कुष्ठ उन्मूलन

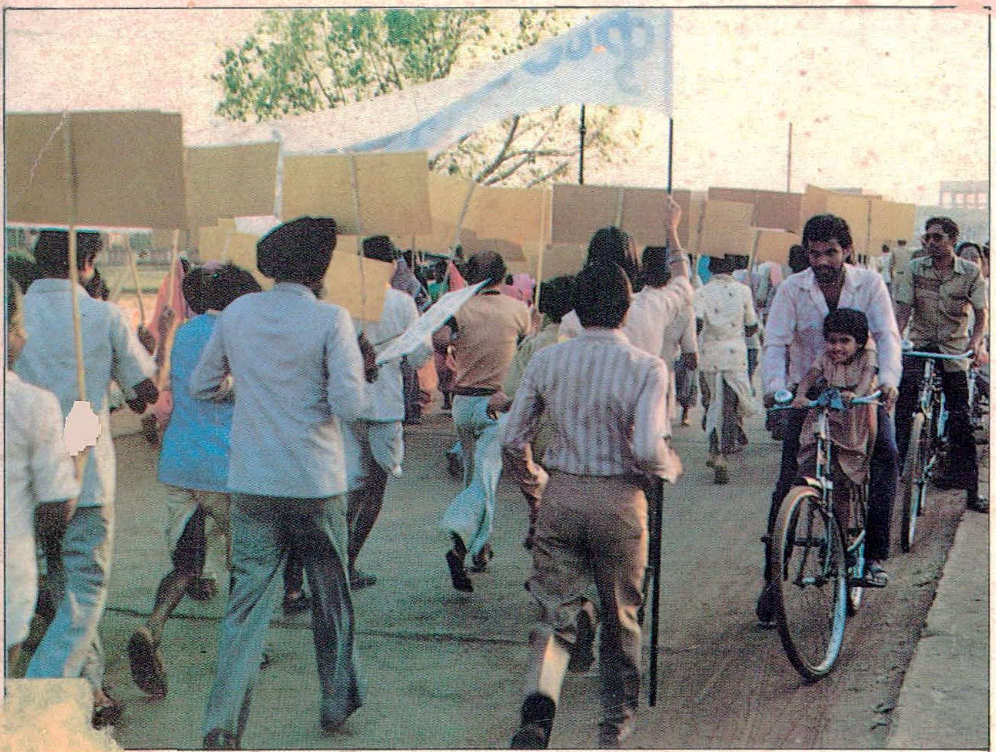
'प्रयास' आरोहण समारोह

भिलाई : 28 मार्च - 29 अप्रैल, 1988

LEPROSY ERADICATION

AN EXPERIMENT IN COMMUNITY ACTION

Bhilai: 28 March – 29 April 1988



Solidarity Run

Leprosy is dreaded! What else could happen ... when 'quick-cures' and 'deformity-devoids' shun their identities ... gag their positive experiences about the treatment? '4th April Solidarity Run' for once proudly paraded the hidden trove of 'Cure' and 'Strength'. 300 strong and sturdy persons with Leprosy history, ran through the city's main thoroughfares, hand-in-hand with 2,000 non-patient Bhilaians.

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   Health & Family Welfare
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   Dr. T.P. Sharma
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2. Director
   Medical & Health Services
   Bhilai Steel Plant
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Foreword

Dr. B.H. Sorensen

What management issues are there in a leprosy programme? After all once you have the vehicles, staff, drugs, what else is there to it? At the time this question was raised, we at Danlep didn't have the answer. But we did know that until patients suffering from leprosy were treated like patients suffering from any other disease, leprosy as a public health problem would not be resolved.

Since then several field experiments have taken place. The names like Kanha, Dongargarh, Purena, Bhilai appearing several times in this publication have come to signify the lessons that surfaced during the training camps organized in those locations.

The first step was taken at Kanha National Park where team training prior to implementation of MDT wa organized for the staff of LCU Rajnandgaon. The Danlep interacted closely with the LCU staff to uncover the barriers between the field staff, the community at large and the patients.

What became clear was that field workers felt lonely and needed link people to associate with in the villages. Since this seemed to be a major barrier preventing field staff from giving leprosy patients their due service, an experimental workshop was organized in Dongargarh with community leaders as potential link persons.

This second step revealed that demystification of leprosy was an important tool in fear removal. That understanding about low infectivity and the possible cure with MDT was crucial. With this understanding the community was willing to come forward and play an active role in the removal of this disease. Not by segregation and isolation of patients as has been done for centuries; but by actively helping them face the disease boldly.

Many skin diagnostic camps followed and people came forward publicly to have their skin problems diagnosed. With no threat of social exclusion, the need to hide suspected leprosy vanished.

Still, the end to isolation and segregation was only talked about. The real test was to see if field workers and community would actually live together overcoming their earlier beliefs. The Dongargarh camp held for 14 days of intensive treatment, by bringing together with patients the health educators and the field staff, achieved many of the objectives set towards this end.

The Purena camp held in February 1988 represented the third step—the final total merging of patients, community members and the field staff. It helped in breaking all barriers between them and in focussing attention on achieving the common goal of treating leprosy as any other disease for which there is a cure. This camp was organised entirely by the local field staff and the local community. The change in management represented also a take-over of responsibility. Acceptance of the 'community action concept'

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by the field staff and the community at large for counteracting leprosy became a reality. This was achieved through the actions of the field staff and the community alone, without any additional external resources.

Dealing with ulcers, this socially unacceptable feature of leprosy, was successfully initiated at the second Dongargarh camp. This has now become a regular feature in our field programme. Of major importance in dealing with ulcers is an understanding of the cycle-anaesthesia - ulcers and deformity - social ostracism.

During the month long 'Prayas Aarohan' programme at Bhilai, April 1988 major emphasis was given to reconstructive surgery. This emphasis has also helped to focus on anaesthesia, opened the eyes of people to the importance of early diagnosis and care for prevention of further deterioration. This latest step was taken as an answer to demands put forward by the patients and the community now that the field staff had entered into an open dialogue with them. Having ulcers, deformities and being socially destitute is associated with leprosy in the minds of most people. We, the health providers may talk of killing bacteria and non-infectivity but to most people leprosy is cured only when the "Social symptoms" are dealt with. If we cannot offer surgical reconstruction and social rehabilitation to leprosy patients, when this is what is foremost on their minds as definition of cure, then who are we to call ourselves service providers.

Historically leprosy surgery was done at a few specialized mission hospitals. For these services to be truly of use to people they must be available in an acceptable setting. In Bhilai the operations were done at the local general hospital by both visiting and local surgeons. Patients were accommodated in the general ward and pre- and post-operative care remained the mixed responsibility of the hospital physiotherapy set-up and the local field staff. Local community joined hands with the hospital administration to meet the payments for this service.

Both successes and failures have been recorded. The lesson learned is that if we accept unconventional solutions, the general health system has the potential of reaching these services to rural people.

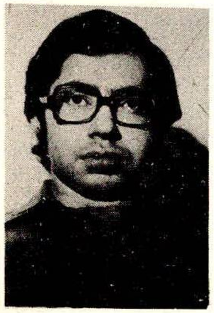
A problem that remains with us is that of the social rehabilitation. Possible paths for rehabilitation are likely to be once again desegregation in the work-situation, given a little assistance a patient can meet his need of normal job or routine work in a mixed employment situation.

We have very convincingly seen that solutions can best be found by entering into a dialogue with patients and the community. Only by taking into account the needs of the people can we find passable roads. If given the opportunity, it is my conviction that the triad of patient, community and the field staff will also be able to find a way of channelling leprosy-patients into a sociably acceptable position in life.

Contents

Overview

Pradip Singh



Manager
Public Relations
Bhilai Steel Plant
Bhilai.

A group of Leprosy patients was gathered before the Health Centre in the monthly ritual of taking the MDT dose and were at a bit of a loss because the person who used to give them drinking water to wash down the medicines was not present. One of the patients, a woman ravaged by the disease, but with a powerful personality which had risen above the vicissitudes of the ailment and social discrimination, asked one of her fellows to go to the house across the street and ask for some water. He was obviously hesitant, and was promptly upbraided by the lady as a shame to the group for being too scared of refusal to even go and ask. More scared of her than he was of possible rejection, he went.

They were given not just a bucket of water and a ladle, but a tumbler too by the householder, who then came to collect the bucket, reminding the group that he had joined them in the mel-jol daud, where leprosy patients and the leprosy-free members of the community had run a marathon together. He was truly leprosy-free, normal, because he had the disease neither in its bacterial form nor in the form of a prejudice.

A single act of self-assertion had revealed a strength in the sufferer and in the society which had contributed to the anguish of the sufferer, bringing cure for both in the real sense of cure. This was result of the new awakening being brought about in this vital, throbbing heart of India, Bhilai, from where the ripples of change may well sweep the entire country and see mankind triumph over an ages old prejudice, making it the first such victory in the long and troubled history of our civilisation.

Leprosy is one of the primal fears of mankind, all societies and all civilisations down the ages have seen in this disease a stigmata, a curse of the Gods, a judgement on the individual and his family, to be shunned and feared in its manifestation by everyone not so afflicted. The terror of the disease for its unfortunate victim then, as now, was not so much the ravages it wrought as the psychological and spiritual desecration of the sufferer's soul that inevitably followed discovery. Yes, discovery, not diagnosis, as it was viewed as something akin to the revelation of a sin rather than the identification of a disease, and the sufferers sought to hide the fact of the ailment until betrayed by the deformities it caused.

The disease then as now is the social reaction leprosy brings—not the affliction of germs or bacteria causing or the loss of sensation, the deformities etc. The revulsion towards the sufferer was the result of ignorance, that it continues today is perhaps symptomatic of the persistence of superstitious beliefs even in our vaunted modern age of enlightenment.

The saddest feature of social prejudices against the disease is the fact that the patients too, as former members of the so-called normal community, accept the discrimination practised against them by the community. The battle against Leprosy can be said to have really begun only when hope and self-respect are created among the Leprosy-afflicted, and society begins to recognise its own shameful role in the perpetuation of the disease. Early diagnosis and proper treatment can become a reality leading to cure only in an environment which encourages people to look upon Leprosy as a disease like any other, caused by bacteria and easy to cure.

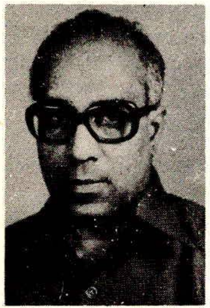
However, today there is hope. Today there are conscious efforts by governments, companies, institutions and individuals in the community to tackle the problem of Leprosy at its basic level. The guiding principle today is to treat Leprosy as any other disease, as it indeed is, and success is measured against the yardstick given by the World Health Organisation's definition of health as not merely the absence of disease but a positive state of physical, mental, spiritual, emotional and social well-being. The disease called Leprosy is easy to cure, and modern methods of corrective and reconstructive surgery can take care of the deformities which may have been caused through early neglect. It is in repairing the self-esteem of the individual and in his mental, spiritual, emotional and social rehabilitation that we see society at last adopt the correct approach leading to eventual eradication of the disease.

The community action programme launched on March 28, 1988 in the Bhilai Steel Township with the active participation of various governmental, private and international organisations sought to go beyond the mere clinical treatment of the medical symptoms to activate the entire society, the patient and family included, towards a recognition of the social injustices involved in our treatment of Leprosy patients, and helping people see that like all superstitions, this too would vanish once the light of reason was thrown upon it.

The case of the "Water Bucket" gives one hope, that the objectives of the national Leprosy eradication may succeed given a continuing response by all the elements, the patient included, in an interaction which would break the social barriers against the Leprosy patients, opening the way to eventual eradication of the disease, in a moral victory unprecedented in the history of mankind.

1. In-group absorption of cured leprosy patients: unfinished task

S. Balakrishanan



D.G.M. (Personnel)
Bhilai Steel Plant

Chairman
Samagra
Prayas Aarohan
Samiti
Bhilai

Some of the Patient Profiles prepared during the month-long Leprosy Awareness Campaign organised at Bhilai reveal that the patient's personal journey down the paths of loss of self-esteem, social awkwardness and depression begins the moment the diagnosis of leprosy is confirmed. The descent into a spiral of goallessness and self-effacement once begun gains momentum with every passing day, and if not arrested in time can and does become almost irreversible.

It is precisely at this point of time, the moment of diagnosis, that needs to be the starting point for the campaign of hope and rehabilitation. By looking to the established colonies of Leprosy patients as the prime targets of Rehabilitation, we are not tackling the problem at its source; giving hope to the hopeless is certainly a laudable objective in itself—but perhaps even more meaningful would be the objective of preventing the seeds of hopelessness from germinating. The patient must be made to realise that confirmation of the disease is the starting point of a journey back to full recovery, to complete normalcy. Without the care which we now hope to provide, the patient's slide into despair is fast, and his possible recovery through continuing treatment doubtful. He may himself soon become uninterested in his own treatment, losing faith in himself and his future.

> ***The patient must be made to realise that confirmation of the disease is the starting point of a journey back to full recovery, to complete normalcy.***

In the Bhilai Experiment, we acted on the premise that the process of Rehabilitation concerns both the patient and the community, as it is the ignorant, unfeeling community which causes the psychological devastation to the patient. If curing the patient was perceived to begin with his hopes and his morale strengthened, the community itself needed a preventive dose, for its moral sense to be strengthened, its nobler instincts to be awakened.

Over the past year and a half, the Department of Dermatology of the BSP Main Hospital has done remarkable work in the interior of Durg and Rajnandgaon Districts, providing a good cover at the diagnostic stage by holding a series of "Skin Diseases Diagnostic Camps", clearing avenues for patients who had been fighting shy of climbing the steps of a Leprosy Clinic openly. These Camps proved a boon to our Mines Personnel, enabling them to take regular treatment of Leprosy through this medium.

Bhilai Steel Plant's Leprosy Eradiction Unit, located on G.E. Road, has been rendering yeoman service to the patient community, administering Multi-Drug Therapy long before it was formally launched in the District. The result has been heartening, with more than 50 per cent of the patients declared cured and advised discontinuance of medication. The remaining have undergone and completed their Intensive Therapy. This was the encouragement we needed to launch the "Samagra Prayas Aarohan Samaroh". from April 4 this year. The march of this steel township to "freedom from fear of infectivity" was demonstrated in the "Mel-Jol" Marathon of Leprosy patients and members of the "normal" community. It was a crystallisation of the dream of rehabilitation while therapy is still on.

The uniqueness of the Bhilai Experiment in Leprosy Control lies in approaching the problem of rehabilitation in "reverse-integration", that is, preventing the scars of social rejection as the first priority, rather than letting the patient develop this disability and then try to cure it.

Yet another remarkable approach here is based on a more rational definition of "infectivity-free patients". one who has undergone Intensive Therapy under MDT and is regular in taking treatment is declared "Infectivity-Free". This helped us initiate early stage rehabilitation, Preventive Rehabilitation as it were, in actual practice.

During the month-long programme, a conscious effort was made to change the time-worn concepts that the community had about Leprosy, to project to the community the wide spectrum of problems faced in rehabilitating Leprosy patients, to vividly portray to the community the conscious choice it had to stretch out a helping hand to the Leprosy patient in a gesture of mutual redemption promoting the "help process". The "Mel-Jol" Marathon was the beginning of the campaign, attempting social acceptance of those who were on the verge of rejection. Seeing the still healthy—physically, mentally and spiritually—Leprosy patients compelled the sensitive members of "normal" society to re-examine their prejudices, opening out promising vistas of rehabilitation for the Leprosy-afflicted.

Members of Youth Forums, Teachers, Trade Union office-bearers, Women's Social Organisations, Students, Sports-persons, Parents, Children, Representatives of Social, Cultural and Religious Organisations were all brought together in a series of Group Meetings. These meetings addressed the problems of those who had ignored timely diagnosis because of fears of social reactions to the disease,were forcefully, even poignantly, brought home to those who could help, those who, unthinkingly, were themselves responsible for the problem. It is to the credit of the community that a number of useful suggestions were thrown up in these meetings, to be eventually compiled into a 22-point Programme entitled "What We Can Do".

The six-day Self-Care Practice (SCP) Camp organised at the Gayatri Shakti Peeth also served to expose the general public to the twin messages of "Futility of Fear of Infection" and "Deformity Prevention in Your Own Hands".

Patient Profiles, developed by Volunteers who were released from other duties by the Bhilai Steel Plant, proved to be valuable agents in the war against prejudice. Not only did they help crystallise the problems of the patients, but the very process helped in "zeroing" the distance between the patient and the community, here represented by the Volunteer, through him his family and peer-group.

The Steel Plant's Medical Organisation took a bold step in the direction of rehabilitation by launching a new Corrective Service for the Leprosy-afflicted at the Bhilai Main Hospital. Availability of eminent Surgeons from distant reaches of the country to perform these operations, contributed significantly to promoting the sense of confidence essential for the success of a new service. Around 50 cases were operated upon during the month.

Another important feature of the Corrective Surgery Campaign was that the BSP Hospital facilities were provided at a heavily subsidised rate of Rs. 500/- per case.

Corrective Surgery was not seen as an end in itself, but rather the first in a series of steps leading the patient back to a life of normalcy. A normalcy they will have fully attained when all of us, officially and in our private capacities, strive together to bring these lost brethren back into the folds of the community—offering them honourable work opportunities admissions in schools, treatment in hospitals where we go for our problems, accommodations within the community. We would all have to strive together mightily to obliterate the "Leper Colonies" housing the cured as well as the still afflicted, the afflicted and their progeny, in a cycle of social injustice which stand as monuments to Man's Inhumanity to Man. The day we have destroyed the walls around these colonies may be marked as the day we have conquered this dread disease—dreaded no more.

Exhibit

SAMAGRA PRAYAS AAROHAN SAMAROH—BHILAI

28th March to 29th April, 1988 (Comprehensive Patient-Care Programme For Effective Eradication of Leprosy)

Programme Outline

Eventhough a person has been completely cured of leprosy and has attained 'Zero Level' of Infectivity, it calls for a special effort to remove from the minds of the people the baseless, superstitious fear which blocks physical contact or social proximity with the ex-patients. This social barrier which exists between two identical group of people has to be razed to the ground. It is not only in the interest of the ex-patients, but in the long run, should be considered ~~crucial for the~~ progress of society as a whole. When the ex-patients find that non-patients are moving freely with them without keeping any distance, the former will gain a tremendous boost in self-respect and self-confidence. It is this boost coming from a new sense of solidarity that will enable them to become respectable members of the society.

More importantly this symbolic but open demonstration of solidarity will encourage the patient who is in the earlier stage of the disease, to overcome his shyness and fear of social isolation and to report to the leprosy control unit for treatment.

We present below a draft of the month-long programme developed by the Committee for approval of the people of Bhilai.

28th March to 10th April, 1988 — MEL JOL (Fearless Intermingling)

Preparation for representative participation in "Mel-Jol-Doud" (Solidarity for Strength Run) — a marathon wherein 500 strong and sturdy Zero infectivity level persons with leprosy history will intermingle with a select group of 1000 Bhilaians representing a cross section of the civic life. The "Run" starts at 5:00 PM on 4th April from Supela Railway Crossing and ends at Pioneers' Monument (Civic Centre).

A three-legged race of Patient-Nonpatient pairs, is organised on the occasion to highlight "Freedom from Fear" that rules the town now in the wake of new understanding about the disease. It is anticipated that atleast 500 volunteers will emerge out of this Mel-Jol exercise.

