioeconomic status of patients can be central to successful rehabilitation. Thus, social and economic rehabilitation may be defined as the restoration and the prevention of the deterioration of patients' social and economic status. Social rehabilitation is principally concerned with health education, while economic rehabilitation comprises the employment and training of leprosy patients, among others.

Social rehabilitation

An essential component of leprosy rehabilitation is the prevention of social displacement, for which education is the basic need. Other more secondary approaches, such as counselling, domiciliary rehabilitation, retraining, resettlement, care of residual disabilities and so forth, are considered elsewhere. Health education may be defined as a set of activities, based on processes of communication and learning, designed to encourage people to behave in a healthy, nonharmful way. Its main aims are: a) to promote acceptance of leprosy programs; b) to dispel public prejudice and social stigma; c) to seek participation of the community in the care of the leprosy patient; d) to facilitate self-reporting of problems by patients; and e) to promote patient self-care and compliance to treatment. A number of valuable texts on the subjects have been published.[209-211]

Need for health education. The need for health education regarding leprosy is indicated by the persistence of public prejudice regarding the disease, and poor self-care and late presentation at clinics by patients. It is of the gravest concern that avoidable morbidity and disease transmission continue to occur. As an example, a higher level of disability has been observed in patients presenting voluntarily at leprosy clinics compared with those identified in house surveys.[56] Lack of knowledge and misconceptions about leprosy are believed to be the root cause, so that even when degenerative changes are noticed, they may be thought to be inevitable consequences of the disease or treatment.

The nature of misconceptions about leprosy have been well documented. For instance, common perceived causes of leprosy include punishment for sins and sexual overindulgence,[207, 212] many patients in the former study confessing to attending clinic late because of shyness. In another study, only 42% of the patients were aware of the bacterial etiology of leprosy, and 62% incorrectly thought that it is highly infectious.[213] Interestingly, the transmission of leprosy is widely believed to be hereditary,[99, 212] and in one study only 14% of patients were aware of the mode of spread of the disease by prolonged close contact.[213] In India, this is likely to derive at least partly from the concept of hereditary inequality (castes).[214]

As regards disability, one Bombay study of 91 patients with grade 2 and grade 3 deformities found that a third had fixed incorrect views regarding leprosy, and while 40% correctly believed that leprosy had caused their deformity, a further 40% were undecided.[111] This has clear implications for health education. In another Indian study, 76% of the patients believed that leprosy inevitably leads to deformities.[215] With the Hindu view of deformity as a divine punishment,[214] it is thus easy to see how leprosy stigma arises. Finally, it is of concern that 39% and 42% of first-time clinic attendees in another study were unaware of the consequences of the lack of treatment or prevention of infection, respectively.[213]

Considering public prejudice and stigma in more detail, a recent Chinese study of 1174 nonpatients found that 75% showed

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[209] Van Parijs, L. G. Redefining health education in leprosy: a personal view. (Editorial) Lepr. Rev. **61** (1990) 97–111.

[210] Van Parijs, L. G. *Health Education in Leprosy. A Manual for Health Workers.* Supplements to Manual. London: ILEP, 1990.

[211] Neville, J. *A Guide to Health Education in Leprosy.* 4th edn. Addis Ababa: ALERT, 1980.

[212] Kasthuri, G. A study on the attitudes of leprosy patients towards their disease, treatment and their status in society. Lepr. India **45** (1973) 239–242.

[213] Raj, V., Garg, B. R. and Lal, S. Knowledge about leprosy among leprosy patients. Lepr. India **53** (1981) 226–230.

[214] Mutatkar, R. K. Society and leprosy. Wardha (India): Gandhi Memorial Leprosy Foundation, 1979.

[215] Shetty, J. N., Shivaswamy, S. S. and Shirwadkar, P. S. Knowledge, attitude and practices of the community and patients regarding leprosy in Mangalore—a study. Indian J. Lepr. **57** (1985) 613–619.

