The Role of Rehabilitation in the Treatment of Leprosy

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The science of medicine has several components: positive promotion of health, prevention of disease, treatment of disease, rehabilitation, and research. The concept of rehabilitation as an integral part of therapeutic response to disease and residual disability has been slow to emerge.

Death has been assumed to be ultimate defeat, the failure of scientific medicine. Extravagant resources are applied to prolong life and prevent death. Consideration of the quality of life that may have been rescued from death has all too often been disregarded.

The role of the community in its effect on health and rehabilitation is now more clearly understood. The community may also have "pathology." Inadequate food production and distribution, inadequate or inadequate water supply, violence, population dynamics and attitudes about disease may be some of the symptoms. Health and rehabilitation of the individual are related to environmental ecology and to human interrelationships. How does an individual become rehabilitated in a community that by its customs and attitudes militate against health?

The language of rehabilitation has tended to reflect a limited philosophy by using expressions such as "fullest possible restoration" or "return of a patient to normal society." There was a tendency to assume that the rehabilitation process began only after all had been "lost." The emphasis had been on "return." The concept has been broadened by emphasizing that the process must begin "on the day of diagnosis." That too is insufficient. We now know that an attempt must be made to anticipate causes leading to rehabilitation. "Preventive rehabilitation" (11) expresses a concept so fundamental as to have become the linch-pin in understanding rehabilitation as a dynamic process. It can not be an addendum to therapeutic failure, a device to pick up broken pieces and put them together again.

DEVELOPMENT IN CONCEPT

The application of the foregoing concepts as an integral part of management and treatment of leprosy have been slower to emerge than for other disabling diseases and causes. Those who study the history of the stigmatization of leprosy can best inform us why progress in making rehabilitation a vital part of treatment has been so painfully slow.

We look back over the century since leprosy because "a disease like any other" with the discoveries of Dr. Armauer Hansen. In doing so it is possible to trace emerging concepts that eventually led to our present day of understanding. Countless humble, often unnamed, workers laid the foundation upon which others later would build. We are fully aware of the danger in naming a few individuals and doing injustice to the many.

In an issue of Pinoy Leprosy News, published and edited by the Philippine Anti-Leprosy Society, dated October 1929, Dr. Lee Huizenga (12), who had been commissioned by American Leprosy Missions, Inc., to survey leprosaria in countries of the Pacific, was quoted as having said:

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No higher type of relief work could be done for the ex-leper than that of making it easier for him to go back to the society from which he had been forcibly estranged by circumstances not altogether of his own making. No other entity could be expected to solve the difficult problem of rehabilitation as it is purely a social one: it is no longer a question of public health.

So far as we have been able to determine that was the first recorded use of the concept of rehabilitation as applied to the management of leprosy and the residual problems suffered by its victims. It could well be that the Philippine Anti-Leprosy Society was responsible for the first organized effort directed to this belatedly recognized need.

In Leprosy on India in 1929 (3), the objectives of the Indian Council of the British Empire Leprosy Relief Association included this statement:

Dispensation: A leprosy dispensary which does not follow up its infectious cases to their homes and examines contacts and tries to carry out preventive propaganda (health education) on the spot, is not likely to diminish the incidence of leprosy in the area it supplies.

Writing in Leprosy Review in 1930, Dr. R. G. Cochrane (4) stated:

... the disproportion that the disease produces in the later stages, the deformities that so often result and the stigma attached to the leper, all make it of utmost importance that something more than a mere sterilization of the disease should be our aim. If the "cure" results in mutilation and physical deformity, the position of the patient socially is in no way changed and cannot in most cases resume normal life. Therefore the object of all treatment is to render the patient free from all signs of active disease and of the stigma which so often accompany the arrest of leprosy.

Writing in the International Journal of Leprosy in 1933, Dr. Ernest Male (5) stated:

During the time of treatment, patients should be educated regarding the nature of leprosy, the danger of contacts, and the importance of maintaining throughout the remainder of life a high standard of general health.

