

Teaching and training for surgical rehabilitation in hanseniasis: results of 20 years activities of the Instituto Lauro de Souza Lima in South America

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"The greatest disease is not TB or leprosy; it is being unwanted, unloved, and uncared for. We can cure physical diseases with medicine, but the only cure for loneliness, despair and hopelessness is love. There are many in the world who are dying for a piece of bread, but there are many more dying for a little love."

Mother Theresa

INTRODUCTION

It is a generally well known fact that Hanseniasis can cause severe impairments, disabilities and handicaps. This occurs in spite of early diagnosis and adequate treatment. The stigma attached to this disease (Leper's) is directly related to the visible, physical deformities. Functional disabilities when present, are severe and the social and emotional handicaps can be devastating. All these problems can occur even 5-10 years after¹

clinical "cure" of Hanseniasis. These impairments, disabilities and handicaps are generally considered side effects of Hansen iasis and are for the most part completely ignored by the health team treating Hanseniasis; sometimes because of ignorance or because rehabilitation is considered to be too expensive. But most often the reason is indifference. The reality is that about 40% of all patients have some degree of disability, impairment or handicaps.

This means that we not only count registered patients with active disease, but also all those that have been discharged and are alive, as well as defaulters and the undiagnosed number of patients.

In the late 1970's the recently transformed Instituto Lauro de Souza Lima in Bauru, State of S. Paulo, Brazil, started to develop into a National and International Training and Research Centre. The leader and guide in this process was Dr. Diltor Opromolla. He also saw

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the need to include surgical rehabilitation as part of the general treatment of the Hansen's Disease Patient and also as part of the Training Program.

With assistance of the American Leprosy Missions, a surgeon, well trained in all aspects of surgical rehabilitation for hanseniasis, was found. The surgeon (ED.) started to train the staff of the Instituto Lauro de Souza Lima and gradually built up the rehabilitation team. There was already an excellent shoe and prosthesis workshop functioning at the time.

Gradually objectives and goals were developed. At the time it was standard to create surgical rehabilitation services for Hanseniasis only very specialized and very effective. We realized that for a large and poor country like Brazil this was not feasible, if only from the financial point of view. But our real objective was to integrate leprosy patients into the general stream of health care and therefore try to diminish the stigma.

The first priority was given to **education and information**. We developed gradually the curriculum for a two week course on Rehabilitation. The subjects taught were clinical Aspects of Hansen's Disease, Social and Psychological problems, Anatomy of Hand and Foot, Pathophysiology of the various Impairments and Disabilities, especially the Leprosy Neuropathy. Surgical skills taught were correction of Facial deformities, Hand and Foot problems, Nerve releases, Eye complications, indications for Shoe Orthoses and Prostheses.

The objective of these courses is to reach as many health professionals as possible. Therefore, they are open to any health care worker. The courses covered the problems and solutions to most physical problems that Hansen's Disease patients could have.

Another avenue we used to provide information to health workers and especially to surgeons, leprosy clinicians and therapists was to present papers on Leprosy Rehabilitation at all Hansenology congresses and also at orthopaedic, Plastic Surgery, Hand Surgery Congresses etc. We also published as many

papers as possible in the various specialty journals in Brazil and South America.

The impact of this strategy is difficult to measure but we know that over the last 20 years, thousands have heard and read about effective Rehabilitation in Hanseniasis.

The second objective we worked on was motivation. To motivate health care professionals is probably the most important factor. The motivation can have various foundations. Some are touched from a religious drive to dedicate time and work for Hansen's Disease patients. Others have simple humanitarian reasons to help where possible. Many find their challenge in motivation in the complexity of the surgical and therapeutic aspects and some that have a government appointment want to fulfil their responsibility in the best way possible.