A week long programme of Community Education through "Activity Participation" follows the rally. These educational activities will be organised by the volunteers in different localities of the town, inclusive of the SADA Area.

11th to 16th April—"SAAWADHANI" (Preventive Care)

Patients who are cured of infectivity but yet remain afflicted by "Anaesthesia" will be brought together in two, week-long Residential Camps where in through practice demonstration a new awareness of "Self-Care" is proposed to be created.

Besides treating Ulcerated Patients in these camps, opportunities will be provided for citizens — both men and women to offer voluntary services through giving Practice lessons to patients in massage and other exercises of Self-Care.

Different neighbourhoods will be managing "Cost Free Meals" for the camping patients as well as the workers.

We invite men and women from different localities to participate in these camps for two hours every evening.

17th to 23rd April—"KHOJ" (Search for Strengths to promote Mutuality of Help)

Patients cured of infectivity who need support from the community for correcting their deformities would be presented to noble Individuals, Institutions and Organisations to ensure a respectable worklife for them within the society. Bhilai Hospital is launching a "Corrective Surgery Service" at the Hospital from 4th April, 1988 on highly subsidised rates of operation fees. Additional patients with promise requiring financial and other worklife supports will be identified during this week.

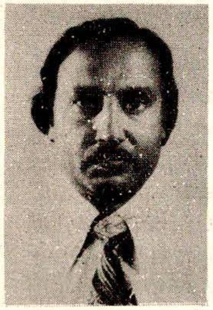
24th April to 29th April—"NAYA MOD" (Launching New Life Projects

Based on assessment of needs of Deformity Corrected Patients, a get-together of such patient groups and willing Adoptors will be organised to develop organisational perspectives to reach such help on a regular basis. Initially required resource assessment will be made and a week long fund collection drive will be launched to facilitate universal participation in "A Rupee For New Life Drive".

A "Samapan" day will be observed on 29th April, 1988.

2. The risk-runners and the drop-outs

R.A. Christy



"For sure, we'll come! ... Tell us what dress we should wear?" Some of the teen-aged girls proclaimed their firm determination. They were thrilled at the prospect of joining the Marathon of 4th April. The girls formed part of a Muslim women's group from a Muslim Mohalla situated near a Mosque in the SADA Area. Thanks to the good offices of the Kazi of the Mosque, we could meet these women in one of their houses. Most of them had watched the 'Freedom Run' on the T.V. They were thrilled with the idea of running in a marathon, where other society women will be participating.

The idea of coming out boldly in the open appealed even to the relatively elders amongst the group. They saw in the Marathon a good rehearsal for the march they have been planning to protest against the acute drinking water problem. They thought the marathon will help the women gather courage for taking out processions and holding rallies, to pressurise the civic administration. No wonder, these women raised their hands when a head count was taken of the probable participants in the marathon.

A dialogue with Muslim women came to us as a windfall. We never anticipated that such gestures would come our way, when we set out on our community-contacts' mission that morning. The meeting was arranged for us in that locality by the Kazi of the Mosque. Earlier he had put us across two Muslim Traders, who generally employed casual labour. One of them was wholesale Fruit Seller who despatched Truck-loads of fruits to other market centres. He was willing to engage about 10 cured leprosy patients on the Truck-loading and unloading work. The other Trader was a grains merchant. He usually employed a few handicapped women on grains cleaning job. He looked upon this work as a command from the Almighty Allah.

We were thrilled to get encouraging response from the Muslim community, more particularly from Muslim Women's group which was not on our cards so far. It almost doubled our enthusiasm. The previous day we had received similar response from lower middle class women residing in the area around the LEU office. This group also discussed about their dress for the occasion and assigned individual responsibilities about reaching the women on time for the marathon. Response from one youth club was equally gratifying.

On the same day, in the afternoon about 100 odd women Jobbers at the Mahila Samaj Gloves factory, enblock expressed their desire to participate in the Marathon. This group went a step ahead and welcomed the idea of a few 'cured' women leprosy patients working side by side in their Workshop.

A social organisation of the Sikh community offered to provide 'Sharbat' for all the marathon participants at the concluding point of the 'run'. A few other organisations offered to arrange on the route 'Sweet Butter Milk' and Cold Drinking water. Some groups agreed to stage a cultural evening at the Rally point. The response from the Townfolks was mounting with every passing day.

The only uncertain factor was the size of participation of Persons with leprosy history. We had approached many more than the number we actually expected on the Run-Track. We were choosey while listing their names. We wanted to present before the society the 'strong' and 'sturdy' amongst them. The paradox lay in the fact that those who were devoid of deformity were shy to reveal their patient identity.

In the evening the organisers met to review the preparatories and decided to print additional 1000 Marathon Badges. They assessed the demand for Badges to exceed 3000. The badges were priced at Re.1/-. Some of our colleagues expressed their reservations over the

Deputy Manager
Sports Council
BSP
Bhilai

estimations on excess demand. They thought the actual tally would not exceed 2000 mark. Our evening review meetings never really helped us get over our anxieties about the size of actual participation. It always remained a guessing game till the 'Run' actually started. All of us had our fingers crossed.

As the zero hour was nearing we didn't see anyone from the Muslim Women's Group reaching the starting point Shamiana. This was specially erected for the Runners to assemble and to wait under shade at the starting point of the 'Run'. Neither could we see any of the lower middle class women from the vicinity of the LEU office. Patient presence also appeared on a low key. To compensate for the low turn out from anticipated groups, fresh participation of non-patient civilians was mounting. We heaved a sigh of relief only when a special coach loaded with patients from Dongargarh reached the starting point. With the arrival of the patient group in sizeable numbers, local patients who were loitering around unnoticed, flocked together. Soon a 300 plus strength of the patient group was seen waiting for the 'go' signal. The three-legged race of patient-nonpatient pairs added fun.

At the Rally point the 'Sharbat' provided the much needed cooling contrast to the otherwise unbearable April heat. The prize distribution and the cultural programme added colour and gaiety to the buoyant mood of a unique gathering assembled in Bhilai at the Pioneers' Monument.

The marathon meant considerable risk for the patient community. Absence of any identifiable marks of deformity had provided them with a safe and secure cover to protect themselves and their families from the prying eyes of the community. By joining the Marathon with flaunting a 'Patient Badge', they were tearing off this protective covert wilfully. The risks they had bargained for had, however, opened floodgates of communiation for the non-patient community.

The non-patient community's participation in the marathon did not carry as much risk, though it did help to install a massive network of communication which operated both ways. One way across to the patient community with an added degree of enormity of new understanding marked by a fresh concern. The other way it opened dialogues with the normal non-patient community to explain their deviant behaviour. With passing of time these explanations acquired a potency that made massive inroads into the stranglehold of social stigma.

While granting the contributions made by these two components towards developing a 'new-wave' communication process in the civic life of Bhilai, some of my colleagues differred in their assessment about the role played by the 'drop-outs' from the marathon by groups like the one of Muslim women's, and the lower middle class ones from the vicinity of LEU office. My colleagues were not prepared to ascribe them any role in the communication process. But those of us who have had some opportunity in the past to work with political systems, disputed this assessment. According to them those who acted should be looked upon as potential 'activists'. But we should have a positive assessment of even those who while consenting to act, and having all the desire to act, shied away from coming in the 'open' from action, should be understood as "Fellow Travellers". They were of the opinion that the letter group should receive our special attention and be cultivated with expectations. In any scheme of value based consolidatation of 'ranks', Fellow Travellers have critical role to play.

3. Understanding and knowledge: poles apart

Rita Pali and Anuradha Ghosh

"Gives us some educational aids ... hotographs, pamphlets, posters ... and things like that ... I mean Materials your Health Education people use ... Rest leave it to us ... Daily we will organise meetings in our areas and spread the "Fear not" message!" One of the women participants responded forthrightly.

We were meeting a group of young Society Women. This was one of those series of group meetings which followed the Marathon of April 4. The group of women amongst themselves represented a spectrum of social organisations from the twin cities of Bhilai and Durg. Some of them were wives of Industrialists, Businessmen, Advocates, Medical Practitioners.

"Why do you need 'educational aids?", someone from our side raised a query. "We're meeting here without any educational aid. Aren't we? ... If 'Fear Not' is the message, won't it suffice, if we arrange for the presentation of four-five live cases with different types of patches? Catch hold of their hand and point to the patch by moving your finger closer to it ... as we do while showing something on a Map!" (Silence)

This way you'd be killing two birds with one stone ... Showing the patch and giving the 'Fear Not' message through a 'practical' ... Won't that be more effective?"

For a while there was abrupt silence in the hall. Almost pin drop silence! They looked at one another. A spate of silent messages got transmitted. A broad smile on each one of the faces was observed. Through their silence they were saying: "You've caught us on the wrong foot!"

Teacher
Sector VI
Higher Secondary
School (BSP)
Bhilai

The group volunteered to spare time for developing 'Patient Profiles' of the patients admitted at Bhilai Hospital for corrective surgery.

Three amongst these ladies, earlier had visited Warora, a place about 250 to 300 kms away from Bhilai. They were keen to see for themselves the social work being done at 'Anand Van', the famous leprosy patients' settlement, developed by Shri Baba Amate, his wife and others.

Our experiences at one of the Teachers meetings at the Bhilai Public School — a prestigeous institution of the town — were equally interesting. Instead of giving lectures on Leprosy, its control measures and treatment, we used to raise issues based on a person's usual responses, and highlight the lack of understanding these showed mainly for want of any feeling for the sufferer.

After a swift round of self-introductions, the first salvo was fired from our side. We asserted that they were all knowledgeable about Leprosy. "You know because you act, react and remain genuinely involved in the processes of action and reaction centred around fear generated in the society, "We said.

What followed was big surprise. The teachers knew so much about the disease, its occurance, the medium of its transimission, the medical treatment of the disease, and its curability. As invariably explained by many of them, source of their knowledge remained the all pervasive T.V.

"With all this knowledge, how would you explain the fears that still linger on you minds?" We asked.

"Difficult to reason out ... But they're there ... No point denying it ..." One of them remarked frankly.

Social Worker
Bhilai

"If you don't mind ... let's imagine for a moment ... someone dear to you like your child, developed a patch on his/her body ... how would you react?"

"We'll show the Child to a Doctor?", quick came the response.

"You mean till such time you showed the child to a doctor you'll hold back your fear! Till such time it's confirmed you'll not keep the child at a distance, only on the strength of your apprehensions and doubts?". We asked.

"Correct!" So many voices spoke out at once.

"Isn't it true, we don't show this patience, when the person involved is not our 'dear' one?"

Abrupt silence pervaded the Hall. None talked for a while.

"Let's go a step further. The Doctor after examination confirmed that the child has leprosy! What happened then?", we asked to break the long spell of silence.

"Well, different people would react differently. First wave of reaction could be disbelief in what the Doctor said. A desire to show the Case to someone else." One of the more articulate voices responded.

Soon many more responses followed. These ranged between 'disbelief'; 'unbearable shock'; 'intense hugging of the child'; 'silent prayers with closed eyes'. If anything was uniformly common in these reactions, it was their all pervasive genuineness.

This tempted us to ask one more question: "How would we behave with that child on returning home?

Would we scold? Would we threaten him/her of desertion?

Would we take immediate steps for the child's segregation?

Would we ask other children to stay away from him/her?"

Once again there was silence in the Hall. Soon we all got up to go. Perhaps the answers were too obvious!

There was major participation of the Teachers from this school in the Marathon.

After women's groups and teachers, we turned our attention to school children — the younger generation. Because of the odd month we had chosen for the 'Aarohan celebrations, our access was confined to only English Medium Schools. The Hindi Medium schools were in the midst of their annual examinations. Three different competitions of different dates were organised for this group. The participation the way it materialised, was very encouraging. The eligibles for the competitions were students from KG upto 12th Standard. Even students from the Russian School took part.

The prize distribution function on 23rd evening brought together more than 400-500 parents. They came alongwith their children at the Gayatree Shaktipeeth Hall. That was the concluding day for the 'Self-Care' Camp as well. The big hall proved too small for the occasion. Nonetheless, it once againt provided an occasion for Bhilaians to mix and jostle together with patients who had attended the "Camp".

Exhibit

Competitions for Children

On the Spot Drawing & Painting Competition

About 355 boys and girls participated in this event. Even though no themes were given for this event, as many as 50 children painted on themes related to leprosy eradication. Sixty six participants deserved prizes. A panel of three judges declared the prizes. The panel members were: Shri Mahesh Chaturvedi, Shri Papa Rao and Mr. Vassilo, the Russian Artist.

Essay Writing Competition

Five themes were given for writing essarys. The participantage-group ranged from 6 to 17 years. 149 boys and girls from 19 schools participated. Judged by the contents of the write-ups, it appeared the message of the Marathon had reached far and wide into Bhilaian households. Forty deserving candiates received the prizes. The panel of judges comprised: Dr B.P. Mukherjee — CHO, Bhilai; Dr. P.R. Mangalani — M.O. LEU (SADA Bhilai); Dr. (Mrs) S. Deewan; and Dr. Ms. Runu Chatterjee.

Messages & Slogans Writing

Thirty five candidates particiipated, one of them was even a teacher. 12 slogans in English and 27 in Hindi were composed. The messages conveyed by the slogans basically covered two themes: (i) Leprosy is not a disease of only the body of the patient but of the mind of the Society as well; and (ii) The disease is curable.

Some of the striking slogans, both in English and Hindi and the commendatory contributions with names of the respective participants are given below:

Student's Slogan Composing Competition Results

Slogan	Name of Composer	School
1. Wherever you take care, Leprosy cannot remain there.	Abhishek Chandra	E.M.M. Sector-X
2. Shake off hear. Leprosy is cured by socio-medical care.	Shonli Sengupta	E.M.M. Sector-X
3. Don't fear, come near. Treat Leprosy my dear.	Geeta Manglani	E.M.M. Sector-X
4. For cure of Leprosy, we should fight but certainly not hide.	—do—	—do—
5. Eradicate Misconceptions and hatred, Leprosy will vanish.	Sanket Mathur	E.M.M. Sector-VI

संदेश व नारे प्रतियोगिता 12 अप्रैल 1988 में उपयुक्त, समझे गये संदेश नारे

नारे	लेखक का नाम	स्कूल
कुष्ठ रोग निवारण जन सामान्य में चेतना से ही होगा। कुष्ठ पीडित को घृणा से देखना, यह घातक कोढ़ है।	श्री अंकित माथुर	डी.पी.एस.
कुष्ठ रोग से डरना नहीं, छुआछूत से लगता नहीं। कुष्ठ रोग छुपाना नहीं, इलाज कराना, शरमाना नहीं। कुष्ठ रोग अभिशाप नहीं है, अन्य रोग सा, पाप नहीं। सबको इसका इलाज बताओ, कुष्ठ रोग को दूर भगाओ।		
अब कुष्ठ रोग है नहीं समस्या, ना चिंता ना करो तपस्या, इसका अब उपचार सरल है, इसे छुपाना काम गलत है।	कु. नुपुर पाली	डी.पी.एस.
नहीं अपाहिज होगा कोई, यथा समय उपचार जो होई। पीड़ित को उपचार चाहिये, हमसे-तुमसे प्यार चाहिए। इन्हें भीख की चाह नहीं है, इनको तो कुछ काम चाहिये।	श्रीमती रीता पाली	डा. एम.एम.एस.
कुष्ठ रोग नाहिं छूत का, बिना छूत के होय जो न मानें कोढ़ी किसी को, वो ही सांचा मानव होय।	श्री हिमांशु माथुर	इ.एम.एम.एस.

4. Raffi's reluctance

Shantilata Varma

Secretary
Bhilai Mahila Samaj
and
Member, SPAS
Bhilai.

My father was in the Orissa Medical Service. I distinctly remember when he was offered the post of Superintendent at the Leprosy Home & Hospital in Cuttack, everyone tried to dissuade him from accepting the job notwithstanding the promotion it entailed. The Superintendent's quarter was just adjacent to the Leprosy Home. That it was on the banks of the river Mahanadi, with plenty of open space around, gave little solace for the detractors. Would it not be risky for the family members to live so close to the infectious patients? A query which came naturally to everyone's mind. Father explained to us that leprosy was not as contagious as was generally feared.

With great reservations we moved to Cuttack.

Over the years, medical science has made tremendous strides. Now leprosy can be made non-infectious within a couple of weeks; and cured in just three to six months. Only in certain cases it takes two years. The treatment of the disease has now become simple, and easily accessible. Reconstructive surgery can rectify the deformities as well. Yet its dread continues unabated.

We lived in Cuttack for about ten years. Every year I saw several patients being cured and discharged from the leprosy home but not many returned to their families. They preferred to stay on in a settled colony nearby called "Gandhi Palli" which was situated on the banks of Mahanadi. It was very close to the Leprosy Home & Hospital from where they were discharged earlier. Here they lived virtually cut off from their families and friends.

Not that it happened only in Cuttack. It is a universal phenomenon. Here in Bhilai, Shardapara Leprosy Colony is settled mainly by such cured patients who avoided returning to their homes. One of the inmates of this colony — Mohammed Raffi, who has an utterly deformed nose, finger contractures and cornea problems of eyes, is an interesting case. He originally belonged to Khandesh in Maharashtra. There he owned a large landed property; and also had an urban housing property in yet another district in Vidarbha. After leaving his hearth and home nearly 25 years back, he had gone to the leprosy hospital at Baitalpur. From there with a 'Cure' certificate in hand, he moved on to the Hospital in Raipur. And from Raipur to the self-settled colony in Shardapara.

He has one brother and one sister. His brother's sons are highly placed in Government Service. After the death of his sister's husband, he held power of attorney for her property as well.

His brother's son nowadays writes to him most affectionate letters. He pleads with Mohammed Raffi saying: "Now things have changed. Sure-cure medicine is available. Government has made arrangements to reach the medicine to patient's door-steps. We see so many patients getting cured and returning to their homes. Why don't you come back? We assure you none of us will feel embarrassed of your presence. Neither will we or our children make you feel embarrassed. I am sure in Bombay, plastic surgeons will correct deformities of your nose. Even your eyes could be put back in good shape. Please write to us of your plans to return home. We shall come and bring you back."

Mohammed Raffi has been getting such letters from his nephew with increased frequency in recent months. Still, he had opted to remain here as an inmate of the Colony in a 8'x10' makeshift hut. Every Friday he is seen in front of the Mosque. Routinely a few chosen families give him "alms" adequate for the week.

One has to go and see how clean he lives; and how clean he has kept his hut. He eats well, drinks enough milk. Prays regularly five times a day. What's it that prevents him from returning home? Or what's it that holds him back at the "Colony"?

Mohammed Raffi's problem is, indeed, confounding. Social organisations interested in rehabilitation work tend to look upon the problem as one involving "Relief" to those who are drowned in despair and destitution. It is like fighting fire by bringing in Fire Tenders. More challenging job in leprosy is prevention of seeds of hopelessness from germinating. Leprosy patients suffer real shock when they are diagnosed as leprosy cases. The patient rejects himself. Social acceptance at this stage can neutralise the sense of dejection. Mohammed Raffi's reluctance to return home highlights the permanent character of shock he received in early stages. Social organisations may have to change the focus of their rehabilitation work to one which has basically preventive overtones; and which begins with the first shock the patient suffers at the diagnostet stage.