In 1935, Dr. James Maxwell (6) wrote:

... that the provinces and municipal Governments be asked to recruit hospitals, clinics and health centers to undertake the treatment of suitable cases of leprosy in clinics, with a view to stopping out leprosy at its source.

... that the Central Government be asked to introduce such legislation as shall prevent discrimination against cases of leprosy as compared to patients suffering from other diseases of a mildly contagious nature.

In the same issue, Everett E. Murray (7) stated:

Have the lepers live at home. Let them go to the nearest clinic once a week for injections. The leper is not an outcast. He is still among friends and loved ones. He can be an economic help, he will be happy because he is useful and has a future.

DEVELOPMENT IN PRACTICE

As far as can be determined, the IV International Congress of Leprology meeting in Cairo in 1938 (9), was the first international conference to refer to "rehabilitation": Rehabilitation of discharged patients is a sphere in which voluntary organizations can render valuable help with government assistance by providing suitable work for them and by helping to reabsorb them into the community.

By 1947, experience was sufficient to
confirm that to make a patient bacteriologically negative was not sufficient. His needs were many and complex extending far beyond being "cured." In that year, Dr. Robert G. Cochrane's *Practical Textbook of Leprosy* (7) was published, and in it he stated: "The number of hospitals or sanatoria dealing with leprosy which can boast a department devoted to work of this kind (physiotherapy and electrotherapy) is comparatively small, despite the prevalence of neural involvement in leprosy." Responding to this need, Dr. Cochrane invited Dr. Paul Brand, then orthopaedic surgeon at the Vellore Christian Medical College, to hold weekly clinics at the Lady Willingdon Leprosy Sanatorium, Chingleput, South India. Together with Dr. Hari Paul, they began a determined study of the causes of bone absorption that had been so widely accepted as an inevitable consequence of the disease. In that same year, Dr. Brand and his colleagues undertook the use of tenodesis as a surgical technique to cure a persistent trophic ulcer on an inverted paralyzed foot. The study of the pathogenesis and potentials for the surgical correction of deformity led Dr. Brand to do his first reconstruction of a hand deformed by leprosy, using the Stiles-Bunnel techniques which had been well-known and applied in hands deformed from other causes. During the years 1948 to 1950, approximately 300 patients were operated and a variety of new surgical techniques developed (4). Later, Dr. Brand was to discover that Dr. Daniel Riordan, working at the United States Public Health Service Hospital, Carville, Louisiana, had begun similar studies within the same period, applying and developing surgical techniques. Their collaboration laid the foundation for further progress. The Gandhi Memorial Leprosy Foundation also took an interest in physical and social rehabilitation, providing funds for research and enlisting the cooperation of many Indian scientists.

The *Journal of the Christian Medical Association of India* in 1950 carried the reprint of an address by Dr. Paul W. Brand (2) on the orthopaedic care of leprosy patients. In 1952, he delivered the Hunterian Lecture to the Royal College of Surgeons (London) on "Reconstruction of the Hand in Leprosy" (3). Physical rehabilitation of the leprosy patient had begun to receive wide and expectant attention. Based largely on plastic surgery techniques developed by Sir Harold Gilles, Dr. N. H. Antia and Dr. Paul Brand in India and Dr. Jack Penn in South Africa applied and refined them for correction of lagophthalmos, eyebrow replacement, correction of nasal deformity and other disabling and disfiguring deformities of the face (4).

By 1955, Dr. Ernest Fritchi and Mr. John Girling in India and Dr. Ernest Price and Dr. W. Felton Ross in Nigeria, had begun significant studies of the cause, prevention
and treatment of plantar ulcers. Dr. W. F. Robertson, working at the Schieffelin Leprosy Research Sanatorium (Karigiri), with other members of the team (Brand, Fritchi, Girling, Ward), further developed a variety of footwear for the prevention and treatment of plantar ulcers. The use of microcellular rubber insoles, especially manufactured for the purpose, was introduced. Molded footwear for grossly deformed feet took its place in physical rehabilitation (4). So far as has been determined Dr. Milroy Paul, working in Ceylon was the first to use plaster of Paris casts for the treatment of trophic plantar ulcers. This method however, had long been used in the treatment of other types of ulceration and of osteomyelitis (4). Prosthetic devices adapted to the special needs of leprosy patients were developed in many parts of the world. Orthotic devices became available to permit the disabled patient to carry out the acts of daily living, to preserve function, to prevent further disability and to prepare him for living in society.