"serious discriminatory attitudes" and prejudices toward leprosy patients, and only 25% believed that former patients should be allowed to return to society.[35] An Indian study reported a similar level of prejudice of 60%.[215] It is likely that lack of knowledge is a major contributor to such attitudes and, indeed, the Chinese study found that 40% knew nothing about leprosy, 70% were confused regarding its cause, and only 23% would have been able to recognize the early skin signs.[35] Such findings clearly indicate the importance of health education if one is trying to solicit community support for the treatment and rehabilitation of leprosy patients.

Nature of health education. The nature of health education regarding leprosy can be considered in terms of its objectives, content and means of delivery. The objectives and content of health education are best defined by researching local attitudes, beliefs and needs. Indeed, variations between countries and communities make it difficult to propose universally applicable policies.[216] Nevertheless, imparted information should include:[199, 216, 217] a) causation of leprosy, traditional beliefs often underlie lack of faith in modern treatment; b) noninfectiousness of most patients; c) early signs of leprosy, reaction and relapse; d) early recognition and prevention of disability; e) location of places of treatment; and f) curability of leprosy and importance of regular treatment.

Additional information could be tailored to local requirements. Where many patients are subsistence farmers, for example, care and moderation in the use of hoes and cutlasses and in trekking over rough ground could be encouraged. Moving on to the means of delivery of educational information, the importance of a multimedia approach has been emphasized in order to reach a wide variety of targeted groups, namely, the patient and his family, health staff, and the general public. Public talks, poster campaigns, and inclusion of leprosy in health education in schools are all methods that can be used. In addition, the education of health professionals could be achieved by giving leprosy a more prominent place in training curricula,[176] and religious leaders could emphasize to their followings that the divine punishment of "leprosy" in religious texts is not mycobacterial leprosy.[218] Fund-raising agencies also have an important role to play in allaying public misconceptions, and the British Leprosy Relief Association (LEPRA) recently led the way by using the phrase "Leprosy can be cured" in its campaigns rather than pictures of horrific mutilations. Other such phrases can readily be invented (e.g., "Leprosy Is A Word, Not A [Jail] Sentence").

Achievement of community cooperation in this way could create a far more conducive environment for successful rehabilitation, enabling leprosy patients to keep their jobs, for example. The increased use of audiovisual aids has been proposed by some, but other workers maintain personal communication to be far more valuable.[216] Nevertheless, for illiterate patients, audiovisual aids and practical demonstrations can be invaluable. Finally, it is important to adopt an integrated approach to health education, with all health staff performing educational tasks as part of their normal activities. This is particularly true in light of: a) the recognized stigmatizing and destigmatizing potential of health workers;[219, 220] b) the importance of a patient's "first encounter" with the leprosy services;[209, 211] and c) the propaganda value of many aspects of rehabilitation.

Impact of health education. Evaluative studies of health education are scant, although it has long been known that instruction regarding the care of anesthetic hands and feet can significantly reduce the inci-

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[216] McDougall, A. C. and Georgiev, G. D. Educational material for the patient with leprosy. Lepr. Rev. **60** (1989) 221–228.

[217] World Health Organization. Report of an informal working group in educational material for patients convened by the WHO Action Programme on Essential Drugs hosted by the WHO South-East Asia Regional Office, New Delhi, 1985 (DAP/85.10).

[218] Lloyd-Davies, M. L. and Lloyd-Davies, T. A. Biblical leprosy: a comedy of errors. J. R. Soc. Med. **82** (1989) 622–623.

[219] Valencia, L. Social science research on social dimensions of leprosy: where do we go from here? Int. J. Lepr. **57** (1989) 847–863.