Doctors, also, can play an important role in protecting the patient from such early stage psychological devastation. They have not fully appreciated the fact that before taking anti-bacterial measures they have to guard against possible fall out from social and psychological factors. Leprosy treatment is not a patient centred clinical phenomenon. It involves shaping of social environment which is in close proximity to the 'person' in the patient.

The workers of the Bhilai Mahila Samaj Gloves Production Unit were asked whether they would like to work along with leprosy-cured patients in their Unit. They unanimously responded in the affirmative. Unfortunately the definition of leprosy "cured" persons as given by medical science and as believed and accepted by the society differs. This difference will persist so long as non-patient groups do not come forward and accept "cured" patients as co-workers at work places.

When a person with leprosy history ceases to be an "infectivity risk" to others, he or she should remain as welcome in work-groups as any other person without such history.

Real problem in such mixed-group work situations would be not so much the reservations of non-patients, as the feelings of social awkwardness experienced internally by the persons with leprosy history. Mohammed Raffi's is not a solitary case. It represents a generality. Unless deliberate efforts are made by socially conscious persons to promote "mixed-group" work, it is unrealistic to expect Raffi to return home.

was devoid of unsound beliefs, socially hurting prejudices, and selfishly protective social behaviours. In effect devoid of such behaviours which denied self-respect, dignity, and freedom of action to the persons with leprosy history.

The 4th April Marathon emerged more out of a conceptual state. But the arms stretched for the open embrace by the non-patient community, perhaps, remained a reality of permanence. Options before persons with leprosy history were clear. Either to welcome the gesture of 'embrace' and seek a breakthrough in the social isolation; or to perpetuate the agonising state of ignoble existence.

It was, however, difficult for them to suddenly pull asunder the early cobwebs of feelings of social awkwardness; and to ignore the fears of ever hanging threats of possible onslaught of disabilities. More particularly because the latter were independent of bacterial activity. Was it at all safe for this group, then, to reveal their patient identity mid-stream; and risk social prospects of their families? Even the organisers of the Marathon did not have clear answers. The answers depended on depth dimensions of the 'embrace'. Its spillover on other social practices. Persons with leprosy history were really put on the horns of a dilemma. Whether to reveal the patient identity and face unclear future or to conceal it and perpetuate the isolated, ignoble existence.

The dilemma surfaced aptly when one smart aspiring young man, one M.B Case on the treatment register, came forward to join the marathon. He was full of hope of winning the prize announced for the fast runners. "I shall run and win the prize. I am sure... But nobody known to me should be seen around ... Or else give me a non-patient Blue Badge", the young man implored. It was obvious! He kept away from the marathon.

The smart young man's hesitations were characteristic of all those strong and sturdy amongst the patient community who easily passed off as non-patients in the eyes of the Society. Originally the organisers of the marathon had anticipated sure participation by at least 500 from this group, against a possible participation of 1500 strong normal (non-patient) group. But on the marathon day only 300 showed up from the patient group as against over 2000 from the latter. Even to get these 300 was a herculean task for the organisers. More than 50 per cent of them came from the countryside of the two neighbouring districts. The fact that at least 100 came from the township, may be considered a major achievement. To reveal one's patient identity in front of a familiar group was, indeed, a difficult proposition. But that there were persons with leprosy history who either had lesser or no hesitations in revealing their patient identity in front of local social groups are-a data of great significance.

Revealing patient identity was particularly problematic with women. Very few from the township participated. Sale proceeds from the Red and Green ribboned badges did not provide data on sex composition of the participants.

In striking contrast the patient group that came from Dongargarh, traversing a distance of about 100 km., presented a more encouraging picture. 19 were women out of the 62 persons who participated. Only 7 were PB cases and 2 were with RFT classification; 23 had MB classification to their credit. The group traversed the distance in a chartered bus, subscribing to the commuting charges on an average @ Rs. 10/- per person. The diesel costs (approx. Rs. 360/-) were donated by a local philanthropist. How this group would have behaved in front of local social groups in their respective areas can only be an inference at this stage. But the fact that they came by paying for their journey, is a sufficient indicator of their level of motivation and also of the depth of the fieldworkers' rapport with the patient community.

Any attempt to draw conclusions by comparing the two sets of participatory performances will not serve any purpose. It would be inappropriate too. The purpose that this data can best serve is to reinforce two sets of conclusions. One: developing openness in social behaviours of such persons with leprosy history but without any outward identifiable marks, is possible. Two: openness blossoms easily, when confronted with stranger groups.

Whether "openness" can be depended upon as an effective tool for reducing stigmatisation is a question that can be examined through assessing outcomes in Bhilai. The "Solidarity-Run", indeed, administered a forceful push in favour of 'open' relationships. between the two components—the persons with leprosy history and the normal (non-patient) civilians. The bold action on part of the non-patient participants did receive social appreciation in a broad sense. The marathon participants, though were not hailed as heroes, did not receive scant attention either. None criticised them. They generated enough curiosity even during the preparatory stage. Maybe because of the element of novelty. But the post-marathon period stir-up witnessed in the social environ of the town gave sufficient proof of the seriousness with which this novel idea of influencing social behaviours of an urban community was received. The unending stream of group dialogues that followed this event and spilled into subsequent weeks, came handy as an effective tool of action-oriented community education.

During the course of these discussions, scope for action was earnestly explored. It was on the basis of suggestions received during the course of these dialogues only the "16 point" handout titled "What Can We Do for the Afflicted Ones?" was evolved. This handout was improved upon subsequently. The improved version became the launching pad for the 'Rupee for New Life Drive' in the third week of the Aarohan Programme. These explorations in 'action' avenues for participation, were of immense significance to Leprosy Eradication Prorgamme. It was these action avenues that carved out a wide variety of Roles for individuals as well as for the community.

The patients who comprised the 300 strong group in the marathon, similarly can play important roles. They can function as shock absorbers for fresh cases. They can serve as harbingers in getting across mixed-group work opportunities. They can also function as vital links in developing patient-to-patient communication through granting a cherishable identity to the total patient community. Can we hopefully develop around them a respect evoking identity? A challenging task, indeed!

Exhibit

Forward with "Acceptance" ... and Down with "Incongruities"*

Rupee For New Life A Gesture in Mutual Redemption

The Rupee you are contributing means much more than money. It is a token of appreciation of the social problems which a Leprosy Patient encounters from day one. Your Rupee signals your desire to restore to him respectable socio-economic existance; and to arrest his drift towards despair and dejection.

Your Rupee is not expendable. It will be utilised as recoverable revolving fund, as "seed money" meant for rotational use.

Your Rupee will be utilised to promote early stage supports to leprosy afflicted persons through restoration of respectful work-life at multiple points in diverse areas of economic activity. More particularly for creating "mixed-group" work opportunities which will match with handicapped skills/capabilities.

The work opportunities so created will be for mixed groups of leprosy afflicted and non-afflicted persons outside the four walls of leprosy colonies.

Your Rupee remains in safe, credible hands. It will be deposited in the Bank Account to be operated under joint signatures of the Chairman and the General Secretary.

While making your Rupee-contribution, please tickmark on the counterfoil in the Receipt Book your willingness to participate in any of the programmes listed under "Aacharan" list "A".

AACHARAN LIST

1. Support for School Going Children of Deformed Leprosy Patients	2. Financial Help to Patients Under Surgical Treatment	3. Absorption in Mixed-up Group Based Work-Life Based Work-Life	4. Social Acceptance	5. Time Donation
a. I would like to offer scholarship.	a. I would like to donate with Corrective Surgery Fees for for Leprosy afflicted persons.	a. I would like to offer apprentice training to but disabled leprosy afflicted persons.	a. I would have no hesitation in purchasing products produced or sold by disabled persons.	a. I would like to: Extend warath and affection to Hsopitalised by visiting them with flowers or fruits during visiting hours.
b. I would like to pay School Fees and School Uniforms.	b. I would like to mobilise small donors, who would together contribute towards operation fees of a deserving Leprosy Patient.	b. I would like to accept cured persons for work in my garden/ workshop/home.	b. I would not object to cured/deformed leprosy afflicted person staying in my Neighbourhood.	b. Offer at least two hours for interviewing hospitalised patients to develop patient case-studies.
c. I would like to adopt a promising boy/girl to facilitate his/her growth.	c. I would like to mobilise small contributors from my friends' circle/neighbourhood who would jointly offer to feed patients in 'Self-Care' Camps.	c. I would have no a 'cured' but disabled leprosy afflicted person. leprosy afficed person.	c. I would like to massage patients in 'Self-Care' Camps.	c. Give one day in a month towards removing misconceptions about leprosy through collecting Case Histories of patients where presence of one MB Case in the family did not spread infection to other members;

1. Support for School Going Children of Deformed Leprosy Patients	2. Financial Help to Patients Under Surgical Treatment	3. Absorption in Mixed-up Group Based Work-Life Based Work-Life	4. Social Acceptance	5. **Time Donation**
	d. I would like to contribute towards the cost of MCR protective chappals (approx. Rs. 50/- for preventing ulcer.		d. I would like to adopt a person with damaged nerves to promote regular practice of 'Self-Care'	d **Cases of persons with leprosy history and physical handicap was accommodated in the work group by other non-patient co-workers;**
	e. Provide goggles with tinted lenses for eye-affected patients. (About Rs. 50/-)		e. I would like to encourage marriages of young boys and girls who are unscathed by the disease but family, through either attending their wedding or by inviting them for dinner.	e. **Person with leprosy hisotory who bravely fought his battle against the disease successfully and led a life which earned for him a circle of vocal admierrs.**
	f. I would like to provide adaptive tools for avoiding injuries to anaestic fingers.			

You may also like to tickmark on the middle slip in the Receipt Book any of the five social behaviour from "Visarjan". List "B" indicating your determination to part company with your past practices.

"VISARJAN" List "B"
Since I know that:

- Leprosy does not spread either through skin to skin contacts or through heredity;
- Leprosy does not affect 98% of the population;
- Patients taking regular treatment do not transmit the disease to others;
- Deformity or disability is not indicative of active disease but of presence of anaesthesia or nerve paralysis;
- Leprosy afflicted persons with Begging Bowls are perpetuating Social Stigma;

I consider it my bounden duty to give up:

1 My early practice of giving "Alms" to beggars who sit in front of places of worship.
2 My reservations about my children studying and playing along with children of leprosy patients.
3 My objections to working alongwith persons with clawing hands or absorbed fingers.
4 My early objection to non-infectious leprosy persons being admitted to General Wards in Hospitals.
5 My early hesitations in eating and drinking in the company or cured leprosy persons.

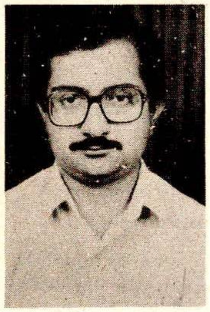
SAMAGRA PRAYAS AAROHAN SIMITI

S. Balkrishnan,
DGM, BSP
Chairman

Dr B.P. Mukherjee
C.H.O. Bhilai
General Secretary

7. New life for whom

Ajaykant Bhatt — Vijay Bhatt



Asst. Chemist
R.C. Lab.
BSP
Bhilai

It was Saturday evening. Samiti Organisers were discussing amongst themselves, next day's volunteers' meet — which was convened to consider organisational details of the 4th and last week's 'Aarohan' Programme. The 'Week' was devoted to a novel Drive titled 'A Rupee For New Life'. Gayatri Shakti Peeth Hall soon started flooding with people—men, women and children. That was the day, two weeks of activities centred around 'Self-Care' camp, were coming to a close. We had put up a small poster — exhibition on leprosy in the interest of the anticipated large gathering of the people.

Looking at the response from people to this exhibition, one of our colleagues remarked: "Why didn't we put up such exhibitions in crowded places like sector VI market, earlier? ... It's so informative."

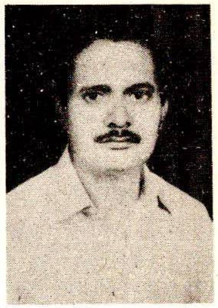
"Are we out to spread 'information' ... or to promote 'action'?" Another colleague who was a sceptic about such exhibitions questioned.

"How do you expect people to 'act' without information and knowledge?"

"Come on tell me: What 'action' you expect from these people, who will go back home well informed?" The sceptic continued.

"Well! Not to get scared when something like leprosy appears ... To approach a doctor boldly, when in doubt!" Prompt came the response.

The Sceptic burst out with laughter and remarked: "That's the paradox in leprosy!"



Raw Material
Inspector RMP
BSP
Bhilai.

Indeed, that's the dilemma promoters of 'knowledge' get lost in. What is logically sound and plausible does not turn out to be so. The scare is deep rooted. You cannot keep away the scare of 'ghost' haunting the child's mind by exposing the child to some pep talk which seeks to prove ghost as a mystical notion. While simultaneously not preventing exposure of the child to ghost stories, day in and day out. Scare of ghost can be effectively exorcised by leading a children's march into a place haunted by ghost in the public eye. The 'scare' about leprosy is in no way different. In leprosy only two amongst the 100 would have had reason to approach the doctor, the rest 98 vie with each other in spreading 'ghost' like myths about the disease which cause devastating scares. There was no other way to counteract such scare (which has its origin in overconcerns for self-preservation) except to storm the citadel of the very sources of the fear.

In Bhilai we just stormed the fountain source of the myth called 'infectivity risk'; and stole a march on it by putting in the vanguard the 'risk-subjects'—the '98 percents'. The 'Marchers' raised a warcry 'Action', not 'Exhortations'. Scope of several actions was examined through face to face dialogues. A wide variety of groups in the town participated in these dialogues. Two separate lists of action steps were developed — the "Aacharan list" and the "Visarjan list". Together these promoted a new understanding not so much about the disease but about the plight of the victims of the disease. The 'Actions' that were proposed were focussed on the problems of the patients. Problems largely created not by bacteria or anaesthesia, but by the'98 percents'.

We had an ambitious plan. We wanted to reach with the 'Aacharan' and 'Visarjan' lists, as many as 50,000 people — approximately 10 per cent of the town's population. They were to exercise their 'choice'. The job was to be accomplished just in two days. It was a response seeking job. Meet a person. Listen to what he has to say. Enter into dialogue. We were to be opinionless. We were never to argue. Never to impose on the person approached, our point of view. We were attempting a novel way of opening a communication. The terminal point of which was 'action'. We wanted to understand on which of the problems of leprosy patients, the other person thinks he can act. There was no scope for thought which did not end in action.

We anticipated that one volunteer would cover a maximum of 50 respondents in two days. The programme thus created a demand for 1,000 volunteers. Twenty organisers were to mobilise such large volunteer strength.

However, what we could actually accomplish was hardly one fourth of this gigantic organisational feat. Not all volunteers covered the response data properly. It appeared the volunteers who could not get tuned to our way of thinking, almost converted the entire 'mass-contact exercise' into a 'Rupee Collection Drive'. What was feared, thus, came true.

In all fairness it must be granted that at least some of the organisers did not either falter or deviate from the original blue-prints. The response they got covered a wide range of reactions. At one extreme they received blunt negative reactions like: "We don't believe in this nonsense!" "We have no time". "It's all a waste of time and effort". "It's all tom-foolery!" Such varied reactions, also, came our way. But they were only a few.

Responses came forth seriously where we had personal relationship with the person approached. Some responded negatively, some positively. But in their intentions, both were genuine. What they could not understand was our insistance on 'Only One Rupee'. "Why not ten or twentyfive?" They asked.

Irony crowned this momentous 'push' on community education. In the 'audit' session on the last day. By and large we indulged in assessing our performance in terms of money earned; and not by the quality and character of the feedback that we received from the community. A feedback which in turn had created demand on our energies to convert these responses into live channels to promote 'in-group-absorption' of persons with leprosy history.

The caselet 'Return of the Prodigal Son' speaks enough and answers the poser: "Who Needs New Life?"

Mohan's embarassment

Mohan must have been hardly 15. He was studying in 10th class in a local government school. His father, Abhimanyu, had been suffering from leprosy for the past many years. That way Mohan was born as son of a leprosy patient. The family was part of the Shardapara Leprosy Colony (Bhilai) now. Though it was being settled since 1958 onward on barren land adjacent to a grave yard. With pressure on space typical of any urban settlements, it has become part and parcel of the new town. In 1981 a 6 ft. high wall had skirted the settlement. None knew who was being protected by the wall! Still murkier was the issue: what treasure was really being protected!!

I was engaged in discussions with Abhimanyu. We were sitting in the open in front of the house of one of the early founders of this self-settled colony. Abhimanyu almost lost his temper at me in response to one of my queries: "Why can't you give up begging? I understand your crippled limbs have handicapped your work life". For a while I paused. I could see anger on Abhimanyu's face, with no sign of abatement. Once again I continued: "Tell me are you prepared to operate one of those Cycle Stands in front of the Cinema House? ... That'll take care of your bread."

"It's not only break!" Losing his cool once again, Abhimanyu almost shouted at me. "My three children are studying. Who pays for their fees? It's easy to run down beggary! ... Difficult to face life as I've faced!" He looked into my eyes with contempt pouring out from his face. "See this boy, I am anxiously waiting for his return from school. Was it not me who saw their education?"

As Mohan reached the spot where we were sitting, Abhimanyu showed his inclination to go home leaving our discussions half-way through. I insisted and made him stay on.

Initially Abhimanyu had lost his cool with me because I had brought a fruit loader's job offer for his able bodied non-patient companion—Dukhiram—who helped him draw his "push cart" on the daily begging errands. On an average they earned between Rs. 50/- and 60/- a day. These earning were shared equally, between the two.

Dukhiram had already rejected my piece-rate based job offer saying: "What happens when there's no work or less work? I suffer, don't I?", he had asked. "I better continue with Abhimanyu!" Saying this Dukhiram had left the scene.

Mohan by now had reached closer. I asked Mohan to come and sit in front of me. As he sat, I asked him: "Beta, don't your friends at the school ask you about your father? ... about what he is doing?"

"Sometimes they do!"

"Then what do you tell them? ... They must be asking how your father earns his living?"

Mohan hung down his head and started running his finger through the soil on the ground. When I repeated my question, still keeping his head down he said: "Without saying anything I get up and go elsewhere. I've avoided replying to this query all these years." Mohan's voice was choked as he uttered the last words.

Sensing the internal disturbance Mohan was facing, I looked at Abhimanyu once again rather piercingly. Turning to Mohan I asked: "Mohan, you tell me: are you good in your studies at school?"

He looked up and affirmatively nodded his head.

Encouraged by this response, I asked: "Come on tell me! What you want to be in your life?" There was a total silence. All those 15-20 inmates of the colony who were sitting by our side also observed total silence. They were anxious to hear what Mohan had to say.

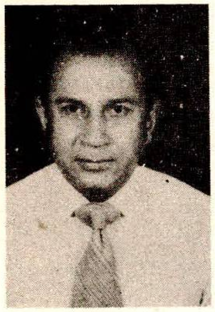
"I want to study Computers!" Mohan broke the silence.

Everyone around looked at each other in utter consternation.

As I patted Mohan with considerable warmth, I looked in the direction where Abhimanyu had parked himself. But, alas! He had already left the place.

8. Stainless steel tumblers

Arun Gupta and Mrs Illa Dutta



Dy. Manager
Sports & Recreation Council
Bhilai Steel Plant
and Member, SPAS
Bhilai.