The bibliographies of early literature dealing with physical rehabilitation indicate the great number of workers throughout the world who made lasting contributions toward ushering in the new day of hope (20). As already indicated much of the progress was due to borrowing heavily from the experience of those who had developed techniques applicable to the correction of disabilities arising from other causes. It is an impossible task to do justice to all who contributed to the creation of presently available "tools" of rehabilitation in leprosy. By 1960, it was clear that a new era had indeed begun and rehabilitation had become accepted as an essential component in the treatment of leprosy.

In November 1960, the World Health Organization Technical Report Series (22) reported the findings of a Scientific Meeting on Rehabilitation in Leprosy held at The Schieffelin Leprosy Research Institute and the Vellore Christian Medical College. The report presented a summary of experience and knowledge that marked significant advances in the understanding of the role of rehabilitation in the worldwide attack on leprosy covering the era beginning approximately in 1947.

**STATUS OF PRACTICAL APPLICATION**

Where do we stand today? How far have we advanced toward a better understanding since the days of Doctor G. Armauer Hansen and his successors?

One attempts to answer this question against the background of having observed countless leprosy programs throughout the world. It is difficult too refrain from expressing despair. With all the accumulated knowledge little is being done that significantly affects countless numbers of patients languishing in various types of institutions and the masses of patients living at home struggling to hold on to physical, social and economic stability. The failure to apply what has been learned about rehabilitation in leprosy remains decisive. Essentially, the failure is political. Social injustice increases the number of deprived and to a large extent determines the distribution of human and material resources available. The strong and healthy prosper at the expense of the weak who are often the "sick" of the community. The strong are the healthy, powerful with money, housing, and sufficient food. The weak are the marginalized poor, often disabled physically and otherwise, forced into a predetermined role by the strong who can afford medical care. Medical knowledge is exploited to permit the possessor to prosper at the expense of the sick/weak. The manner of applying and distributing medical knowledge by professionals and by institutions is very often a dehumanizing process. Health budgets most often are ineffective and mal-distributed, ranking low in national priorities. Injustice is seen in the maintenance of costly segregated leprosy institutions for the few, at the expense of the many with improper or no health delivery service. Buildings, often including churches, may be costly, even lavish, while the physical deformities of those within them are ignored.

Injustice frequently characterizes the rehabilitation services which are offered. The criteria for rehabilitation of the "producer"
are usually imposed upon the "consumer." How is it decided that the costly restoration of the function of a thumb should constitute the rehabilitation service offered when the patient's real needs are ignored or while thousands go without diagnosis, treatment, or preventive rehabilitation? To this fact, in his book, Health and the Developing World, Dr. John Bryant (5) replies, "Every effort and cluster of resources must be divided by the total number of people." Into the understanding of rehabilitation must come the realization of the effects of social, political and professional injustice, and the need for liberation!

In the treatment and management of leprosy, rehabilitation speaks of failures:

2. Failure to develop leprosy control programs based upon principles of Public Health used against other communicable diseases.
3. Failure to develop personnel sufficiently trained to recognize and treat early warning symptoms which lead to disastrous crippling complications.
4. Failure of the medical profession with the skills but not the will to share those skills to include the needs of leprosy patients.
5. Failure of general hospitals to change their antiseptic "closed door policy" to permit admission of the leprosy patient.
6. Failure of medical and paramedical training institutions to insure that every graduate will know about leprosy and treat it "like any other disease."
7. Failure of the world community to develop an understanding that will promote rather than deny the chance of the leprosy patient to be truly "healed."