[220] Volinn, I. J. Issues of definitions and their implications: AIDS and leprosy. Soc. Sci. Med. **29** (1989) 1157–1162.

dence of ulceration and deformity.[221] Other findings have not been so favorable, including a Bombay study of 129 leprosy patients which found that health education had no effect in dissuading disabled patients from taking up hazardous occupations.[50] Indeed, employment was observed to aggravate deformities, perhaps as a result of economic hardship, which forced patients to take any type of work. Another study in Africa found that health education had little effect on patient compliance for follow-up examinations, which reached only 40%.[222]

As regards the means of delivery of information, a Bombay study found that the most memorable advice was that which could be demonstrated and practiced under supervision.[111] Massage and exercises, for example, were remembered by 92% and 79% of the patients, respectively. Conversely, information alone regarding ulcer care and footwear was poorly recollected (33% and 32%, respectively). It was also notable that those patients who accepted their deformity as a consequence of leprosy had the greatest confidence in physiotherapy.

Two assumptions underlie health education: a) people's behavior is relevant to their health; and b) people's behavior can be modified through health education. As regards the latter, Van Parijs has argued that enlightenment alone is not likely to change behavior, unless properly presented.[209] He proposed that health education be more vigorously based on the principles of communication and learning, with emphasis given to the appeal of a message in addition to its content. Thus, for example, health education could be made less one-way, and more "receiver-oriented" (listening and observing in addition to talking). It is of concern that training curricula for paramedical workers are often inadequate when it comes to communication and human interaction teaching. Van Parijs further suggested that more attention be given to processes underlying behavior, such as coping mechanisms and belief systems, with an eye to devising strategies for their modification.

Despite the inconclusiveness of evaluative studies of health education, and its undoubted costs in terms of time and resources, the potential benefits of health education are great.[111] False notions about the inevitability of deformity in leprosy and the disease's contagiousness and "uniqueness" can be undermined, but it is likely to be a long process, and further research is needed both on the impact of health education and on related areas, such as the level of health workers' communication skills, and on the means by which to improve the quality of education programs.

Economic rehabilitation

Options available in economic rehabilitation include:[184, 223] a) vocational training; b) job placement for educated or skilled patients with minimal deformity; c) domiciliary rehabilitation (self-employment) for patients not yet displaced from home; d) sheltered employment; e) pension schemes if self-sufficiency is not possible; and f) care homes. In addition, various more common sense measures, such as birth control to avoid the economic strain of additional children, should always be considered.

Vocation training. Vocational training comprises teaching patients how to overcome their disabilities so as to be able to work without damaging anesthetic hands, eyes or feet or, if disabilities prevent patients from resuming their old job, to retrain them for another job. Retraining is also necessary when a patient's work is harmful or closed to him. If unskilled, patients could be trained in some suitable craft according to their aptitude and ability. The precise nature of vocational training would depend on local attitudes, opportunities for work, and the availability of farmland. Vocational training is essential in countries with large-scale unemployment, such as India, since employers find it hard to understand why they should accept handicapped people.

Open employment. If a patient has the physical ability and motivation to work, he should be encouraged and helped into open employment (employment in the open mar-

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[221] Selvapandian, A. J. Rehabilitation problems in leprosy. Int. J. Lepr. **39** (1971) 653–658.

[222] All Africa Leprosy and Rehabilitation Center (ALERT). Annual Report for 1987. Addis Ababa: ALERT, 1987, pp. 70–134.

[223] Kumar, J. H. R., Sivasankaran, S. and Fritschi, E. P. Domiciliary and field work. Lepr. Rev. **53** (1982) 133–139.

ket), preferably the work he was doing prior to developing disability. Open employment has a valuable role in teaching the community that leprosy patients are able to work, but it is highly susceptible to the effects of stigma, arguably the greatest hurdle to successful employment. Stigma is usually not a problem in Africa, but in South America and India it results in both a lack of initiative on the part of patients, and marked employer and co-worker prejudice.