Bhilai made history during Samagra Prayas Aarohan Samaroh largely because of the heart-warming response received from several social, cultural and religious organisations of the Town. We were in search of a suitable place to hold the two-week long Residential Self-Care Practice-Demonstration Camp. We required a place which was clean, central, frequented by people, adequately accommodious and also available for round the clock use spanning over a fortnight. Various possible sites and proposals were being examined.

A suggestion came forth about the Hall belonging to Gayatree Shakti Peeth Trust. We thought the place was ideally suited for the purpose. However, some of us were apprehensive of the likely response from the Management of the Trust. It was our experience so far that places generally used for marriage ceremonies remained beyond our reach for holding functions which involved leprosy patients.

Last year in Dongargarh, a town known for its philanthropic traditions, a famous Community Trust refused to hire out even its utensils for the use of campers whose ranks avowedly included leprosy patients. In fact, we were desirous of hiring from the Trust about 150 stainless steel tumblers for ten days. The Trustees who were highly appreciative of the noble cause for which these were required, expressed their helplessness in hiring out utensils from the Trust's stores. They apprehended strong, adverse reactions from their clients, if tumblers used by leprosy patients were re-mixed with total inventories of utensils used by marriage parties. Alternatively they offered to collect contributions and donate newly purchased 150 stainless steel tumblers to the patients on take home basis.

The proposition remained unacceptable to the Organisers of the Camp, even though what they would have spent on hiring charges came to about 20 per cent of the cost of the tumblers.

With this Dongargarh experience at the back of our minds, we decided to approach the Gayatree Shakti Peeth Trust only for provision of accommodation; and not for any of the Trust's utensils. Some of us, however, had questioned the appropriateness of this decision which meant submission to responses which were segregatory in the ultimate analysis.

The Trust acceeded to our request for accommodation without any hesitation. May be they were aware of the debate that had preceded, in our organisational committee meeting earlier. Our request covered only accommodation.

The 'Self-Care' Camp was primarily directed toward practice demonstration of simple, easy to practice methods of preventing and arresting deformities in leprosy patients. On the first day the group of about 60 campers were received by the Trust Management with beaming faces and folded hands. We were rather taken aback by such warm reception, despite the fact that our group inluded 14 men and 21 women with obvious signs of deformities.

We hardly realised then that more surprises were in the waiting. At the strike of lunch hour as we

Social worker
Bhilai

were busy washing the 'Pattals' and 'Donas' (makeshift dinner plates and bowls made out of tree leaves), the Trust Manager opened the store room and brought out an array of stainless steel utensils. These included the 'Stainless Steel Tumblers' as well. He asked how many did we need. Drinking water tumblers, small bowls for serving dal, and dinner plates. "We have all stainless sets", he said and counted sixty pieces of each category for handing these over to the camp organisers. "Use these as long as you are here... Keep in safe custody and return only when your camp is over", said the Manager. "One of our volunteers will stay with you all through, to look after your needs and comforts. Please don't hesitate ... he is there to serve you", he added. These surprises, one after the other, ushered in a new wave of enthusiasm amongst the camp organisers.

But this did not deter them from introducing a practice of not mixing the utensils used by patients with the ones used by the System Workers. Patients were asked to keep their utensils in their own personal custody. Only the utensils used by the workers and organisers were pooled together after use.

There were critical comments on this subtle discriminatory practice.

This practice had to be discontinued during the second week of the Camp, as a sequal to the debate that raged amongst us throughout the week. Next week saw pooling of all utensils. This resulted in more scruplous monitoring of utensil cleaning practices.

Nonetheless certain other subtle reservations in inter-mixing with patients, did creep in. We are sure these could not have escaped a keen observer's critical eye. Joining the lunch in second shift — after the patients finished their eating. Opting to join the 'Serving Batch' rather than sitting with patients and eating with them. Sitting in separate rows under the pretext of non-availability of space in the patients rows. Practically all of us were guilty of avoiding unreserved intermixing with patients during lunch and dinner sessions. Unlike other camps in rural areas our eating-place behaviours here reflected more of hesitancies and reservations than warmth and understanding. Indeed, these behaviours had nothing to do with either 'rural' or 'urban' settings. It was a product of laxity shown in practising the 'stay together' character of the camp.

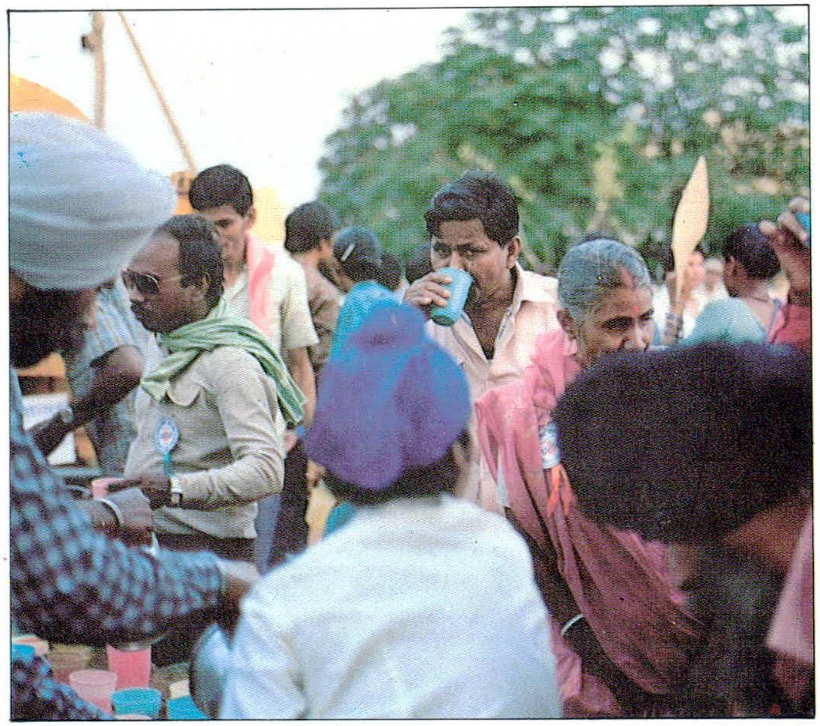
Despite such managerial shortcomings, operation of the "Camp" from the central place like 'Shakti Peeth' turned out a powerful medium of community education for social action. Besides exploding the myth of infectivity, the camp practicals for the first time, highlighted the preventive-action dimensions of deformity/disability control which the patient and his well-wishers could act upon easily. No wonder the concluding day witnessed intermixing extravaganza. About 500 to 600 socialites, both men and women who ostensibly were attending a prize-distribution ceremony, joined the campers in the evening hours and intermingled with the patients without reservations.

A large number of social and cultural organisations of the town had come forward earlier to express their solidarity with the cause, by offering to make cost-free feeding arrangement for the campers. The response was rather overwhelming. Not all those willed to extend their hand could be accommodated within the restricted schedule of 12 days. List of the organisations who thus participated is given below:

Programme of cost-free feeding arrangements by Socio-Cultural & Religious Organisations. Location—Gayatri Shakti Peeth, Sector-6, Bhilai

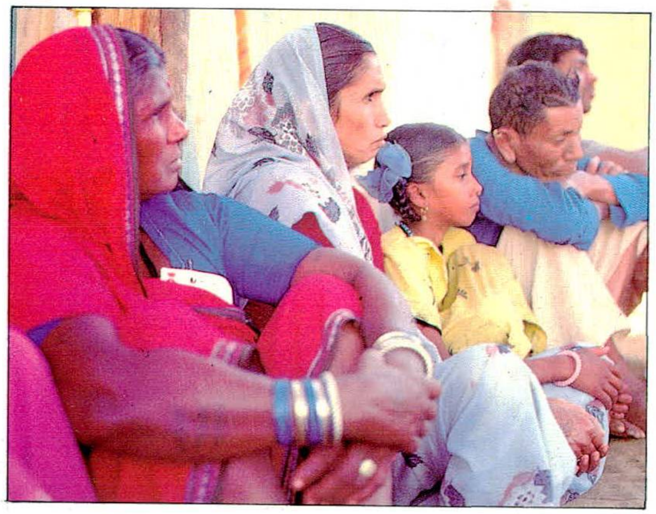
11.4.88	Sanatan Dharma Sabha	— Breakfast; Lunch; Dinner
12.4.88	Mantri Stores, Sector IV	— Breakfast
12.4.88	Smt. Ranu Chatterjee	— Lunch
12.4.88	Shri S.L. Soni	— Dinner
13.4.88	Bhilai Nagar Kalibari	— Breakfast; Lunch; Dinner
14.4.88	I.N.T.U.C., Bhilai	— Breakfast; Lunch; Dinner
15.4.88	Adarsh Sanskritik Mandal	— Breakfast; Lunch; Dinner
16.4.88	Gayatri Shakti Peeth	— Breakfast; Lunch; Dinner
18.4.88	Classical Club	— Breakfast; Lunch
18.4.88	Jan Kalyan Samiti, Maroda	— Dinner
19.4.88	Roman Catholic Church	— Breakfast; Lunch; Dinner
20.4.88	Malbi Nagar, Durg	— Breakfast
20.4.88	Guru Singh Sewa	— Lunch; Dinner
21.4.88	Sangam Dairy	— Breakfast; Lunch; Dinner
22.4.88	Baba Saheb Ambedkar Samiti	— Breakfast; Lunch; Dinner
23.4.88	Uttar Bharat Kalyan Samiti & Maharaj Surajmal Samiti	— Breakfast; Lunch; Dinner

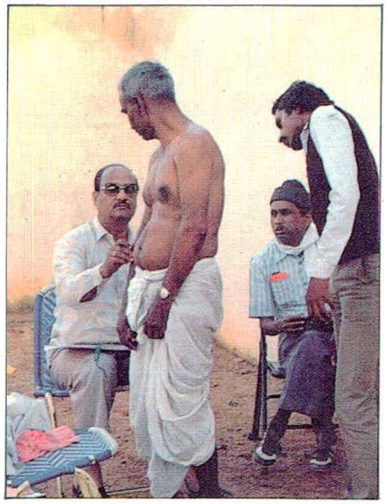
Some of these organisations additionally offered to pay for medicines to leprosy patients. The Satsang has expressed a desire to adopt students of leprosy patients; and even to assist their parents in organising marriage functions of their daughters. On condition that no dowry transactions were involved. The local Roman Catholic Church welcomed requests for MCR Chappals and Goggles for lagophthalmos patients. There were some offers from individual members as well. These included space for installation of Stalls and provision of light work for cured leprosy patients as Gardeners and household servants.



Zeroing Distances

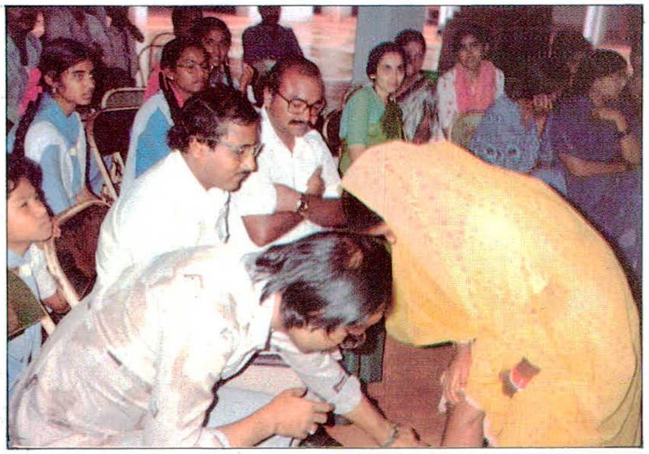
Children's imagery? Beggar in Push-Cart syndrome ! Bhilai beamed new messages ... Compassion, Charity ... old hat now! Re-examine prejudices, instead. Stretch out helping hand in a gesture of mutual redemption!

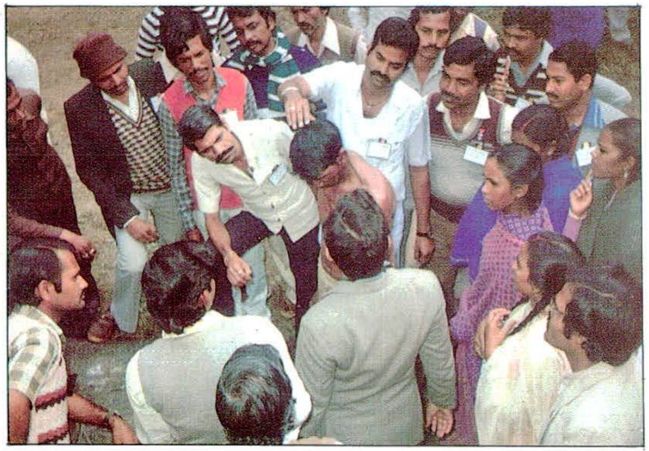




Idealising “Endeavour”

Arousal of man's positive self-concept in relation to his social environment remained the central theme in training for attitudinal change. Freedom to learn through explorations and exchange of experiences with other members of the group while examining 'Live Cases', became handy tool for self-learning. Acceptance tempered with expectations became the strategy for promoting responsive endeavour.

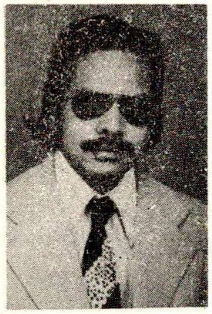




9. Nursing the group identity: critical factor in leprosy patient care

T.S. Natarajan

Former Programme Officer Health Education DANLEP



I had the privilege of participating in the preparatories of Mel-Jol Doud — the Solidarity Run in Bhilai during April last. The Bhilai programme represented a step by step build-up of 'mixed-group-techniques' of 'patient care'. These techniques and methods were tried and tested earlier in a rural setting in Madhya Pradesh, since March 1987. Underlying these new methods was a basic premise: "Unlike in other general health care practices only patient or patient-family centred and medicare oriented 'clinical' methods and approaches, have inherent limitations in promoting 'Patient Care' in leprosy. Here 'patient care' remained intricately interwoven with the three 'arms' of the 'Care Triangle' viz. the 'patient and his family'; the 'value-infuser'; and the 'treatment provider'. While initiating these 'mixed-group-techniques' we had further assumed that the quality and character of 'patient care' in leprosy depended on the quality and character of the 'interaction' that emerged in the local communities between these 'three arms'."

> ***Never have we cared to view the Health Educator Role as facilitator for reviving, and restoring such communication between the 'patients' and the 'valve infusers'....***

Conventionally the provider system has tended to view the 'patient' and 'treatment-provider' interactions as purely bilateral phenomenon. Secondly, it had erred in considering the 'third arm' (the 'value-infuser') as an adjunct which called for dealings independent of medicare programming. The 'value-infuser' component was never recognised as a critical and powerful medium for reaching effective medicine to the patient.

A third lacuna in conventional thinking related to strategic appreciation of stigma. Unlike the common belief, social stigma represented not so much a prejudice or distortion of facts, as an utter break down of inter-group communication between the 'patients' and the 'value infusers'. Rarely has it been realised that restoring or reviving channels of inter-group communication between these two components was as critical to 'patient care' as to developing suspicion-free or scare-free social existence for the non-patient community. Never have we cared to view the Health Educator Role as Facilitator for reviving and restoring such communication between the 'patients' and the 'value infusers' in the society. Instead we appreciated this role as one of message-giver' or 'educator'.

Blue Prints of social action in Bhilai projected a major sweep away from these conventional formulations. Instead it was aimed at reviving such 'patient' — 'value-infuser' inter-communication as a major task. The almost total isolation of conventional and operative character of medicare-based intervention in the community, was made possible in Bhilai mainly because of the radical definition of 'infectivity-risk-free' person with leprosy history. Such isolation, though notional, helped put the 'value-infuser' in a key reverse role. And a fair trial could be given to the influence of restored communication.

The 'social stigma' indeed, needs to be appreciated primarily as breakdown of such communication. In its ultimate analysis, social stigma does not as much represent want of knowledge as it connotes absence of 'understanding'. Here 'understanding' presupposes recognition to 'identity' and an effort at satisfaction of the 'identity' needs. Identity helps one audit one's worth in terms of socially significant role which has a worth by and large in the eyes of others. It remains a satisfying experience when the cues one receives from others remain congruent to one's own estimation. This is exactly what happened to Ramchand — one of the four cases appended to this write-up. His close circle of friends fondly called him "Thudda Ramchand" (a person devoid of toes and fingers). But to himself he was 'complete man'. We have also to realise the nature of the identity problem which the patient in leprosy confronts; and its import to patient care. Identity for a leprosy patient has a dual view· as viewed by the patient himself and as appreciated by the social setting around. Significance of identity lies in the mutuality of its appreciation.

More often than not, the patient himself remains a willing party to destruction of his identity in the context of this mutuality. Ignoble docility of the patient manifests this phenomenon of self-destruction. How identity restoration helps patient care is amply illustrated by the 4th case — Mantora Bai.

The docility in this sense is wilful because of feelings of guilt which overpower the patient. The guilt not so much on account of notions of 'curse' or 'sin', but because of an awareness of himself being a party to inflicting the curse earlier on other patients when he was not a patient. The hangover of old beliefs and such belief ridden behaviours persist even after a change to patient status.

The patient—non-patient hand-in-hand Solidarity Run of 4th April in Bhilai, was a landmark development . It formed part of a long chain of measures aimed at solidarity—solidarity through understanding of mutuality of strengths. Once again 'understanding' presupposes restoration of vital communication. These measures were earlier initiated at Dongargarh in March, 1987. I was actively associated with these initiations then.

The 'identity awareness' which is considered critical to promotion of intergroup communications between the 'patient' and the 'value-infuser' in the society, should not be mistaken with commonly present reluctance amongst patients to reveal their disease status of leprosy, which we call 'patient identity'. These are diametrically opposite psychological states. Whereas the former connotes innate priding on socially meaningful role-based strengths, the latter speaks for 'shying' about a state, which is considered demeaning or undesirable.

The phenomenon of 'innate priding' on strengths which I am talking about need not be considered as relevant only to individuals. It can be equally or even more relevant to groups. We have always wondered if there is anything like group priding involved or possible for a leprosy patient. We should realise that suppressed or oppressed priding often gives rise to sharpening of needs of group identities. Similarly, one Ramchand giving fight worthy of humans, justifying human existence, provides enough sustenance to group priding if only it remains on communication line. One of the four cases appended to this write-up, viz. 'Sabdi Bai' forcefully underlines group centred identity awareness.

I am told that in the village where 'Sabdi Bai' incident took place is not a solitary place. The non-patient community's gestures of solidarity in the villages around have gone far beyond the 'bucket' and the 'laddle', extalled in Sabdi Bai's. In recent months on pulse dates the villagers have been treating the patients with tea and some light snacks.

In my view the Marathon Run in Bhilai created heavy demands on both 'individual' as well as 'group-centred' identities. One young man (a M.B. case) drew considerable attention from the Field Workers. He was a seasoned athlete—a 'fast-runner'. He was confident of winning the Fast-Runner Prize announced by the Marathon Organisers. But he was in the midst of an acute identity crisis. He made his participation in the Marathon conditional. "None of my close acquaintances should be on the scene of the Track; and I will not wear patient identification (Red Ribboned) Badge", he insisted. He was, however, prepared to run in a Race, in front of a 'stranger' group even with the 'Patient Badge'. It is worth noting that this young man had no physical marks on his body which revealed his patient identity. And yet he was conscious of the need to hide it. So overpowering was the impact on his mind of the devastating character of his own imagery of the disease. He was not aware of the fact that the wide acclaim from his 'fast runner' prize could have overshadowed his patient identity. He had also not stretched his imagination to understand that the din of applause and the glory of the 'prize', would have dazzled even the critical or punitive eye of his own close social groups whom he was hell bent on avoiding.