Compounding this scandalous list of defeats by medical science and political systems is the knowledge, that the disabilities caused by leprosy (physical, social, psychological and vocational) are preventable. Ultimately then, the result of failure is a worldwide reservoir of debilitated patients who now require the best efforts of teams with specialized skills but at a cost beyond that which can be paid with any reasonable expectation in the foreseeable future.

PRIORITIES IN FUTURE APPLICATION

What of the future? What are the priorities? It has been pointed out that rehabilitation must concern itself with what has been or may be "lost." Among those losses are:

1. The physical capacity to function normally and productively.
2. Family and community acceptance because of disfigurement.
3. The preservation of self respecting self and social identity.
4. Economic viability and independence as a person of worth.
5. Vocational skills and work habits.

Several "losses" may be experienced at the first impact of a diagnosis of leprosy, long before there is visible evidence of disease, before there is physical disability. The earliest and most destructive force may be fear, initiating the long process of dehabilitation. Who makes the diagnosis, how it is made, and where, may all profoundly affect the beginning of the dehabilitation process.

Those that need rehabilitation may be categorized:

1. People who do not have leprosy but who may profoundly influence the well-being of those who do. In the "global village" in which we live this means the world.
2. Patients in an early stage of leprosy who have few or no disabilities, living at home with a reasonable "security margin."
3. Patients in an advanced stage of leprosy with severe disabilities. Some will be living at home but in a precarious social and vocational position. Others will be wandering or hiding alone. Others will be in leprosaria.
4. Patients with irreversible physical deformities, who have been in institutions the greater part of their lives. Rehabilitation programs for each category require specialized skills directed to them.
Out of a recognition of their separate needs emerge concerns that suggest priorities.

The first concern. This relates to what has been referred to previously as "preventive rehabilitation," a concept that has been excellently documented by Dr. S. Karat (14). Preventive rehabilitation concerns itself with the danger of impending "losses" that may endanger singly or in a variety of combinations, and attempts to deal with them before they have become fixed. Such efforts must be concerned with primary and secondary physical deformities, as well as social, economic and vocational dislocation, present or threatening.

The second concern. This relates to the need for restoration of the partially disabled person. Implied is that the "losses" are reversible, however costly the professional skill and resource required. Some of the earliest attempts at using well-known rehabilitation technics as therapeutic measures were directed to this area of need. An indirect benefit derived from early dramatic success even for the severely disabled and dislocated, was the atmosphere of hopefulness created. Something could be done, even for the severely handicapped; now there was hope for all! Another benefit was, that almost immediately the devoted skills of surgeons, therapists, social workers and vocational rehabilitation specialists were attracted. In leprosy as in other disabling diseases, the team approach to rehabilitation was recognized as essential. A third benefit was the intensification of efforts by medical scientists, to more adequately understand the disease processes involved in the resulting physical disability.

Offsetting the benefits was the early recognition that the cost-benefit ratio needed to be reckoned with. Many leprosy institutions were caught up in the attractiveness of the support generated by dramatic results of surgical procedures. Resources for public-health-oriented control measures were diverted to "rehabilitation" at a time when increasingly the maintenance of segregated leprosy institutions was being questioned. Those responsible for regional and national leprosy control programs expressed deep concern about the distribution and application of human and financial resources. Concentrating on the few at the expense of the many, did not convince the decision makers of health delivery systems of its value; the public health approach to the problem of leprosy had already waited much too long.

The third concern. This is related to the very real needs of that large body of patients that languished in leprosaria all over the world. These were the physically, socially, and economically totally disabled. Most were dependent for survival on the compassionate custodial care of benevolent health workers. Some had disabilities that could be improved even if not fully corrected. For all, some kind of better life could be designed when enormous resources of time, funds, and professional skills could be directed to their needs. For some, diversional therapy offered temporary escape. Others learned to engage in productive work that if not sufficient for self-support did restore a sense of worth. Unfortunately, many were exploited as a source of earning power to support the status quo of the institution. A few reached the stage of self-support in sheltered workshops or cooperatives outside of the institution. The very worthy object of most rehabilitation efforts was to help the patient learn to live with his disabilities, that is with what he had left after leprosy had run its destructive course. The problem remains a grave one. The economics of the situation creates an agonizing dilemma. In spite of all effort, many institutions spend eighty percent of their resources on the care of perhaps twenty percent of their patient load who are totally disabled. The mal-distribution of resources leaves twenty percent of the resources for the equally demanding need to help the vast majority of patients living at home on a precarious "security margin" from becoming part of the twenty percent.