Employer and co-worker prejudice. One study in Brazil found that 74% of 104 interviewed employers had no handicapped workers, for reasons including their inability to do the job, "company policy," and, for leprosy patients in particular, that employees and customers "would not like it."[224] As a result, disabilities in leprosy are often hidden, and of 500 leprosy patients interviewed in the same study, 37% with jobs admitted to hiding their disease. On the positive side, however, employer attitudes toward hiring leprosy patients were good, particularly if noncontagious and nondeformed, with a 74% positive response toward retaining employees found to have leprosy.

As regards employee attitudes, another Brazilian study of 440 employees found that 56% were "for" working alongside leprosy patients, 22% "somewhat against," and 20% "very against," the reason in 82% of those against being fear of infection.[225] While prejudice exists, therefore, it is by no means insurmountable, and having identified underlying fears, the job now is to educate employers and employees that leprosy patients are capable of doing many jobs without risk of contagion. As evidence that this can be achieved, a higher rate of placement of leprosy patients in open industry compared with other handicapped groups has been observed.[224]

Self-employment. Domiciliary rehabilitation (self-employment) may be defined as the process by which a patient is provided with the capital and materials required to enable him to cope with economic crises in his work. Enabling the leprosy patient to remain in his home and usual occupation in this way helps to facilitate social acceptance and the retention of family ties. Indeed, over 20 years ago, Karat proposed the phrase "re-education for re-settlement" as more appropriate than rehabilitation.[10] A good example of domiciliary rehabilitation was one Indian study administering financial and material assistance in the form of a bond, in an attempt to maximize patient responsibility and involvement.[223] Of the 60 patients investigated, the most common hereditary trade was farming (36%), such that aids for milking cattle proved to be in the greatest demand. After careful selection by such factors as previous experience and aptitude, 68% of assisted patients became self-sufficient within 5 years, despite 80% having gross deformities. Moreover, stigmatized patients were found to become accepted again once they were able to support themselves financially. Another study in Gudiyatham Taluk made similar findings, with the further observation that assistance was most effective when a patient had just given up work.[226]

Such findings illustrate the great potential of domiciliary rehabilitation, which could become self-perpetuating if successful patients repaid a "bond" or assisted new patients. Moreover, self-employment is cheap compared with sheltered industry, and does not carry the same risks of social displacement in the event of failure. Unwarranted emphasis should not be placed on levels of productivity of the disabled, however, since this could result in the pursuit of job-oriented rehabilitation for some at the expense of services for others.

Sheltered industry. When deformities are severe, sheltered work environments may be more suitable than open or home employment. Problems of employer and co-worker prejudice experienced with open employment also favor sheltered work, although open employment remains the best long-term option and the only practicable way to cope with the large number of lep-

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[224] Frist, T. F. Employer acceptance of the Hansen's disease patient and other handicapped persons. Int. J. Lepr. **48** (1980) 303–308.

[225] Frist, T. F. A study of community attitudes and knowledge in relation to leprosy. Hansenologia Int. **1** (1976) 184–190.

[226] Ranjitkumar, J. H. and Fritschi, E. P. Domiciliary rehabilitation (preliminary report on an experiment in self-employment of disabled ex-leprosy patients). Lepr. Rev. **47** (1976) 295–305.

rosy patients involved. Moreover, sheltered employment itself has a number of limitations, including:[227] a) risk of perpetuation of prejudice; b) lack of effective management; c) lack of investment; d) lack of government legislation reserving markets for products and providing financial incentives; and e) lack of guidelines.

The area of operation should be chosen carefully to be safe for anesthetic hands, for example, although it has been argued that few jobs are entirely unsuitable, and intensive searches may be counter-productive.

Pension schemes and care homes. For crippled, severely deformed, or blind patients, pension schemes and care homes may be helpful. Particular care is needed in these patients to ensure that they do not take up begging, since they are the butt of considerable prejudice and, indeed, for this reason an active policy of gainful employment could prove to be invaluable in reeducating the public.