No wonder on the Marathon day young man chose to keep away from the Race Track.

The only flicker of hope that we could see in this case was his preparedness to run the race in front of a 'stranger' group. This response constitutes significant data. Why underestimate the impact of acclaim even if it flows from a stranger group? Who knows, even the 'stranger-group-acclaim' might have opened vital communications with the 'known-social-group'?

What critical roles, the Treatment Providers — the Field workers-can play in reviving and restoring the vital channels of inter-group-communications between the 'patient' and the value-infuser' was quite convincingly demonstrated in Dongargarh, more particularly in Puraina. Equally convincing has been the quality of Patient Care that the communication restoration processes have unshered in. Besides bringing forth the highest ever rates of fresh-case-reportings, the proportion of 'patient' and 'value-infuser-influenced' reportings has reahced as high as 97 per cent. Shri Nehru Sharma and Jitendra Kalchuri have extensively reported elsewhere (pp) the quality of patient care that has made this a ruling reality.

The Aarohan (Step-up) programme in Bhilai provided a new edge to the communication restoration function. Here the conventional 'Treatment Providers' played secondary roles, leaving the major task of restoration of inter-group-communication to the 'value infusers' almost unilaterally, rather un-aided by conventionally practiced 'programmed medicare'.

This is a development of great significance to assessing scope of revival and restoration of inter-group-communication on a far wider scale. It indicates possibilities of linking de-stigmatisation processes and also concerns for Patient Care with spheres where 'medicare' is not called for. The Forces which will eradicate Social stigma in this sense, point towards a new possibility — a broad based social movement, responsibilities of which would be shouldered mainly by the 'value-infusers'.

Ramchand confronts his identity crisis in a forthright manner. In the process he derives considerable strength to 'stretch' and rise high. By any chance if his father had not thrown Ramchand out in the wilderness what course Ramchand's career would have taken is a hazardous guess.

Similarly in the second case, but for the stubborn fight that Janak Ram had put up against his neighbours and near relations, the teeth that 'Badi Maa's Care' acquired during the process, might not have been as biting; and the results as enduring.

Even the thunderous 'hit' of Sabdi Bai (in the third Case) at one of the patients, has provided as noble a setting to Seth's heart-warming gesture as one could have ever imagined. The gesture meant reassuring character of the desirable two-way help processes in leprosy. These provide the basis for inter-group communication.

The fourth case 'The Community Tank' unravels group dynamics in an overt form. It is centred around the issue of non-discriminatory use of a common tank for bathing by leprosy patients. To me it gives a clear message: scratch the surface of any problem in leprosy, you will find somewhere underneath 'group identities' engaged in action and reaction: whether overt or covert. Dig into them a bit deeper, release of communication becomes a reality.

Our experience of personal life tells us: priding identities break barriers to communication, so long as they do not turn malicious but remain authentic. Authentic messages are always received! Barricaded social communication causes hinderance to Patient Care.

9.1. Thudda Ramchand

Amita Prasher

Audio Visual Specialist
DANLEP
New Delhi

"Did you mark the difference in height? ... It's not just tall ... it's one and half times taller? ... Twenty years back my father literally threw me out from that house! ... My fault?... I had contacted leprosy." Ramchand's voice was surcharged with emotion. He was standing in the doorway with hands stretched across the door-frame. His brother who was not on talking terms either with him or his family, was standing in the other doorway barely ten feet away and was watching us with intense curiousity ...

"I constructed my house bit by bit with my own hands ..." raising both his hands and pinpointing his two digits-absorbed fingers of both his hands Ramchand took me towards the main entrance of his house. "You see this big door-frame? ... This was made with these hands! ... Fingers or no fingers! He started at me pouring out pride from his looks. I saw a sparkle in his eyes which sent across stirring messages of accomplishments.

Soon I went inside. Sat on a bench. Ramchand called his wife. As she came forward beaming he remarked: "She has been my contant companion through thick and thin... even in my carpentary work. I've never been left alone. Her father was a great help too. Like a solid rock he stood steadfast by my side. You know, this house stands on a piece of land earmarked for a garbage dump in my father's large courtyard? Thank heavens! I was thrown out within the court-yard. My mother who, too suffered from this disease was thrown out God knows where. The family does not know when and where she died."

None else in the family, either his three brothers, or their families who stayed just across this wall, ever contacted the disease. He stayed on in the father's family for over 5 years after initial doubts raised their head... Once it was confirmed as Leprosy he was mercilessly thrown out by his father in league with other brothers. He was married then.

It was Ramchand's father-in-law who took him to different Hospitals. Those were the days of unsure treatment. Ramchand wandered for years tossing between hospitals. Even Mission Hospitals were not spared. He wandered here, there, everywhere. Never giving up hope of recovery. His unflinching faith in himself, his acute sense of self respect and strong determination were his constant companions. Undaunted by loss of two digits of all fingers from both hands, almost total loss of toes and wet ulcers on feet, he set out to build a new life for his wife and the three daughters. His inner strength and a robust sense of self awareness were the sustaining forces in his life.

His daughters were married happily, thanks to his father-in-law's undaunted support. No one ever condemned them as diseased father's children. His grand-children preferred to stay with him, even though the daughters were married in distant villages. His social acceptability, according to him, was a product of his strong sense of determination to lead a respectable life. There never was any occasion when his close circle of friends felt awkward because of his presence. They would rather canvass for his carpentary skills and get him work. Fondly they called him: Thudda Ramchand.

His workplace always resounded with laughter and gossip of daily visitors. His friends coming and eating with his family was almost a regular feature. His grand-children moved about in the family unawares of anything amiss. They were fond of playing with him. Despite his other preoccupations, he would fondle them with utmost warmth, leaving his work aside.

Rickshaw with Badi Maa by his side. Janak Ram's wife nursed her religiously. Through careful nursing they prevented her anaesthetic hands and feet from developing ulcers. No wet wounds ever developed. For want of effective medicine, they could not effectively arrest the process of absorption of her fingers. With daily massage and bath they managed to keep her skin smooth like that of a child.

Children played and grew in her lap. Younger ones always preferred to sleep with Badi Maa in her bed. Such a large family of about 25-30 persons staying with a leprosy case and none contacting the disease was a strange phenomenon. Janak Ram always highlighted this fact whenever he talked to others about Badi Maa. He made everyone wonder and question the general belief about the spread of this disease.

But while trying to disprove the general belief, he never made any secret of early Leprosy history in Badi Maa's father's family. Her uncle, her sister and her nephew had leprosy.

Janak Ram, an ardent believer in regular treatment always contrasted total absence of transmission in his own family, with the spread history in Badi Maa's father's family. With great pride he would underline the scrupulous patient care which he and his wife unsparingly provided in his family right from the word 'go'. He thought he got deeply involved in Badi Maa's 'care' largely because of the challenge his relations and neighbours threw at him.

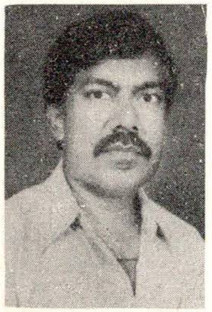
"Whenever I moved with Badi Maa to Dongargarh enroute to Baitalpur, people stared at us with sniding looks. But what they received in return were contemptious looks from me", concluded Janak Ram.

We sat together alongwith Badi Maa and sipped our tea.

While listening to Janak Ram I felt as though it was not a history of Badi Maa's care but that of the travails of Leprosy patients over past few decades. What I was not sure about was the motive force behind this 25 years long uninterrupted service. Was it his love for his Badi Maa, or his ebullient, unbending personality which was out to scoff at the humiliating social boycott clamped on the family by his relations and neighbours?

9.3 Sabdi Bai

Ram Lakhan Sahu



Para-Medical Worker
Dongargarh Town
Rajnandgaon LEU.

We are now reminded of a similar incident at village Musra DDP subsequently, on a Pulse date—24th of April, wherein identity concerns of the patients came to the surface. At Musra usually we distributed drugs at the PHC Sub-Centre located in that village. The woman Health Worker at the Sub-Centre was on leave that day. Her house was under lock and key. The house was our usual source of drinking water supply for the patients who swallowed drugs with a glass of water.

I asked a local woman patient why alternate arrangements were not made — if not from anywhere else, at least from her own house? Of course her house was a little far away.

Each one started gazing at other's face. 28 MB and 12 PB patients were present on the spot. None moved into action.

Sabdi Bai, the 52 year old MB patient who had reached there from her village about 3 km away, took initiative and asked Sukhi Ram—a male patient—to go and get water from the nearby Seth's house. Sabdi Bai was the self-appointed leader of Leprosy Patients from the villages covered by Musra DDP. She was herself a footdrop case. The fingers of her right hand had developed contractures.

At the command of Sabdi Bai, Sukhi Ram got up alright. But did not move. He was not sure if the Seth would oblige him with a bucket full of water; and also hand over a "lota" to drink the same.

Perturbed by Sukhi Ram's hesitations, Sabdi Bai thundered: "Persons like you have run down a leprosy patient's image. You are a disgrace on us. Let the Seth say 'No'. Why do you anticipate that?... You could've at least gone there and made a request?" She swung back and leaned against the trunk of the huge peepal tree in utter dejection. Her face was emitting fire.

Sukhi Ram was shaken by this outburst. He moved forward and approached the Seth. To his utter surprise the Seth brought forth not only a bucket full of water but also a lota and a stainless steel tumbler.

All took their medicine.

It was not for Sukhi Ram now to return the bucket. The Seth himself came forward to take it back. The Seth in this case was none other than Ganesh Agarwal who was on the forefront of a combined procession taken out in the village during the first-phase I.T. camp days in February. Perhaps the patients' memory had failed. But to Seth it was as unfading and green as ever.

Seeing Seth's gesture Sabdi Bai moved forward with a glint in her eyes. She felt doubly proud today. Her anticipation of community's response had come true. Her dejection at the unjustified lowly self-image, which was generally held close to their hearts by patients like Sukhi Ram, was well vindicated.

Vindication of her stand, apart, today she was proud and behaved like a leader, because she had brought with her a new MB case—a woman of 35—for treatment.

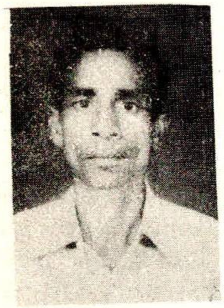
Whatever happened today caused no surprise to those who had known Sabdi Bai at the Camp. While at Cheepa Camp during the I.T. first phase, she had similarly thundered at Preet Ram who used to come to camp in the morning, take medicine and skip away till next morning. Preet Ram avoided staying with rest of the patients. While at Purena, she noticed Preet Ram at the drug distribution time. She called him and pronounced her punishment:

"No medicine, no food till you apologise for the tricks you played with the group at Cheepa; and agree to stay on at this Camp".

No need to say that Preet Ram stayed at the Camp. He remained on the forefront of the 'cleanliness' committee in his subsequent unreserved participation in the Camp life.

9.4 Mantora Bai

Udai Lal



Social Communicator
Khalari Village
Dhundhera Sector
Rajnandgaon—LCU.

Indeed a marked change has come about in the quality of the people's response to leprosy in the wake of the mixed-group-residential camps. Even in Khalari, a village which we generally consider as highly responsive, things were different before the camp. Khalari is about 2 kms. away from the nearest DDP.

Last year one Senior Officer visited this place in August. Because of rains, the village was not approachable by Jeep. As we walked, on the way we came across two small children — one boy and the other a girl. Both had patches on their body. These were fresh cases, not reported to LEU before. The girl's father was standing close by. We asked him whether he was aware of those patches on her body. He just laughed, indicating how did it matter! The visitor did not like the couldn't-care-less-attitude of the father. He even didn't know if the girl was going to school. The officer looked at me in utter surprise and asked: "Now tell me what will bring this girl under regular treatment? Your workers frequent this village. You say this is a good responsive village; and yet your system is not aware of the presence of these two cases."

I didn't have a straight answer.

Then I took the visitor to meet an old woman patient — Mantora Bai—who was in her fifties. She was a M.B. case and had discontinued her treatment in utter dejection much against the advice of Workers and village elders. From whatever reactions the Visitor had gathered so far from the villagers and myself it did not take him long to realise that Mantora Bai was a difficult person—not easy to handle. Her two sons had almost given her up as a gone case. They, too, had failed in their persuasive effort. Similarly her neighbours were quite unhappy about her non-cooperative and, at times, offending behaviour.

She was not clean either.

Here too, the visitor raised a pertinent question: "Do you really expect her to walk two kilometres to the DDP and collect her medicine when you start the MDT?"

It was a question to which there was no clear cut answer.

Mantora Bai is a changed person today. At first she joined the five day, first phase RIT Camp organised in her own village — Khalari in February. She developed an intense liking for the Camp life. She moved to Purena on her own steam, primarily because she liked the company of other patients; and also the cordial atmosphere that prevailed in the Camp.

She returned to Khalari after spending 8 days at Purena.

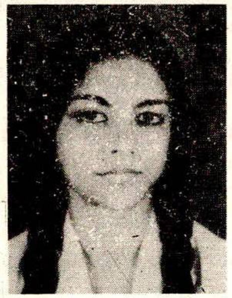
She was a totally changed person after Purena. She remained clean and moved closer to her two sons. They too liked her new responsive behaviour. No more irritating responses towards neighbours either. She moves out, visits neighbours' houses, spends time gossiping and has made herself socially acceptable. Her sons who had almost deserted her earlier, now take turns to take her to DDP on their bicycle.

On the 3rd 'pulse day' in April, both her sons were away. But then Mantora Bai didn't miss her 'pulse day' visit. One young boy of 17 from the neighbourhood took her on his bicycle to DDP; and she had her drugs.

Judging from the change that has taken over Mantora Bai, one starts wondering if 'Patient Care' in leprosy was at all an individual centred 'clinical' phenomenon — an affair between a doctor and a patient alone? The treatment and the response that came patient's way from the social environment around mattered most in materialising the 'Care'.

9.5 Return of the prodigal son

Runu Chatterjee



House Surgeon
Bhilai Hospital
Bhilai

Ramkisan who is in his late twenties contracted leprosy about 10 years back. Then he was part of village Kathua in Bilaspur district. For about 2-3 years he took the medicine on the sly. But clawing of his fingers subsequently made it difficult for him to hide his disease anymore. He found staying on in the same village difficult. One day he decided to move out. He knew another patient Baisakhi from a close-by village. Baisakhi had moved out; and was staying at Shardapara in Bhilai.

Shardapara, a newly settled area, renamed by towns people as slum area, was known for one of it self-settled leprosy colony. Baisakhi stayed in this colony. he gave Ramkisan much needed shelter in the ramshackle verandah of his equally ramshackle hut.

During his stay at Shardapara, Ramkisan took his medicine regularly. Further clawing of fingers stopped and he was earning his bread respectably. He was a cured person. He stayed on with Baisakhi happily for about six years working as contract labourer.

One day, God alone knows how and why he decided to return to Kathua; and start life anew. For sometime his parents also were insisting on his return home.

For about a year and a half, he stayed at his home in Kathua and managed his farm. But his heart was not there. His thoughts kept straying to Shardapara and to his friends in the colony. What he liked about his stay at Shardapara he was not sure. But he couldn't resist compulsive pull of whatever he liked about his stay there.

One fine morning Ramkisan got up pushing aside all his hesitations. Approached his mother and said: "Mother, I don't like being here!" Mother looked up; but not with big surprise. Perhaps she already had sensed her son's mood. Nonetheless she asked: "Hope we have not caused you any agony?"

"No not at all... But I don't like being in Kathua", replied Ramkisan with tearful eyes.

On his return to Baisakhi's place whosoever asked him about why he returned, he had only one standard reply: "I didn't like it in Kathua!" To avoid misunderstandings about the treatment he received from his parents, occasionally he used to add: "I didn't like it... inspite of the love and affection, my parents showered on me... But now I'll stay on here...I've even got back my old job."

I asked him: Since he was a 'cured' person now; and has a job too, why didn't he stay out of the leprosy colony? Ramkisan smiled at me, shrugged his shoulders and left me alone, wondering all along why?

9.6 The common village tank*

Ishwari Soni

Physio-therapy Technician Rajnandgaon LEU

Village Khairbana was known for its high concentration of leprosy patients. With its 2000 population, the village had about 60 cases. Not all were regular in taking medicine from the official Control Agency. A few of them even refused to accept their patient status. Such high prevalence of leprosy cases in the village, has remained an enigma and simultaneously a cause of unnerving anxiety for the villagers.

In early days, say about 15-20 years back, this village was extremely harsh with leprosy cases. People in the village were threatened with social boycott if they maintained any kind of relationship with a leprosy patient or his family. A patient could not participate in any social function. He could not move freely everywhere even in a weekly market. A place was fixed for him. He could not bathe in the common village tank.

Over the years the LCU workers tried to soften the villagers' attitude to a certain extent. Now the patient does not face social boycott. His movements too are not restricted. But the problem of bathing in the tank still has not been resolved.

Between 18th and 26th May 1988, LCU workers planned a combined community and patient education camp while launching Intensive Therapy under MDT. The camp was fully residential. Local Gram Panchayat leaders had offered to make arrangements free of cost for food and stay for about 50 leprosy patients and another 30 Social Communicators and LCU workers. While agreeing to give suport for the camp, the villagers had taken an assurance from the Gram Panchayat leaders that the patients in the camp will not be allowed to bathe in the common village tank. Water required for bathing of the patients will be provided by the Gram Panchayat through hiring a tanker.

The LCU workers attending the camp obviously did not relish this particular condition which was earlier acceeded to by the Gram Panchayat leaders.

They decided to tackle on priority this issue of patient bathing in the common Tank. Frenzied activity followed. For the first two days meetings after meetings were held with prominent villagers and Gram Panchayat leaders, to reconsider the earlier decisions.

The ordinary village people did not take lying down the vacillations of the Gram Panchayat leaders. They insisted that the camp should be moved out to some other village in that case. Everybody in the village was asked by the villagers to boycott the camp activities.

The situation was getting out of hand. The village sarpanch who was one of the organising committee members of the camp, also panicked, sensing the mood of the village people. All got worried.

Surprisingly the third day dawned with a glimmer of hope. There was yet another round of talks between the LCU workers and the prominent villagers. Amongst the numerous alternative propositions, one appeared to find favour with all.

It was decided that prominent villagers from localities around the tank and all the LCU workers in person would join the patients in their bath. The bath was nicknamed 'Ganga Snan' (holy bath). Like a bath in the holy river Ganges, this bath was anticipated to wash away all sins. The workers hoped that though not sins it would at least wash away the fear of leprosy from the villagers' minds. Three prominent persons from the village, all the patients, and the entire LCU staff (which included even the DLO) joined the bath.

As they bathed, they heaved a sigh of relief. Thought the nightmare was over once for all. The problem was solved.

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* Adapted from the Report on Khairbana Mixed-Group-Residential (MGR) Camp.

But surprises were still in the waiting. As the bathers were on the return trail from the bath, they were scolded by the village women using choicest unprintable abuses. Menfolk threatened to stone them if they dared to take bath in the tank again. Even a few stones came hurling as a test of things to come if the LCU workers persisted in their designs.