The fourth concern. This relates to the community that may be either supportive or so destructive of the chance for the leprosy patient to get well without "loss" and to remain well. As the emphasis has swung further and further toward the employment of preventive methods, it has become increasingly evident that efforts
along these lines will, to a large extent, measure success in terms of the attitude and cooperation of the healthy community.

In any country, prevention in medical terms means rational methods in guarding against the contraction of the disease; in social terms, it means a community which is rational in its attitude toward people who have leprosy so that they never need to undergo social disintegration with loss of status in the community; in vocational terms it means recognition by the society of each person's vital contribution to the well-being of the community as a whole, and a loss of any one of its members is by force of circumstances noncontributing. What happens to the well-being of an individual cannot be separated from the well-being of the community.

The basic method by which cooperation of the healthy community is enlisted to achieve the dynamic environment of preventive rehabilitation is public health education. To be truly effective, such education must be directed to every segment including medical and health workers, students of medicine and the allied medical sciences, community leaders, opinion and decision makers, families of the patients and the general public. Unless the manner in which medical authorities manage the disease is consistent with health education, the latter cannot succeed. No one can be expected to believe the health education that states, "leprosy is only mildly communicable" when the medical and allied professions exclude those who have leprosy. Leprosaria that fail to apply modern medical-scientific principles in the management of the disease, knowledge that the experience of the last three decades has provided, remain the greatest obstacle to obtaining significant results from health education. The large number of segregated institutions that have failed to become oriented to providing short-term hospital care of complications and have failed to become centers of domiciliary based leprosy control programs, deny every truth that health education attempts to project. The danger of segregated institutions devoted only to rehabilitation of leprosy patients, in isolation from patients with disabilities due to other causes, are also in danger of being a handicap to progress. Such institutions obstruct progress by the very image they create.

Very possibly health education may prove to be the ultimate weapon in rehabilitation if it is logically and consistently directed to the patient and community.

THE UNIFIED APPROACH

It seems clear that considering the magnitude and complexity of the task of rehabilitation, the problem of leprosy must be looked upon as a whole. To fragment it, to separate rehabilitation from the total needs of control, is to perpetuate disaster. Consideration must be given to the following guidelines.

1. Highest priority belongs to the application of resources directed toward the prevention of dehabilitation by early diagnosis and regular, sustained, effective treatment including special regard for susceptible individuals in exposed populations.

2. With a minimum of training and little additional expense, experienced leprosy workers can learn how to use the basic tools of physical rehabilitation that have been developed. Plaster casts and other applicable methods may be introduced for the healing of early plantar ulcers. Basic preventive and therapeutic footwear in the management of anesthetic feet and early plantar ulceration can readily be introduced into any leprosy control program. Exercises based upon fundamental physical therapy principles can be used to prevent deformities becoming fixed and to extend function. Most important, systematic and persistent teaching of patients how to prevent injury to anesthetic or paralyzed hands and feet, need not belong to the specialist but should become as routine as the distribution of medication, given by personnel
related to direct patient care. These principles are now so basic that it is questionable that they should be classified under the heading of rehabilitation, but rather belong to standard treatment of all patients.

3. Programs of leprosy control require the application of public health principles employed in the management of all communicable diseases. The delivery of health care requires that the personal and social identity of the patient be preserved by insuring that he remains at home during treatment, and that in so far as possible he maintains normal vocational and avocational pursuits.

Experience informs us that the great majority of patients with leprosy "prefer to be deformed than to become alienated." Any approach to the management of leprosy that does not accept this principle as axiomatic, contributes to dehabilitation. One carefully documented study concluded, "feelings of insecurity over-ride considerations of vocational needs." A "security level" or "security index" if carefully arrived at, can tell us more about rehabilitation needs than any other determinant (11).