Impact of socioeconomic development

Socioeconomic development and associated urbanization can have marked benefits for the leprosy patient, which, though strictly beyond the scope of socioeconomic rehabilitation, deserve brief consideration. Negative correlations between leprosy incidence and urbanization have been reported from 16 African countries,[228] and a recent Chinese study in Baoying County correlated the observed exponential increase in the economic product index between 1965 and 1981 with a greater than exponential decrease in leprosy incidence over the same period.[35] Similarly, leprosy has been observed to disappear from Norway[93] and parts of the Far East[94] in association with socioeconomic development. The mechanisms by which socioeconomic development may benefit patients include: a) improved food production and distribution, and water purity and availability; b) improved living conditions and health services; c) improved welfare benefits and community services; d) reduced infection rates, owing to fewer carriers and less favorable conditions for transmission; e) diminished concealment of infection in towns; f) lower tolerance of the condition among families; g) improved compliance with treatment; and h) better technical aids.

Urbanization is no panacea, however, and has many negative aspects, such as road traffic accidents, the urban homeless, pollution, abandonment of the extended family system, and the economic encouragement and necessity for all adults to leave home to work. The latter changes result in fewer people being at home to look after the disabled and a consequent decline in care, which is increasingly viewed as a job for government and not the family. On the other hand, increased job availability could greatly benefit the moderately disabled. Clearly, it is difficult to weigh up the costs and benefits of urbanization, or define specific ways in which it may benefit the leprosy patient, and further research into these areas is needed.

PREVENTIVE REHABILITATION

The old concept of rehabilitation as care of an already "damaged" patient has been slow to change, although the primary step in rehabilitation is now widely accepted as the prevention of physical disability and its sequelae; so-called preventive rehabilitation.[6] Indeed, rehabilitation in the "conventional" sense would not be necessary if every person suffering from leprosy was detected early and treated adequately, which poses an exciting challenge for leprosy workers. In addition, as leprosy is increasingly brought under control and the number of patients under therapy declines, the opportunity should be taken to intensify the monitoring of patients for reaction, relapse, disability, and so forth.

That rehabilitation should begin prior to "cure" is illustrated by findings of worsening nerve function and disability during chemotherapy, such as diminished sole sensation in 8.2% (39/475) of PB patients during the 6-month WHO-MDT,[199] and deterioration in 24% (28/118) of disabled patients over 4 years of treatment.[229] An-

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[227] Samy, C. A. Industrial rehabilitation for leprosy patients—merits and limitations. Lepr. India **53** (1981) 1–5.

[228] Hunter, J. M. and Thomas, M. O. Hypothesis of leprosy, tuberculosis and urbanization in Africa. Soc. Sci. Med. **19** (1984) 27–57.

[229] Smith, W. C. S. *Evaluation of a leprosy control programme in India.* MD Thesis, University of Aberdeen, 1986.

other major advantage of preventive over "traditional" rehabilitation is its relative cheapness and simplicity, which makes it within the reach of every leprosy worker with minimal training and inexpensive equipment. This is of particular relevance to developing countries.

Considering preventive rehabilitation in more detail, disability prevention may be divided into three types: first-level (prevention of impairment), second-level (prevention of progression of impairment to disability), and third-level (prevention of progression of disability to handicap).

First-level prevention

The primary prevention of impairment is best achieved by early diagnosis and adequate treatment both of leprosy and of its complications, such as secondary infection and reaction.[11] Eradication of leprosy by immunization or population improvements in standard of living or health care would have the same impact. As regards vaccination, for instance, four major trials have found attenuated *M. bovis* (BCG) to have a protective effect of between 20% and 80%, apparently indicating genuine variations in the efficacy of BCG in different areas. Developments in molecular immunology, such as the identification and characterization of various *M. leprae* antigens, should, in the future, lead to better vaccines capable of eliciting effective protective immune responses against *M. leprae*. Any proposed vaccine should be carefully investigated, however, to compare its efficacy with BCG vaccination alone on a suitable control group within the same trial area at the same time.