Tempers once again rose high. At this stage even the patients lost their cool. They started answering back. Situation was slipping out of control.

The workers held yet another round of meetings. But no movement from the earlier held positions resulted.

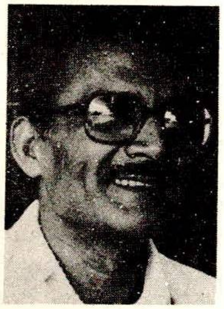
The workers thought it was high time they moved a step beyond discussions. Alongwith patients they started taking out morning processions (Prabhat Pheris). This activity led the group closer to the villagers in the far flung localities. Even understanding between the patients and the villagers developed positive overtones. The hardliners from localities adjacent to the tank preferred to go into shells when they realised the campers included people from the Revenue Department.

Finally it was decided in a large meeting of the villagers that everybody would be allowed to take bath in the tank. On the last day all including patients, prominent villagers and workers jointly took their bath in the tank. Some villagers from the adjoining localities also joined.

It's more than three months now since this incident occurred. The ban on patient bathing on the tank has not reappeared. Those who remained on the forefront during this episode have been championing at village forums in other villages, the cause of unrestricted bathing in common tanks.

10. Developing Communication in Leprosy Work

Bhagwan Lal Sharma



Even after granting the obvious limitations of the 'word of mouth' based communcation, we decided to harness it as a prime tool in Bhilai. Whether it was a sensible decision to adopt this medium in a City of over half a million population was a debateable point. Indeed, the medium we preferred was not based so much on 'word of mouth' as on 'action'. Action was used as a prime tool because no other medium could have effectively transmitted the two key messages which formed the basis of the Bhilai programme. As one would see, both messages had strong action orientations.

Message 1

Person with Leprosy History is no more an 'infectivity-risk' to society if he is undergoing Multi-Drug Therapy. Overcome the scare of infectivity in Leprosy by accepting the 'person' in your social and work life as a co-partner.

Message 2

A large majority of persons with Leprosy History are as "strong" and "sturdy", as hale and hearty as any of the normal healthy persons in the Society. Their capacity to serve the Society and to enrich the community life is in no way inferior. Discard the age old 'weakling' image of this person by giving him opportunities to demonstrate his capabilities and strengths.

> *...a person who acquires on 'insider' role, and feels proud about it, becomes critically important in developing communication.*

Not only the medium for the message but even the anticipated outcome was 'action'. That way the marathon put together both the messages into one. Even the targets for these messages were the patient as well as the non-patient communities. "Speak through action became the organisational culture during the month-long programme. It automatically carved out an 'insider role' to all those who formed part of the 'action' programme. One was reminded of the programmes given to people during the early phases of our independence movement. For example the bonfire of foreign-made clothes in those days was a simple action-programme. It provided opportunities for those peopel who had a desire to act. Their action in turn carved out for them an 'insider' role; and the bolstering that followed shaped their ideology. Ranks of freedom fighters swelled through such simple programmes during those days.

Thanks to the 'action orientation' of the Bhilai programme, we soon saw numerous persons from different walks of civic life playing 'insider roles'. Generally a person who acquires an 'insider' role, and feels proud about it, becomes critically important in developing communication. The person could be relied upon for providing contents to the communication which, with passing of time, become more meaningful to the people. This way he helps in widening the effective range of the communication thereby enlarging the target group. In a way the person who acquires an 'insider role' in a communication process helps not only in ensuring its spread but also in its growth on sound lines.

DANLEP
Health
Education Advisor
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Districts (MP)

We could see such a process materialising in Bhilai during the Aarohan Samaroh month. My friend Nand Kumar Soni's involvement with the programme could be cited as an example. We saw in him a detraçtor in our first meeting. But soon he acquired the 'insider' role; and got engrossed in developing with the help of his wife, a network of communication which soon acquired the pattern of oceanic circles. A pattern which makes it difficult to find out where one circle ends and the other begins. We could see how a living communication not only grows in its content and in its range but also in its design by forming numerous intermixed circles with independent epicentres.

Leprosy work needs communication to be developed in such networks, partly because one Health Educator seeks to develop communication in about 500 villages, which is a next to impossible task, unless viewed as a function of developing network, based on circles with independent 'epicentres'. Each epicentre representing one 'insider" role. Facilitating multiplication of 'insider' roles therefore, becomes the prime task of Health Education. In Bhilai we could see how 'action' helps in accomplishing this task of facilitation.

The futility of a Health Educator's conventionally assigned task also arises because he never plays the facilitator role of a 'mid-wife' who nurses situations that are pregnant of 'insider roles'. Situations which have rich action propensities do not attract his attention. Instead he is made to feel comfortable with a parrotry for messages which do not solicit 'action'.

A communication which originates from a role carries with it a potential of spread. Whether the role is that of a supporter or of a detractor, hardly makes any difference so long as it emerges out of an action-based role. A role-based communication has the propensity to spread so long as the role-taking process is marked by volition or an element of free-will. The degree of freedom enjoyed by a person while taking a role, indeed makes all the difference to the diffusion potential of the emergent communication. Whe we facilitate role taking by a potential comunicator at his free will we are ensuring simultaneous growth of the communication. One could safely define the potential communicator in leprosy work as a person who has a desire and capability to act on his free will. The real issue before communication development therefore boils down to whether or not the communication facilitator has the capacity to promote role-taking.

I had learnt about this distinct character of a communication facilitator role at a personal cost in Dongargarh last November. It was the first day of the "Mixed-Group-Residential" (MGR) Camp. About 92 M.B. Cases had reported for the 14-day event. A problem cropped up in the evening when shifting of the Campers from one Dormitory to another was undertaken to facilitate Bed-Rest to ulcerated cases under one roof. There were 4 Dormitories and the patient had occupied these earlier on considerations of social proximity. The women patients' group was comfortably settled in the process. The male members however felt slighted.

Once the Physio-Therapy Technician (P.T.) announced the need for shifting all the ulcer cases under one roof, the Male Group snatched the opportunity by rushing to occupy vantage positions, leaving the women no alternative but to adjust with the open Varandah. Both the groups became adamant and took a rigid stance of wanting to occupy the beds inside the dormitories. The issue resulted in a big row. The problem acquired serious proportions. It soon crossed the management capability limits of the P.T. The P.T. called in the Seniors.

The Seniors thought of converting the developing situation into a learning experience for all. They declined to intervene and expected the patients to evolve a 'criteria' to allot the beds. "It's a problem created by your behaviour. You have to solve it. We shall not intervene." They said and left the Campus.

I had been away from the scene of the incident, unaware of what had happened. When I came back and knew about the impasse, I worked out a solution. Presented the same before the patients. Earlier they had put their heads together for devising a 'criteria'; and had spent over an hour without evolving one. They were tired. They welcomed my plan and complied with it promptly.

When my colleagues returned to the Campus, I informed them that the problem was solved. One of my colleagues snapped back cryptically, "But what was the problem?" After a brief discussion with my colleagues, I realised that in my anxiety to overcome the impasse, I had deprived the potential leadership talent amongst the patients, a role. I had curtailed their freedom to deal with the problem.

The processes involved in facilitation of role taking appear to be slow to start with. But once matured they become highly productive. These create demands on patience from both sides, on the part of the facilitator as well as the potential role-taker.

We saw how all those who had a desire and capability to act developed into perpetual communicators in our circle of volunteers in Bhilai. How we could easily draw in more and more hands and minds with a wide variety of roles.

The entire range of activity, developed through dialogues with different groups from the civic life of Bhilai, showed how roles emerged. The statement titled "What can we do?" underlined the potential in the society to take up a wide variety of roles in leprosy related work. The "Acharan" list presented elsewhere on page — indicates the scope for further enlargement of the list. The three items listed under column 5 of the 'list' highlight the possibilites of removing misconceptions about leprosy through promoting participatory process. Something like community surveys. Such surveys would present unlimited scope for enlarging action orientations of community education activities.

A small group worked in the patient Wards in the Bhilai Hospital. They remained absorbed in developing Patient Profiles. This activity kept them busy all along. "Babuji aap ayen. Hamare saath baithe. Hamari sooni. Lagata hai, hum beemari se pare ho gaye!" ("You came, you remained with us. The awareness that someone had time for us ... itself has given us a great relief. Perhaps far greater than what the actual 'cure' would bring"), one patient said. The activity created 'insider' roles for two volunteeers and exemplary mannger.

This activity exposed us to one more dimension of the process of communication development. This can be stated as 'interactional' communication. In leprosy work, interactional communication is critical because interaction alone can develop understanding. And understanding presupposes mutuality of concern. Promoting mutuality of concern and facilitating transaction of such concerns remains the prime function of communication in leprosy work. Presence of the two entities required for this transaction, need not be that of individual alone. These could be group or even communities. Involvemennt of groups and communities in this process of communication by itself would mean initiation of one of the noblest forms of community action.

Interaction communication does not preclude Agent or Agency Roles. These roles, too, are basic for promoting such communication. They are distinguished by their function. Agent identifies the 'focal point' for 'action'. Then promotes and facilitates interaction; and helps in improving the quality of 'concern' in the ongoing transaction in understanding. While initiating the 'action' he gets in. Plays an 'indsider' role. But then to ensure uninfluenced transaction of understanding between the patient and the empathiser he gets out. He therefore plays both, an insider as well as an outsider role. This character of a communication facilitator role is distinct from that of an 'activist'. The latter tends to have a perpetual 'insider' character.

11. Corrective surgery in leprosy at general hospitals: missing linkages

Dr. R.J. Choubey

Chief Surgeon &
Director
Medical & Health
Services
Bhilai Steel Plant
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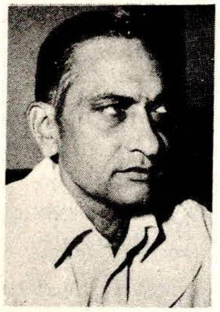

Why launch one more Corrective Surgery Service when those that are already on the Map, remain grossly underutilised? What is it that leaves the existing services underutilised when, as Dr. Antia puts it, a staggering 750,000 surgical corrections would be required and not even a fraction of this requirement is met by the existing facilities? What is the guarantee that a 'pay-for' service would score over the 'cost-free' ones available elsewhere? Would leprosy patients show preference for services at General Hospitals over the ones offered at the specialised Leprosy Centres? These were some of the issues the Hospital Management had to steer clear before launching the Service at the Bhilai Hospital.

Indeed, the decision to launch the Service was a logical and conscious extension of the management's manifest concern for meeting the service needs of the leprosy afflicted persons. We always considered leprosy an unjustifiably stigmatised and isolated disease; which required 'image-lift'. Installation of facilities for treating the disease within the galaxy of general medical services, we considered one of the critical devices for counteracting the stigma.

> *The line of distinction between leprosy services at the general hospitals and the ones at the specialised leprosy centres is likely to blur with slight weavering.*

In 1982, the Dermatology Unit of our hospital started Multi Drug Therapy. We were, perhaps, the first to replace monotherapy in this part of the State. Since 1986 our Dermatologists started providing diagnostic help to Skin Disease Diagnosis & Treatment Camps, in the countryside of the two neighbouring Districts. The Camps were organised by the governmental leprosy control agency. Eventually these camps turned out to be respectable diagnostic channels for the stigma-shy leprosy cases.

In January 1987 while still continuing the MDT Services in our Dermatology Unit, a special Leprosy Eradication Unit of NLEP pattern, was launched in the SADA area to effectively serve the slum dwelling patient population located at the outer fringe of the township.

Our decision to launch a Corrective Surgery Service only underlined our deep-seated concern to provide 'image-lift' for the disease and the patient. It was also indicative of the management's keen desire to bring the hospital services within the reach of leprosy patients in the villages of at least the two neighbouring districts of Durg and Rajnandgaon. We have reasons to believe that the leprosy patient who generally remains conscious of the deep erosion in his image in the society, holds strong preferences for a treatment centre which provides the much needed 'image-boost'. Bhilai Hospital met this need with its 'pay-for' services for non-BSP patients. Its 700 Bed facility; 8 fully equipped modern Operation Theatres; 2000 daily average OPD attendance; and over 1900 Staff manning the Services which catered to 75 specialities, all these factors did boost the Hospital's image in the eyes of the leprosy patient.

The need for initiating a well integrated corrective surgery service at this Hospital was being experienced and articulated by both the governmental as well as non-governmental agencies over past few years. Its location at a General Hospital like Bhilai was viewed with great expectation. A proposal was jointly sponsored by the two District Leprosy Eradication Societies of which the respective District Collectors were the Chairmen, and the Hospital Management, to operate the Service for one month and to assess the organisational implications for its effective operation in the interest of patients coming from the country-side.

Even though the Hospital had well reputed Orthopaedic and Plastic surgery units, we invited known Surgeons in the field of leprosy from far off places like Agra, Bombay and Kumbhakonam in the South. We even arranged for services of a Physio-Therapy Technician from a Mission Hospital who had experience in pre and post operative Physio-Therapy. The sponsoring Societies intended to mobilise properly selected 100 patients for operations during the month.

We could, however, operate only 44 patients; 31 for Claw hands; 6 for Footdrops; 4 for Lagophthalmos and 3 for face-lifts. How do we account for this low performance especially when our Surgeons worked on their free days? The patients flow remained erratic.

The shortfall has brought to surface certain organisational weaknesses of the programme. The purpose underlying our 'pay-for' services (Rs. 500/- per operation) was two fold. The service should reach those who feel handicapped for want of an 'image-boost'. Obviously, those who were swearing to continue with their practices of 'begging', did not require image boost and as such were thoughtfully kept out of the purview of this service. One third of the initially selected patient list comprised professional beggars. A large majority of them were habitual beggars for whom 'worklife' with improved functionality was an anathema. Here the issue of their incapacity to pay for the Operation was not at stake. The community did come forward to support the deserving. Only 6 operated patients paid the fees in full out of their own pockets. The rest paid only partially which subsequently was made good by donations. There were 14 patients in this list who were entitled to have cost-free services because of their lineage with Bhilai Steel Plant—the parent organisation provided the Hospital facilities free of cost to its employees and their dependents. 'Pay-for' services, therefore, did not create any hindrance for the needy.

The other purpose behind 'pay-for' services related to testing the depth of intensity of need for the 'Correction' in the context of experienced occupational handicaps. Intensity of the 'felt-need' was imperative for post-operative responsive patient behaviour, to ensure consolidation of the gains from the Operation.

We were found wanting in providing adequate educational support to orient the patient community, the community of well-wishers of the patient; and also the staff of the Leprosy System, both in the interior as well as in the Bhilai Township areas. In no other way could we explain what happened in an area like Dongargarh. Out of 11 Cases who were willing to avail of the facilities, only 4 reported at the Hospital. I hear that all the 4 Cases do not speak now, of their happy experience. Only one out of these 11, was handicapped in making the stipulated payments, In this case too, local community came forward to support the cases financially. I am speaking of Dongargarh, because by far we consider it fairly advanced in matters pertaining to patient education and community orientation.

This was a glaring flaw. The NLEP pattern does not fight shy to admit low priorities in its programme operation, to deformity prevention. No wonder, at the stage of proper selection of Cases for corrective surgery, or subsequently during the post-operative phase, the LEU staff could do precious little in meeting the physio-therapy requirements of the operated patients. To keep them as indoor patient for lengthy periods was cost prohibitive.

I am of the view that in future the patient selection for corrective surgery should be confined to only those areas where physio-therapy based patient care has made adequate headway, and where the field staff is well trained for rendering desired pre and post operative care to the patients. Our planning for the next corrective Surgery Camp would have to provide for such training well in advance. May be as we did for skin diagnosis camps, we may have to take the first step. Neither the hospital nor the patients dwelling in rural areas, would be in a position to avail of the much desired education within the closed shell of 'indoor' facilities. It will be cost prohibitive.

Similarly succumbing to temptations of making improvisations through creating low-cost, post-operative care facilities else where. It would mean segragation through back-door. It would be self-defeating. The line of distinction between leprosy services at the General Hospitals and the ones at the specialised leprosy centres is likely to blur with slight weavering. It is imperative to guard against subtle pressures to adopt lines of least resistance.

All said and done the 'in-group' — 'out-group' sociology remains operative not only amongst the rural or urban communities. It is likely to operate surreptitiously even in a liberal and outgoing hospital system like Bhilai. Eternal vigilence is all that can be provided for.

12. Management of corrective surgery delivery

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Bhilai

It was not all smooth sailing. In a way it was a new experience for us. We were, however, fortunate in having with us the country's eminent surgeons during the month-long Camp of corrective surgery for Leprosy Patients. Organisation of the Camp at the General Hospital like Bhilai was a major step towards integration of leprosy treatment with general health care. In our hospital the patients admitted for operation were not isolated or segregated in separate Wards. They were mixed with other indoor patients during the pre as well as post operative phases. If all the major hospitals and surgical departments in the country take over this task of surgical rehabilitation of leprosy patients as a part of general health care, then social intricasies of this problem will be on its way of assured resolution.

Besides removing all the barriers between leprosy and the general health care patients, we were making special efforts to reach our services to the countryside, at least, in the two neighbouring districts of Rajnandgaon and Durg.

> *We were anxious to reach our services to the poor patient but with a difference.We looked upon the functionality restoration as a means to respectable living.*

The National Leprosy Control Programme so far has not given adequate priority to disability/deformity prevention aspects or to corrective surgery. As a result no specific programmes in this sphere were operative at the field level. In its absence we faced a wide variety of problems. The end-product — patient satisfaction — did not mature in a manner rewarding to the Surgeon. The field staff needed special orientations about selection of proper cases for surgery, the character of patient motivation that needed to be developed; and in-depth understanding about pre and post operative care.

We were operative on a third Front as well. We were anxious to reach our services to the poor patient but with a difference. Our interest in corrective surgery was not restricted to mere restoration of function to disabled limbs. We looked upon the functionality restoration as a means to respectable living. The corrective services were, therefore, restricted to sponsored patients. Efforts were made to locate a sponsor wherever a deserving poor was in need of it.

Retrospectively speaking, our 'pay-for' services stand indicated. It promoted almost obligatory search for sponsors which in turn put the patient in a supportive social circle. Indeed, this approach should form a major plank for organisational effort in future. Based on hind sight, I consider advance planning for subsequent camps may have to initiate simultaneous action on all the three fronts — (i) Advance selection of Cases with identified sponsors or with organised social supports; (ii) Field worker training in appropriate skills so as to enable him to effectively function as a referral internee; and (iii) developing planned service schedules directed toward corrective surgery at the Hospital level.

A few common tips to field staff which will help initiate action in the direction of proper selection are given below: Most important consideration while selecting a case for surgical operation was cleanliness. The person to be selected must be physically clean.

There should be no source of infection such as a trophic ulcer or a septic finger which will contaminate a surgical wound.

Since leprosy is a Microbial/Bacterial disease, whenever Bacterial Index is high, it is likely that a surgical procedure may cause complications. It may either precipitate "Lepra Reaction" or lead the surgical reconstruction to a failure. It may also cause dissolution or absortion of bone grafts.

Bacillary presence in small bones of hands may also cause failure of bone and joint corrections. So it would be better to wait till Bacterial Index is brought down from high (3+ — 6+) to low (1+ or less). If a person is prone to Lepra Reactions then it would be safer to stabilize him under good medical and anti-leprosy treatment.

Similarly bacillary presence in skin can cause failure of skin grafts, such as Eye Brow grafts or Face Lift and Ear Lobes correction. It is better to have a Zero Index or Negative Skin Smear before setting on such fine surgical procedures.