4. Programs that do not make the patient a key member of the rehabilitation team will be "producer" oriented and not only fail to meet the "felt needs" of the patient but fail in the very purposes for which they are established.

5. Rehabilitation can not succeed without taking into consideration the ecology of the community environment. We may decide the patient needs a correction of his claw hand and "demand" that he submit to surgery, when his real need may have to do with keeping his children in school, or have a source of potable water that will stop the chronic bowel diseases that have taken the lives of several of his children.

6. Long-term institutionalization can be as dehabilitating as the disease process itself. The patient may be "cured" by expert medical treatment but become socially, vocationally and psychologically dependent for the rest of his life. If the institution is one set aside exclusively for the care of leprosy patients, every danger of institutionalization is intensified.

7. When specific rehabilitation procedures require the specialized services of a hospital or any other rehabilitation facility, whenever possible these efforts should be undertaken in an institution other than those set aside exclusively for the treatment of leprosy.

8. Rehabilitation services require integration. Where they are available for leprosy and not for other disabilities, they need to be thrown open to other community needs of the disabled. Where services are available for disabilities other than those caused by leprosy, they must be open for all. Discrimination and segregation in leprosy does not require "busing," to be overcome.

9. The use of resources for rehabilitation programs that are not integrated into the program of leprosy control must be questioned. Rehabilitation services must strengthen and be related to case-finding and case-holding.

10. The skills of orthopedic, plastic and reconstructive surgeons are needed particularly in special centers of rehabilitation. New and more universally applicable techniques are yet to be developed. New improvements learned in the operating room should more and more relate to leprosy control programs in the field. Additional knowledge and techniques are yet to be developed that can be more universally applied in field conditions.

11. Equally important are the specialized skills of health educators, social workers, physiotherapists, occupational therapists and vocational training specialists. Increasingly,
they too must break out of the prisons of brick and mortar in order to apply their disciplines to patients living at home. Prevention of social, economic and vocational dislocation of the patient is for them also an objective of primary importance. Concern for the individual patient needs to be enlarged to include family members in the normal home environment. Preserving skills is more important than learning new ones unless it can be insured there is a market for the new skill. Sheltered workshops have an important role to play for the permanently disabled. Ideally such facilities should not be confined only to the needs of leprosy patients but to all in the community disabled by any cause. Rarely should such facilities be developed within an institution for the active treatment of leprosy patients; instead they should be removed sufficiently far away to insure that the stigmatization resulting from institutionalization is not carried with them.

12. Research into the cause, prevention and treatment of disability in leprosy (physical, social and economic) continues to be a crucial need. While there are those who can give full time to research in specialized institutions, the most fruitful source of new understanding will come from the field worker who takes the trouble to keep efficient records and shares widely through the publication of his experiences.

CONCLUSION
A resolution passed by the VIII International Congress of Leprology in 1963 (+), correctly summarizes where we ought to be today, ten years later:

This Congress is gravely concerned that under the very eyes of doctors and para-medical workers in many anti-leprosy campaigns, deformity and blindness are being allowed to develop which could be prevented by simple advice and inexpensive treatment.

This Congress therefore resolves that in every anti-leprosy campaign the doctors and para-medical workers should be trained to look for dangersigns in hands and feet and eyes, and should give advice and simple treatment to prevent deformity and blindness. The ratio of patients to workers should not become so high as to make this impossible.

The backward look provides perspective for assessment of what has been learned. An evaluation of the present provides the inescapable conclusion that, tragically, only a few patients profit from what is known about leprosy. For the future it is devoutly hoped that the TENTH INTERNATIONAL CONGRESS ON LEPROLOGY at Bergen, Norway, will stimulate worldwide impetus to more effectively apply what the last hundred years have taught.

REFERENCES
11. HAMBELMANN, W. L. and STREET, N. L. Study for the rehabilitation of rural leprosy patients. Unpublished report of work done under the auspices of the Vocational and Rehabilitation Administration, March 1964, pp 3-44.