Second-level prevention

It has been estimated that good second-level prevention of the progression of impairment to disability could reduce the incidence of disability by some 10%–20%.[16] It is of concern that rates of disability among newly diagnosed leprosy patients remain high, such as 21.9% and 30% in Malawi and Tanzania, respectively,[199] which suggests that intensification of case-finding and health education is needed. In 1988, the WHO outlined six managerial requirements for disability prevention:[11] a) team leader has overall responsibility (usually a physician); b) specific objectives and activity plans set; c) disability data incorporated into clinical records; d) aids provided where necessary; e) patients instructed about self-care; and f) staff suitably trained.

Considering the impact of antileprosy chemotherapy on disability, the LEPRA Evaluation Project in Malawi recently reported a lower incidence of disabilities during (2.9 per 1000 person-years) rather than after (8 per 1000 person-years) dapsone monotherapy.[63] In the case of MDT, one would expect an initial increase in the disability rate among new patients following its implementation, reflecting the release from control of many PB patients in whom disability is rare.[230] Subsequently, successful MDT would be expected to reduce the disability rate, and one program in India observed such a reduction from 6.2% to 1.5% over 3½ years.[231] Findings have been inconsistent, however, and the LEPRA Project in Malawi found that the percentage of patients on MDT developing new disabilities or experiencing a deterioration (5.7%) was little different from the rate of 6.1% previously observed with dapsone monotherapy.[62] A greater percentage of potentially reversible disabilities did improve with MDT, however. In other studies, it has been of concern that even when bacterial cure has been produced, many patients have gone on to develop incapacities.[46]

Finally, an interesting apparent propensity for patients receiving dapsone monotherapy to develop disabilities has been identified,[47, 51, 88, 232] although studies have been limited by their cross-sectional nature, such that it is not known if disability developed during treatment or before. This is important since already disabled patients would be more likely to seek treatment. Nevertheless, the findings deserve consideration, and one of few longitudinal studies

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[230] Jesudasan, K., Vijayakumaran, P., Pannikar, V. K. and Christian, M. Impact of MDT on leprosy as measured by selective indicators. Lepr. Rev. **59** (1988) 215–223.

[231] Chopra, N. K., Agarwal, J. S. and Pandya, P. G. Impact of multidrug therapy on leprosy in Baroda district (Gujarat). Indian J. Lepr. **61** (1989) 179–189.

[232] Srinivasan, H. and Noordeen, S. K. Epidemiology of disability in leprosy. Int. J. Lepr. **54** (1966) 170–174.

of a possible link between dapsone therapy and deformity supported the possibility.[48]

The value of drug therapy in regard to disability thus remains unclear, although current findings would certainly not support sole reliance on chemotherapy for second-level prevention. Further studies are needed of the impact of earlier case detection and treatment on disability incidence, together with that of attempts at preventing deterioration in established cases.

Third-level prevention

Third-level prevention comprises all measures aimed at preventing a disability from becoming a handicap. Traditionally, this was the extent of rehabilitation, which gives an indication of how far rehabilitation has progressed since its inception.

Early detection and management of reaction

The early detection and management of reaction, particularly reactive neuritis, is central to successful disability prevention. Clinically, neuritis may be obvious or silent.[46] Obvious neuritis is usually acute, and thus noticed and reported by patients, while silent neuritis can easily be missed, with changes in sensation only noticed when formally assessed. Even silent neuritis, however, can produce marked disability.[20] The common use of the term neuritis solely to indicate pain and tenderness over a nerve trunk should, therefore, be discouraged and every patient examined for signs of reaction, however small. In general, reactions involving the nerves, eyes, or testes should always be considered serious, regardless of severity, since they are prone to cause permanent damage.