Certain important considerations about physical condition of the patient also need careful attention:

* Healthy with good Blood Count (Haemoglobin 10 to 12 Gms.);

* The paralytic deformities should be well established and not partially affected or of recent origin, as such deformities can be recovered spontaneously or with Medical treatment and physiotherapy. So it would be good for persons affected to be under observation of the Surgical and Physio-Therapy teams for at least six months before surgery. This also gives the teams opportunity to undertake Pre-Operative Physio-Therapy.

* Fixed Deformities of bones and joints will need complex Orthopaedic Procedures and can be undertaken at the convenience of the surgeon.

As a special consideration, young, hopeful and needy persons should be generally selected on priority for an operation.

Main problem area relates to patient motivation. Both while selecting a case and while educating him about his role in making the alterations to be introduced through surgical interventions, a functionally satisfying experience. The quality and character of his relationship with the Physio-Therapist, remains critically important in this entire chain of operations beginning with initial patient motivation for corrective surgery, then the understanding of his role during the pre-operative stage; and then his responses to 'reeducation' involved during the post-operative stage.

The relationship between the Physio-Therapist and the patient remained splintered during our Camp. The communication process encountered three stage barriers. The Physio Therapy at the field level in the LCU remained to be organised. The ad hoc lines of communication with patients, therefore, reached the right quarter only through a lay person who was not a physio-therapy trained person.

The second stage break in communication occurred at the Bhilai LCU level. The Unit located in SADA area did not have a Physio-Therapy technician yet appointed. In his absence a make-shift arrangement was made by bringing in a temporary deputationist. He was supposed to function as a liaison between cases coming from the districts and the Physio-Therapy Unit at the Hospital.

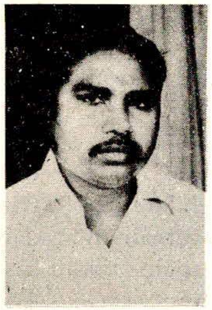
The third stage break occurred at the Hospital level. A Physio-Therapist who had considerable experience in handling reconstructive surgery cases, did function at this end. But then he was not regular Hospital Staff. No wonder this level could not effectively play the co-ordinating role expected of it.

Things shaped reasonably well, notwithstanding these staggered communication processes, largely because of overall motivational climate prevalent in Bhilai during the Aarohan Samaroh month. We surgeons worked on our 'Free' days. Not only did we work on days marked free for Operations, we received focussed attention from the total system. We were at the Centre Stage during those days.

With more streamlined communication well installed up to the patient level in the field and little brushing of the skills through training at all the three levels, Bhilai would keep on to its forward march in promoting leprosy patient care at General Health Care Hospitals.

13. Flow of corrective surgery cases and the fieldwork

Shyamrao Meshram



Para-Medical Worker
SADA Bhilai LEU
Bhilai

I was in frequent contact with the patients during the entire course of the Corrective Surgery Camp in Bhilai. I would visit patients' homes; explain to them about the scope of rectifying deformities; and encourage them to undergo the operation. I would also help them in getting admission in the hospital and attend to odd outside problems faced by them after admission. During my visit to these patients, I realised that some of the patients were unable to pay the fees of Rs. 500/- although they considered the surgery essential. To forego the operation for want of money would have been most unfortunate for them.

One incident involving Nabibeg comes to my mind afresh. He was a poor vendor who earned his living by selling bangles. Both his eyes were affected by Lagophthalmos. He was incapable of paying the prescribed Hospital Fees. Any delay in surgical operation would have resulted in total loss of his eye-sight.

I was in a dilemma. On one hand humanitarian considerations were pushing me into questioning the ‘pay-for’ service introduced by us. On the other, since I was myself a party to the decision; and had insisted on introducing a ‘pay-for’ service mainly to usher in an element of seriousness about post-operative care. I could not ignore the compelling logic lying behind the decision. Free of cost services would have left no links between the patient and the hospital in post-operative phase if we had not mobilised adequate social support for facilitating the operation.

Other ways open to reduce the burden of operation costs on the patients was the hospitals recovering in full or in part the costs through reimbursements from some other philanthropic Trust or the Government, on the basis of operations performed. This also appeared to be the usual practice. But then such practices pushed patient local social group interactions to the background. This path led the leprosy patients to increased isolation. When their absorption in the social mainstream was more desirable. We therefore considered more appropriate to develop patient's linkages with Hospital Services through the medium of local community supports.

I discussed these various issues arising out of Nabibeg's case with my colleagues and others who were busy making preparations for the Camp. Soon we could mobilise support from some social organisations. Some small donations also came our way. As a result he was operated upon. The settings thus provided by the social support might prove a great help in his post-operative life if properly harnessed. Didn't such social mobilisation of support mean humiliation for the patient: some people argue. We were aware of such pitfalls in our approach.

Indeed, there was no occasion during the camp when the patient had to approach any donor. The well-motivated camp organisers remained active on mobilising financial support. It is true approaching a donor does become embarassing for persons who do not have any record of self-less service or transperancy of purpose. On occasions it even becomes humiliating. It is also true that approaching a donor is not just the same as approaching a patient with Application Forms for securing him reimbursement grants on his operation costs. It is also not the same as sitting across the Admission Desk for screening applications for cost-free surgery and passing on ‘admission slips’. The latter functions carry with them a benefactor aura.

The benefactor role certainly differed from the one of a ‘seeker’ (Yaachak) which we had carved out for us. In Dongargarh we did expose ourselves to ‘Yaachak’ roles.

We had seen with our own eyes how the collections of one and two kgs. of rice boosted our confidence and augmented our strength vis-a-vis the patient. How we succeeded in raising the credibility of our work to new heights. For us mobilising social support had become a charter of faith. Even for providing a MCR chappal for Rs. 50/- we insisted that 50 per cent cost should come from local people and not from governmental subsidies. We were aware: leprosy work basically involves mending of fences with local communities around the patients.

Approaching the society with problems of patients like the ones of Nabibeg, brought the patients closer to the Society. Otherwise the society behaved with utter indifference to patient's problem.

The patients not having adequate cash to pay for the Hospital fees was just one of the hurdles. It was overcome with tenacity and effective liaison with society. Their real problems, however, were different. To put these patients in a setting which ensured perpetual attention from the social groups required greater attention. Attending to their needs of work opportunities after the Operation, required priority consideration.

While moving amongst the patient for selection and then for motivating cases so selected for undergoing operations, I quite often encountered several misgivings about the 'pay-for' character of the services provided by us. Patients were made to understand that all services anyway required to be paid for. Who pays for it is the aspect that concerned the patients. Normally in a 'free-of-cost' services, the costs were either borne by the Government or a non-governmental Philanthropic Trust. A third alternative was all that costs remained available without making any payments.The patients could easily understand these implications of cost-free services. Their concern was not so much about 'pay-for' or 'free' service. They were anxious to minimise their own contribution to the total costs of Rs. 500/-.

It was explained to the patients as well as to the 'donors' that Bhilai Steel Plant had generously subsidised the cost of these operations. There subsidies ranged between 150 to 300 per cent per operation. Whereas actual cost of an operation was in the range of Rs. 1,250/- to Rs. 1,500/-, a fee of Rs. 500/- only was actually recovered at the 'pay' counter.

It would be of further interest to note that the actual burden of financial costs was minimally passed on to the patient. In our scheme, the real poor patient remained at advantage.

Incidence of Sharing of Operation Fees with the Community

Extent of payment by Patient	Fully Paid (Rs. 500/-)	Less than Rs. 500/- But above Rs. 250/-	Less than Rs. 250/- But above Rs. 250/-	Rs. 100/- or Less	Fully paid by the Community
Number of Patient	6	2	8	12	2
% of total patients operated	20%	6.7%	26.6%	40%	6.7%

The Table above makes it amply clear how the 'pay for' services in actual practice worked because of the social supports mobilised by the organisers. With all this organisational work, how could we explain the large numbers who did not avail of the services?

Our patient cards showed 189 cases with deformities of fingers. Out of these, 93 were found technically fit for operations. Only 53 were willing for operations. But actually 27 reached the operation table.

There were 25 Foot-drop cases according to data on Patient Cards. 12 were found fit for operation. Only 7 reached the operation theatre..

Out of 11 Lagophthalmos cases on Patient Register, 9 were fit for operation. Only 4 reached the Operation Theatre.

One important factor accountable for low reportings, was the bar put on persons actively engaged in begging and unwillling to shift to non-begging pursuits. Such cases were not considered for operations during the Camp.

It may not be therefore correct to understand the gap between cases fit for Operations and those actually reached the Operation Theatre as resulting from incapacity to pay the Operation Fees.

For want of scope for sharing of experiences of successful operations, a large number developed second thoughts.

The case of 'free-service entitled' BSP cases is quite an eloquent example in this respect. According to our initial surveys, based on patient cards, we had 56 BSP cases fit for corrective surgery. Out of which 33 consented. But only 14 came to operation theatre.

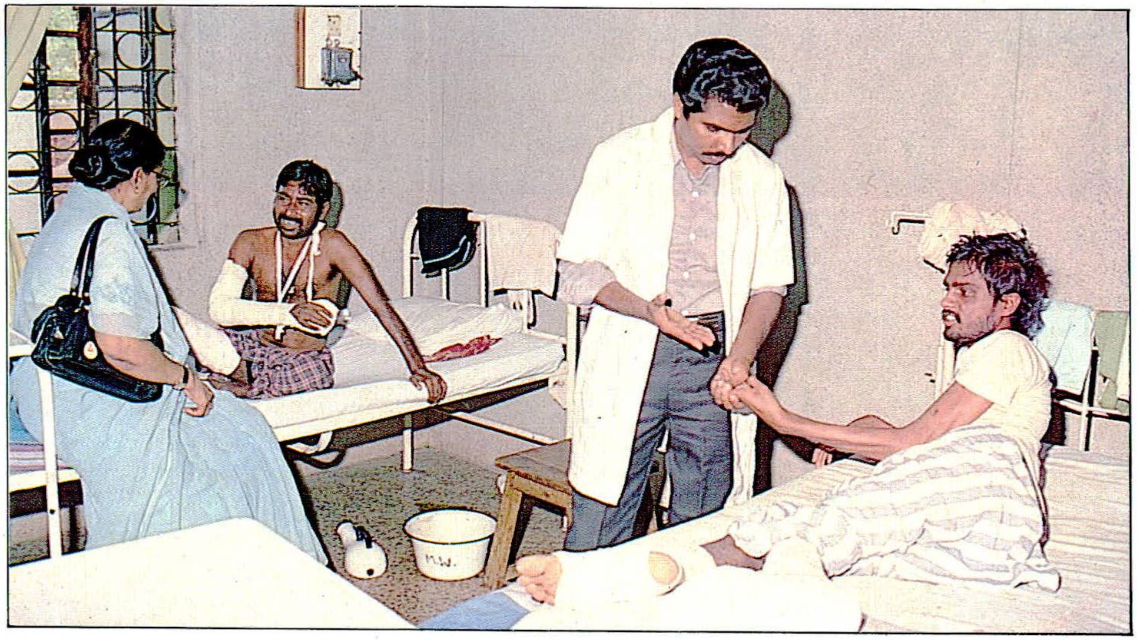
Exhibit

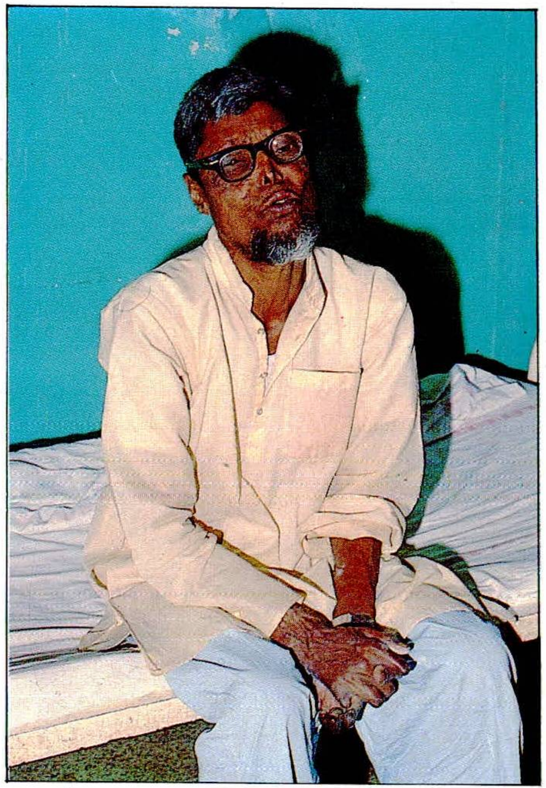
Patients operated during corrective surgery camp at Bhilai hospital

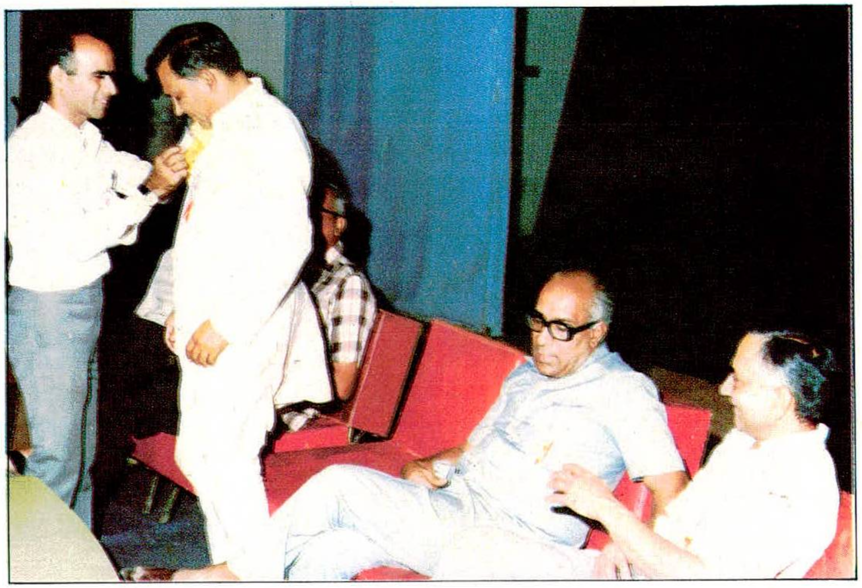
S.No.	Name of Patients	Age	AddressDate of	Site of Operation
1.	Sudershan Sharma	35	Camp-I Bhilai	Left hand
2.	Pyare Lal	30	Jat Kanhar D. Garh	Left Hand
3.	Devi Prasad	19	Berala Kumhi Durg	Left Hand
4.	Darivao	55	Karamtala Singhola Sirsa	Left Foot Drop
5.	Dilip Kumar	23	Moharam Kala Rajnandgaon	Claw hand
6.	Bideshi	45	Budhwari Mohalla Ward-14 D. Garh	Left Hand
7.	Surendra Kumar	15	Basant Para Ward-18 D. Garh	Claw hand
8.	Ramesh Kumar	14	Hatkhoj Bhilai	Face Lift & Lagophthalmos
9.	Navi Beg	55	Sharda Para Bhilai	Both Lagophthalmos
10.	Khorbahara	46	Pitora Nandini Mines	Both Lagophthalmos
11.	Ku. Sakhi	25	C/o Dr. Gude	Face & eye brow
12.	Devendra Kumar	20	Bhilai-3	Left foot drop
13.	Dukhu Ram	50	Bhandarpur D. Garh	Left hand
14.	Prem Lal	55	D. Garh	Claw hand
15.	Gandhi	35	Semariya Nandani Mines	Right hand
16.	Tej Nath Parganiha	57	Durg	Left foot drop & Claw hand
17.	Gorakh Nath	51	Sector-I Bhilai	Left food
18.	P. Chiranjivlu	42	Bhilai	Left hand
19.	V.N. Takey	46	Sector-6 Bhilai	Right hand
20.	Lobeddin	40	Sector-6 Bhilai	Left hand
21.	Ramlu	44	Sector-2 Bhilai	Right foot drop
22.	Khuman Lal	41	Ruanbandha Bhilai	Left hand
23.	Abdul Haque	35	Bhilai	Left hand
24.	Awadhu	15	Camp-II Bhilai	Claw hand
25.	Jagat Ram Khare	28	Sector-6 Bhilai	Ulnar hand
26.	Kundan Singh	46	Sector-4 Bhilai	Right claw hand
27.	Kedar Kumar	25	Kosa Nala Bhilai	Left hand
28.	Mohammad Rafi	60	Sharda Para Bhilai	Face lift
29.	Rajesh Kumar	21	KP Bhilai	Claw hand
30.	Nar Singh	24.	Sector-6 Bhilai	Right hand
31.	Bideshi	50	Pushpa Hospital Rajhara	Both Lagoph.
32.	B.L. Gupta	38	KP Bhilai	Claw hand
33.	Ku. Jarina Khatoon	14	Baba Colony Bhilai	Foot drop
34.	Vinod Kumar	20	Housing Board Bhilai	Claw hand
35.	Smt. Parwati	26	Supela Bhilai	Ulnar hand
36.	Kum. Tileshwari	10	Arasnara Patan Durg	Claw hand
37.	Prabhat Kumar	18	Vaishali Nagar Bhilai	Claw hand
38.	Net Ram	24	Vaishali Nagar Bhilai	Claw hand
39.	Kum. Usha	12	Ravidas Nagar Bhilai	Claw hand
40.	Suresh Kumar	25	Bhilai-3	Foot drop
41.	Nivaz Ahemad	42	Bhilai	Ulnar hand
42.	Shivaji Sharma	40	Bhilai	Ulnar hand
43.	Munna Lal Gopal	40	Bhilai	Claw hand
44.	Ghanashyam Singh	42	Bhilai	Claw hand

Corrective Surgery

Firm steps towards 'In-Group-Absorption!' Leprosy Patients admitted for Corrective Surgery in common, General Ward Beds!! Corrective Service at the Bhilai Hospital simultaneously stimulated a robust awareness of 'oneness' ... of "overcoming"; and cultivated a spirit of "combat", while restoring functionality to damaged limbs!





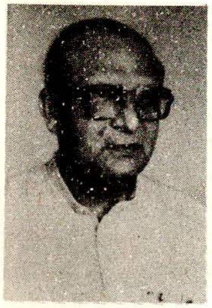


Samaapan

Dongargarh to Bhilai ... journeying off the bondage of senseless fear ... Blazing trail of merging identities. ... Lionizing "endeavour" – price of dignified existence.

14. Role of corrective surgery in leprosy rehabilitation

Dr. N.H. Antia



Director
Foundation for
Research in
Community Health
Bombay.

WHO estimates that about 25% of the 12 million persons suffering from leprosy in the world suffer from deformities; and (at a very modest estimate) about 10% of these could benefit from reconstructive surgery. This would still present a staggering figure of about 300,000 patients requiring about 750,000 operations at the rate of about 2½ operations per patient. There is no way of fulfilling even a fraction of this need with the surgical facilities at our disposal. Even if we should want to invest our meagre resources in creating special centres for this expensive aspect of leprosy treatment, experience reveals that it will be difficult to find surgeons who will attend these centres on a regular basis because most of such special centres that have been built and equipped at considerable expense are underutilized. Moreover such specialized centres while helping individual patients tend to perpetuate the stigma of this disease, which in turn is the main reason for corrective surgery.