The reality is that low government salaries and the virtual absence of funding from NGO'S for Rehabilitation lead to a lack of financial incentive for this work. The best way to wake up motivation is by example. This is what the rehabilitation team at Lauro de Souza Lima Hospital has tried to do through these 20 years. When health care professionals have been informed and motivated, they need **training** and that is our third objective. The fact that we start with basically fully trained professionals makes this task easy. We do not need to teach basics of surgery, physiotherapy, occupational therapy or social work etc. We can focus directly on the specific aspects of Hansen's Disease. Some get enough information from one course or may repeat the course several times for reinforcement and new information.

Usually the most difficult part is to get started at home. To motivate the rest of the team and get support from an Institution to carry the new Program is quite difficult. At this point a visit by a senior member of the teaching team usually helps to get over the first hurdles. To start with reconstructive surgery we usually have the routine of sending a physiotherapist before the date of surgery to prepare and select patients together with the

local therapy team. Then F.D. or M.V. teaching surgeons, go for a week and guide during operations. Usually they also give lectures to the local medical community, providing Education and Motivation. This process is repeated until the local team is secure technically and also has found a strong supporting Agency or Institution.

Continuity of the Program is our next objective. This is done through regular visits by the senior surgeon (ED.) every 3-5 years. This allows the local team to show problem cases, discuss failures but probably most important, be proud to show some excellent results as well. Lectures for the team and community are also planned. Friendships are made and strengthened.

Another regular way continuity is secured is the direct contact by phone or mail with the Instituto Lauro de Souza Lima. Many questions and problems are solved this way.

Growth is also a very important objective. As nobody works full time treating Hansen's Disease, everybody has several other work places or teaching activities which might satisfy growth needs. But it is fundamental that we all also grow in the area of Hansen's Disease. Otherwise activity becomes stagnant and sinks. Interest and motivation slip away. We encourage each team to publish as much as possible and participate as teachers in all regional courses to disseminate the news about Rehabilitation in Hansen's Disease.

We also regularly organize Surgeons Meetings. In September of 1999 we are planning on holding the 5th Surgeon's Meeting for Hansen's Disease. This is a week where we network as friends, share experiences, get freshly motivated and everybody presents

papers. We invite a well known guest speaker or speakers in some specific area. This furthers our education and we also always get good suggestions and criticisms from our visitors. In the past we have had as visitors Dr. Ernest Fritschi, Dr. Paul and Margaret Brand, Dr. Dinkar Palande, Dr. Roland Kazen, Dr. Ben Naffs and Dr. A. Pardini.

RESULTS

As a result of 20 years of teaching and training Rehabilitation and Reconstructive Surgery at the Instituto Lauro de Souza Lima in Bauru, we have been able to see that 23 fully independent Rehabilitation Teams have been established. Three of these have disappeared after more than 5 years of work. The reason in all 3 were political and not at all related to the team itself. We like to acknowledge here also the participation of Dr. Renzo Silvano *in* the training of several of the surgeons in our group. We believe that it is fundamental that the Rehabilitation Team work in dose relationship with the treatment program. This strengthens both. The patient with neuritis, claw hands, club foot, etc. knows that there is a place where help is available. The Rehabilitation Team knows they have a knowledgeable person close by to treat reactions and other complications and also to make sure that the patient is in a safe state for surgery, and good result can be expected. Almost all of our programs have this close relationship.

It goes without saying that the Prevention of Disability Program is fundamental to both the Control and Treatment Program as well as the Rehabilitation Program. Neither can do without a good Prevention of Disability Program.

From 1978 to 1988 68 courses have been given at I.L.S.L.
 Total Nr. Participants 1403
 Surgeons and Therapists 1100

The other participants were nurses, social workers, psychologists, paramedical workers, etc.
 Left Program

Surgeons that worked more than 5 years in a program	70	23
Therapists (Q.T. and PT.)	70	7
Social workers	30	5
Psychologists	25	6

- we have today
- 47 surgeons
 - 72 Therapists
 - 25 Social workers
 - 19 Psychologists

Still working in 20 independent programs. The 23 original Rehabilitation Programs are located as follows:

- Colombia: 1 - Aguas de Dios Hospital
- Argentina: 1 - Baldomero Sommer Hospital in Buenos Aires
- Paraguay: 3 - Hospital Mennonita
 KM81 - San Lorenzo - Patronato de Leprosos.
- Brazil: 19 – Instituto Lauro de Souza Lima, Bauru
- Belem - Para - Demetrio Medrado Rehab. Centre
- Manaus - Amazonas - Alfredo da Mata Treatment and Research Centre
- Rio Branco - Acre - Hospital de Base and Catholic Hospital
- Belo Horizonte - Minas Gerais
- Santa Isabel - Hospital Betim - Minas Gerais
- Tres Corações - Minas Gerais
- Fortaleza - Ceara - University Hospital

- Porto Alegre - Rio Grande do Sul - ex Leprosy Colony Hospital
- Curitiba - Parana — Hospital Sao Roque
- Guarulhos - S. Paulo - Ex Padre Bento Hospital
- Riberão Preto -S. Paulo - University Hospital
- Porto Velho - Rondonia - 3 different Hospitals
- Salvador - Bahia - Catholic University Hospital
- Brasilia - Federal District - Sarah Hospital University
- Campo Grande - Mato Grosso do Sul — Hospital São Julian
- Recife - Pernambuco - Federal University Hospital
- Rio de Janeiro - RJ - Federal University Hosp. Clementino Fraga Filho

No longer active are the programs in Colombia / Padre Bento (S. Paulo) and Patronato de Leprosos in Paraguay.

By now every one of these services is fully integrated into the general health care routine and needs very little economic support. Most are integrated into the budget of the hospital where they serve.

Nº of surgeries done per year: 1,400
Total since beginning of the program: 35,000

Of special note are the programs incorporated into University Hospitals. They have a very far reaching influence; first because they show that stigma in Leprosy is not a problem anymore. Second, the surgeons training at the University learn the specific techniques to treat leprosy problems. We have in the interior of States about 7 surgeons operating who were trained in University Hospitals. Third, medical students, nurses and Medical colleagues, nursing students, P.T. O.T's and their students all learn about Disability and Leprosy and how to deal with it. We have the experience that if the Rehabilitation Program is

located in a University Hospital, the problem is basically solved for that State. At this moment we have started to work on getting new programs started at the University Hospital in S. Luis, Maranhao — the University Hospital in Cuiaba, Mato Grosso - Vitoria, Espirito Santo - Governador Valadares in Minas Gerais and have invitations to come and assess possibilities for Rehabilitation Programs in 5 other cities, (3 of which are University sites).

In summary, we can say, based on 20 years of experience, that with **education** and Information - waking up a **motivation, training** in areas of each team members, keeping **continuity** by regular supervision visits and allowing and furthering **growth** through courses and Congresses, stable and effective Rehabilitation teams for Hanseniasis can be established and maintained at a very low cost. More than half of the programs listed have worked with the same team members for over 10 years. We thank God for his blessing.



Picture n. 1 The first Surgery Course given in 1978. The trainees were Dr. Leonildo and Dr. Germano Trapple both in white in this picture.



Picture n. 2 Typical group of participants of a Rehabilitation Course at Bauru



Picture n. 3 Dr. Marcos Virmond demonstrating a patient to the group at one of the courses. Standing at the right background is Dr. Jose Garbino, the chief of Rehabilitation at Instituto Lauro de Souza Lima.



Picture n. 4 Professor of Orthopaedics, Dr. Jairo Andrade de Lima with a group of residents demonstrating on a patient at the University Hospital in Recife.



Picture n. 5 Surgery and Hansen's Disease Control working together. Dr. Cabral, surgeon and Mrs. Valle in the State of Roraima. There is a very close cooperation between the Surgical and Control Program in the State.



Picture n. 6 This picture shows one of the Surgeons Meetings that are held periodically. In the front row squatting third from left is Dr. Ernest Fritschi who was our guest speaker and in the back row second from right Dr. Arlindo Pardini who was also a quest speaker. Most of these surgeons are still active in the program.