Principles of the management of reaction include: a) control of neuritis with antiinflammatory drugs, nerve surgery, immobilization, heat application or exercise; b) avoidance of eye damage; c) adequate analgesia; and d) prevention of disease progression by antibacterial chemotherapy. Early nerve function loss (< 6 months) can often be reversed with appropriate treatment. One point of some concern is the common management of corticosteroid treatment by a medical officer, which necessitates referral to hospital. This is likely to deprive many patients of adequate treatment and, indeed, in the ALERT program in Ethiopia it was estimated that 60% of those patients needing prednisolone treatment did not receive it for reasons including the scarcity of doctors and hospital facilities in endemic areas, patients' family and work obligations, and lack of money or transport.[46] A more field-oriented approach to the treatment of reaction would seem to be needed, therefore, and Becx-Bleumink and colleagues have written a manual for this purpose.

Apart from treatment during the active phase of neuritis, little can be done once peripheral nerves are damaged, although hopeful recent developments include a microsurgical technique of nerve decompression,[233] and the use of ACTH analogs such as Org 2766.[234] The latter has been shown to prevent cisplatin-induced neuropathy in ovarian cancer patients, but its use in leprosy remains to be studied.

FUTURE OF LEPROSY REHABILITATION

With increased political commitment to leprosy control, and more extensive and effective implementation of multidrug therapy, Noordeen has predicted that a reduction in caseload of 60%–80% over the next 5–10 years may not be unrealistic.[12] In the future, therefore, rehabilitation is likely to play an increasing role in leprosy control, with the emphasis of the latter shifting from the early detection and treatment of leprosy to disability prevention and management. It is important to ensure, however, that resource allocation does not diminish in line with the number of active leprosy cases and, to this end, policymakers should be made aware that disabilities and other problems in leprosy are likely to persist for many years

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[233] Theuvenet, W. J., Finley, K., Theuvenet, P. J., Eatock, M., Myazaki, N., Battaraj, S. P. and Pradhan, S. P. New boundaries for the indications for nerve decompressions. (Abstract) Int. J. Lepr. **57** (1989) 344.

[234] Van der Hoop, G. R., Vecht, C. J., van der Burg, M. E. L., Elderson, A., Boogerd, W., Heimans, J. J., Vries, E. P., van Houwelingen, J. C., Jennekens, F. G. I., Gispen, W. H. and Neijt, J. P. Prevention of cisplatin neurotoxicity with an ACTH (4–9) analogue in patients with ovarian cancer. N. Eng. J. Med. **322** (1990) 89–94.

after active leprosy has disappeared. As regards future rehabilitation research, key topics include: a) Immunological detection of subclinical infection; b) Determination of risk factors for disability for use in monitoring and prevention; c) Integration of rehabilitation into the general health services; and d) Means of overcoming ignorance, prejudice and fear.

In addition, McDougall and Georgiev have questioned the discrepancy between the resources put into laboratory-based research and the relatively neglected operational aspects of leprosy.[235] Certainly, operational research has much to offer, including insights into such areas as patient compliance and the early recognition of disability.

CONCLUDING REMARKS

In this essay, the pathogenesis, nature and sequelae of disability in leprosy have been discussed, together with aspects of the historical development, principles, nature and impact of rehabilitation. It has been shown how rehabilitation has developed to form an integral part of leprosy control, from which it cannot be divorced. Moreover, as leprosy is brought under control and the number of active cases diminishes, the role of rehabilitation is likely to increase. Many aspects of rehabilitation require further research and improvement, but it is perhaps useful to recognize the great progress made to date; the average patient no longer suffers from extreme mutilations, most patients live in their own communities, diagnosis is often early, treatment effective, and cure without residual disability. Even the intensity of social stigma seems to be declining in some countries. The future of even the deformed leprosy patient is brighter than ever before, and as rehabilitation becomes yet subtler, should continue to improve.

—John Stephen Gilbody

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[235] McDougall, A. C. and Georgiev, G. D. Priorities in leprosy control. (Editorial) Lepr. Rev. **60** (1989) 1–7.

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