One of the major causes of stigma of leprosy is the unscientific fear of the medical profession and no amount of persuasion will help overcome the stigma in the public mind so long as the medical profession does not accept leprosy on par with all other diseases.

Surgery and research have to a considerable extent helped in overcoming the fear of leprosy among the medical profession. Once interested and involved in these, what are inherently very interesting problems, the fear and stigma, which are very superficial, quickly disappear. The Tata Department of Plastic Surgery (TDPS) was the first non-missionary general hospital to accept leprosy patients in its general wards in 1958. Thirty years later it is no novelty to see such patients being treated in general hospitals throughout the country. Given encouragement and modest support I believe many more hospitals would follow suit. The integration of leprosy into the medical colleges and general hospitals and overcoming the stigma among the doctors is by far the greatest contribution of TDPS to this disease, not the devising of new operations or the number of operations that have been performed.

Even though the chance of deformity is very low if the disease is diagnosed early and the patient is regular in taking treatment. Percentages mean little, for if he is the unfortunate person to get a deformity, to him his deformity is 100% and a branding for life. Today he knows that it is possible to correct it. Surgery has therefore not only helped those who have been deformed but has given new hope and encouragement to all patients to come forward for treatment.

The surgical techniques for the correction of deformities of the face, hands and feet have been much simplified of late by surgeons like Dr. Arolkar and can even be prevented by nerve release. They can hence be undertaken by any general surgeon with the facilities of any general hospital. These new simple techniques need better dissemination.

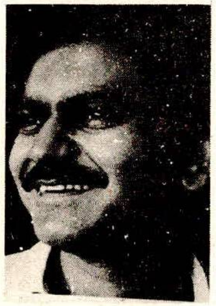
The most dehabilitating condition in leprosy is the ulceration of anaesthetic feet. While the microcellular rubber car tyre chappal may be worn in a leprasorium it is seldom used outside due to the stigma which it carries. An acceptable footwear which can prevent damage to such feet would be a boon to treatment.

In conclusion I would repeat that leprosy medicine and leprosy surgery must be integrated into general medicine

15 पथराये नयनों में महत्त्वाकांक्षी सपने

नंद किशोर सोनी और आचार्य

कर्मचारी
भिलाई इस्पात संयंत्र
भिलाई



कुष्ठ रोग! एक तस्वीर उभरती है इस रोग से पीड़ित भिखारी की, जिसे लोग भीख भी देते हैं तो इस तरह कि कहीं उससे स्पर्श की हुई हवा उन्हें न छू ले। कुछ ऐसी ही धारणा हमारी भी कुष्ठ रोगियों के प्रति थीं, लेकिन २ अप्रैल, १९८८ को भिलाई होटल में हुए विचार विमर्श में हमें कुष्ठ रोगियों की समस्या के प्रति कुछ महत्त्वपूर्ण बातों से अवगत कराया, जिसने हमें अपनी पुरानी धारणाओं और मान्यताओं पर पुनर्विचार करने के लिए बाध्य कर दिया। विचार-विमर्श ने हमारे अन्दर एक उत्सुकता जगायी, क्यों न हम भी कुष्ठ रोगियों से जुड़ने का प्रयत्न करें? दिनांक ४ अप्रैल, १९८८ को आयोजित "मेलजोल दौड़" में सैकड़ों कुष्ठ पीड़ित भाइयों के साथ स्वस्थ लोगों ने भी हिस्सा लिया एवं तीन तंगड़ी दौड़ में एक कुष्ठ पीड़ित और स्वस्थ व्यक्ति जोड़ी बनाकर दौड़े।

दूसरे दिन से हमें अस्पताल में भर्ती मरीजों के अध्ययन लेख (Patient Profiles) लिखने का कार्य सौंपा गया। एवं पहले दिन जब हम अस्पताल में मरीजों से मिलने गये तो कुछ भयभीत अवश्य थे, लेकिन अपने कार्य को मूर्त रूप देने के लिए समर्पित होकर कार्य करने से बाध्य भी। मरीजों से बातचीत करने पर हमें यह एहसास हुआ कि इन लोगों के साथ समाज का अर्थात् हमारा व्यवहार बहुत गलत रहा है। इनके शरीर में भी वो दिल है और इनकी रगों में भी वही खून दौड़ रहा है, जो हमारी रगों में है। फिर भी ये समाज से बहिष्कृत हैं। इनके साथ हुए बुरे व्यवहार का इन्हें बहुत दुख है। हम यह जानने लगे कि किसी भी रोगी को समाज का प्यार एवं अपनत्त्व की भावना उसकी आधी बीमारी को दूर कर देती है और उसे बीमारी से लड़ने की शक्ति देती है। कुष्ठ रोगियों के प्रति न सिर्फ समाज, बल्कि उनके अपने परिवार के सदस्यों का व्यवहार भी अच्छा नहीं था।

एक १९ वर्षीय मरीज इसलिए दुखी है कि कुष्ठ रोग होने के बाद माँ ने उसके कपड़े, बिस्तर, यहां तक कि खाने के बर्तन भी अलग कर दिये। माँ उसे दूर से खाना दे देती है और वह अपने झूठे बर्तन स्वयं साफ करता है। भाई के छोटे बच्चे को जिसे वह बहुत प्यार किया करता था वह अब छूने के लिए तरस गया है। उसे बच्चे को न छूने की सख्त हिदायत दी गई है। यह मरीज अपने घर में अपने ही लोगों के बीच निर्वासित जीवन जीने को मजबूर है।

एक ६० वर्षीय मरीज जो कि बचपन से ही इस बीमारी से ग्रसित है, उसकी पत्नी बुरे समय में उसका साथ छोड कर चली गई जब कि उसे जीवन साथी की अति आवश्यक्ता थी। लेकिन अब इस उम्र में एक साथी की जरूरत महसूस होने पर उसने उस महिला से शादी की जो इस बीमारी से ग्रसित है। मरीज का कहना है कि इस स्थिति में हम दोनों को एक दुसरे की आवश्यकता है।

एक २२ वर्षीय युवक, सफल भवन निर्माण ठेकेदार बनना चाहता है। साथ ही उसकी यह भी इच्छा है कि वह स्वस्थ होने के बाद कुष्ठ पीड़ितों की सेवा कर सके।

यूं तो समाज कुष्ठ रोगियों को बहिष्कृत करता है, परन्तु इनकी दौलत से कोई परहेज नहीं करता है। ५० वर्षीय एक मरीज, जो कि अस्पताल में अपनी बीमारी से संघर्ष तो कर ही रहा है, साथ ही उसे अतिरिक्त चिन्ता यह है कि कुछ ही समय पूर्व विवाहित उसकी इकलौती लड़की को ससुराल वाले २५,००० रूपये की मांग करते हुये मायके छोड़ गये, यह कहते हुए कि पैसा नहीं दिया तो परिणाम बुरा होगा। अपनी पुत्री के सुखद भविष्य के लिये किसी भी तरह रुपयों का इन्तजाम करने का विचार वह फिर भी कर रहा है।

२८ वर्षीय एक युवक से मिलने पर हमें पता चला कि उसका चयन मध्य प्रदेश पुलिस सेवा में सिपाही पद के लिये हुआ था, प्रशिक्षण काल में ही वह इस बीमारी से ग्रसित हो गया और उसकी छोटी उँगली में विकृति आने के कारण सलामी के समय वह उँगली सीधी रखने में असमर्थ हो गया। इस बात को लेकर उसे बहुत प्रताड़ित किया गया एवं अन्य अच्छे आचरण के बावजूद भी उसे नौकरी से बर्खास्त कर दिया गया। इस संदर्भ में दो जिला कुष्ठ चिकित्सकों के द्वारा प्रमाणित प्रमाण पत्र भी प्रस्तुत किये गये थे लेकिन उसका कोई **महत्त्व** नहीं रहा। प्रशिक्षण काल में ही अन्य प्रशिक्षु साथियों ने उसका बहिष्कार कर दिया।

इस रोग से ग्रसित एक ४७ वर्षीय देश प्रेमी व्यक्ति ने हमें बताया कि वह **स्वयं** तो देश सेवा नहीं कर सका परन्तु अपने दोनों पुत्रों को देश कि रक्षा के लिए भारतीय नौ सेना में भेजना चाहता है। उसने हमें बताया कि इस बीमारी के कारण पिछले १४ **वर्षों** से वह चिन्तित था। हमसे बातचीत होने के बाद वह बहुत प्रभावित हुआ और कहने लगा कि अब में चिन्ता छोड़कर हमेशा खुश रहूंगा क्योंकि, आज समाज हमें स्वीकार करने के लिए तैयार है।

इस कुष्ठ रोग से पीड़ित कई मरीज ऐसे भी मिले जो कि मानसिक एवं शारीरिक रूप से **अक्षम** होते हुए भी भविष्य की कई योजनाएं बनाये हुए हैं। कोई बेकरी खोलना चाहता है तो कोई ट्रक ड्राइवर बनने का सपना संजोए है। कोई स्कूटर मैकेनिक बनना चाहता है तो कोई टेलीविजन मैकेनिक बनने की तमन्ना रखता है। एक युवक पी० सी० एस० उत्तीर्ण करने के बाद डिप्टी कलेक्टर बनने की तैयारी कर रहा है। अगर समाज ने इन व्यक्तियों का साथ दिया तो ये अपने सपनों को साकार कर सकते हैं।

इस कार्यक्रम ने हमें कुष्ठ पीड़ितों को समझने का अवसर दिया ताकि हम कुष्ठ रोग के बारे में नया दृष्टिकोण अपना सकें। आज हम लोग पोलियो जैसी बीमारी से ग्रसित मरीज को अपना सकते है, तो असंक्रामक कुष्ठ रोगियों को क्यों नहीं? माह भर के इस कार्यक्रम के द्वारा आज हम लोग इस मानसिक स्थिति में पहुंच चुके हैं, कि हम या हमारे परिवार का कोई सदस्य कुष्ठ रोग से प्रभावित होता है तो हम उसे बहिष्कृत नहीं करेंगे। बल्कि उसका सही समय पर उचित इलाज करायेंगे जैसा कि अन्य बीमारी से प्रभावित होने से हम करते है। आज हमें कुष्ठ रोग को छिपाने की आवश्यकता नहीं है। आज हमें एक ऐसे समाज के निर्माण की आवश्यकता है जिसमें हम कुष्ठ पीड़ितों को स्वीकार कर सकें एवं उन्हें एक इज्जतदार एवं जिम्मेदार नागरिक की जिन्दगी जीने का हक दे सकें और उन्हें यह अहसास दिला सकें कि **वे** हममें से एक हैं और हम उनमें से एक। कहीं कुछ अलग नहीं है।

16. Deformity & leprosy today

Dr. Dinker D. Palande

Chief Surgeon
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Today Leprosy is curable at any stage. With modern Multi-Drug Treatment (MDT), the duration of therapy is reduced to lesser periods of six months to 2 years. With early detection and treatment of the disease, as well as with early and prompt detection of nerve involvement, deformities need not occur at all. Even if they occur, these can be corrected by surgery. Nerve paralysis caused by Leprosy is recoverable in the beginning and becomes permanent if untreated at early stages. Nerve destruction leads to muscle paralysis which in turn causes deformities and disabilities. This can be corrected by surgery.

There is also loss of sensation in the area supplied by the affected nerve. This cannot be recovered. Loss of sensation leads to injuries. Untreated injuries cause infections since these tend to get neglected because of absence of pain. The result is several types of mutilations.

Education in the "care" of those parts of body with loss of sensation, can prevent injuries, infections and mutilations. All this is in the realm of "possible" thanks to the fund of knowledge available today. However, what is possible can be transformed into an observable reality, only through patient s cooperation and effort.

The fund of knowledge as well as its application has remained operative on a much restricted scale. It is not reaching major segments of the society. The result is fear, fear of onslaught of deformities. One must realise that here fear is born out of ignorance, out of misinformation regarding the disease, regarding its complications and its treatment. All these are underlying reasons of social stigma and the aversion that we see around. It signifies the distrust of the unknown.

Surgery of paralytic deformities is a specialised and delicate skill. It can be successfully performed by a team of well trained, skilled persons—surgeons, physiotherapists, nursing staff and most importantly a motivated patient. In excisional surgery—like removal of appendix—only passive cooperation of the patient is required. But in case of reconstructive surgery, since patient's learning is critically important, active cooperation of the patient is essential. The surgeon only performs a technical job. The actual teaching and training of the patient is done by the physiotherapist and the occupation therapist who teach care and safe use of insensitive hands and feet. Wherever all these facilities are not available, the result of the surgery is unlikely to be promising. Moreover there are financial constraints.

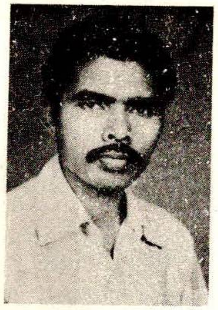
Today such facilities are available only at a few centres. Railway travel concessions are available to the patients. Financial help from trusts and the Government is also available. For various reasons knowledge about these facilities is not reaching the needy families : the patients, the doctors and the public.

All this indicates the direction in which work needs to be done. The month long camp at Bhilai is one step forward in that direction. But its success can be assessed only after a few months, after observing how the patients have been using the new capabilities.

Many such efforts are needed to minimise the difficulties to overcome the constraints and to achieve the goal: treating leprosy like any other disease, reaching the various services to patients easily and effectively.

17. Role of physio-therapy in corrective surgery

Kesar Das and M.I. Khan



Sr. Physio-Technician
Bethesda Leprosy Hospital
Champa

Physio-Therapy plays a crucial role in facilitating functionally satisfying results from Corrective Surgery to Leprosy Patients. Skin tends to become dry in anaesthetic palms and feet. It thickens/toughens and eventually develops fissures and cracks.

Similarly in Leprosy affected paralytic hands, feet, fingers and toes, when the affected joints remain unused and uncared for over long periods they tend to become stiffer. The stiffness results from joint-capsules and ligaments becoming thick, consequently leading to shortening of tendons of long muscles. Condition of shortened tendons, because of constancy of position of flexion, progressively worsens. It eventually leads the bones to get fixed in flexed positions.

It is necessary that patient is made to understand how he could care for his anaesthetic skin and paralytic spillover affecting joints. PhysioTherapy helps the patient to prevent or overcome drying, thickening and cracking of skin and stiffening or contracture of joints, tendons and skin.

To undo the damage done by early neglect which has necessitated corrective surgery, some routine procedures are practiced to alter the fixed position of flexion before corrective surgery is undertaken.

Pre-operative Physio-Therapy

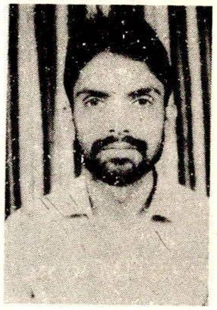
Water, Oil, Wax are the materials that are used to facilitate the procedures. Plain water can help soak and soften dry skin. Oil can be rubbed to further smoothen the water soaked skin. Warm wax can provide moist heat which can act on tissues deeper than skin, such as joints, ligaments, tendons, etc. Warmth thus provided increases blood circulation as well. This procedure is called Wax Bath.

Soon after wax bath the warmed hand with increased blood circulation and softened ligaments is massaged with warm oil. This treatment helps in further softening the skin and in stretching of ligaments and joint capsules. Tenderness and care are of utmost importance while dealing with anaesthetic limbs.

Pre-operation Exercises

Specially designed series of exercises help the joints, ligaments, tendons and the contracted skin to stretch, extend and move in a better range and in improved positions. These exercises are mostly active when done by the patient himself. Therapist can also assist by passively moving and stretching skin or joints if found necessary. Patient himself can learn to perform the passive exercises under the supervision of a therapist.

Improved positions gained by Wax therapy, Massage and Exercises can now be held in maximum extension angles by using Plaster of Paris (Gypsona) ,circular bandages applied to individual fingers making cylindrical splints or tuck-in splints for thumbs, or slab splints made by the therapist. These can be removed everyday and fresh ones applied. This gives progressive opening to stiff joints and facilitates stretching of skin to positions of full mobility. It also provides opening of contracted thumb webs or joint skin flexures.



Physio-Technician
Therapy
Kawardh Leprosy
Control Unit
Rajnandgaon

Towards Plan of Operation

Records kept on range of movements through angle measurements can show progress; and if after adequate time and therapy there is full gain of mobility then attention of surgeon is drawn to consider suitable operative procedures. If the progress stops at some lower than desired level, then the surgeon can consider modified or different procedure to suit the patient's need while preparing the plan of operation.

With the Plan of Operation prescribed by the surgeon the Physio-Therapist further helps the patient to learn and identify the muscle that will be used as a transfer to move the paralysed joints, fingers or toes, and to do the job of paralysed muscles. These substitute muscles are then trained to work as patient's voluntary movements, so as to turn them into a habit for using them independently. This phase is very important for reactivating these muscles under voluntary action after muscle transfer operations; and to make new joints, tendon, fingers and toes and hand or foot functional. This is followed by electrical stimulations. Such stimulations may be needed to make individual muscles contract and stretch as demonstration of their actions for patient's education.

Post-operative Physio-Therapy

Immediately after surgery the hands and feet are immobilized by the surgeon in chosen positions, using Plaster of Paris (Gypsona) bandage Casts or Splints, for periods ranging from 3, 4 to 6 weeks, in cases of hand, foot and bone surgery respectively. This period of forced rest heals wounds, helps set firmly the junctions and unions made by the surgeon; and secures unions of muscles and tendons attachments to bones, joints, tendons and grafts or bones and joints reconstructed.

After removal of the plaster, dressings and stitches, the hands and feet are inspected by the surgeon.

The patients are then turned over to the physiotherapist once again for his care. The patient once again undergoes Wax bath; Oil massage; protective splinting; Graded, selected exercises; and Gradual education. He learns the use of transferred muscles to ensure desired actions.

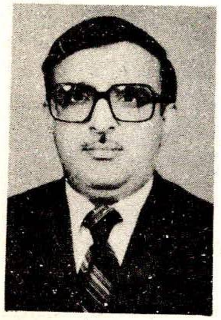
Utmost care and soft handling is necessary while doing anaesthetic limb massage and exercises, primarily to avoid over-stretching, detachment or rupture of new junctions so meticulously constructed by surgeons. Care is also necessary to gain good response to transferred muscle functions.

The early education during pre-operative phase helps the patient now to regain the use of his paralysed limbs.

The patient is delighted to see the recovery, strength and utility of his limbs. The therapist is happy over results of his personal efforts. The surgeon derives satisfaction at the outcome of his performance. After all Reconstructive Surgery is a team-work of the Patient, the Therapist and the Surgeon.

18. Corrective surgery: need for pre- and post-operative patient care

Dr. G.N. Malviya



Leprosy being a disease of skin and nerves, the outcome of the disease in most of the untreated, mal-treated and advanced cases is deformity and disfigurement. Long after the disease is inactive, the loss of sensations and paralysis caused by nerve lesions continue to affect the patient.

The deformities in a leprosy patient can be broadly grouped into three categories:

- Those resulted from paralysis of muscles subsequent to nerve involvement—**Paralytic** deformities.
- Those resulted from the destruction of skin and its appendages—**Non-paralytic** deformities.
- Those resulted from the effects of loss of sensations like ulcers, etc.—**Anaesthetic** deformities.

Paralytic deformities influence functional aspects of limbs like hands, feet, eyes, etc. These need correction usually for occupational rehabilitation.

Non-paralytic deformities are mainly cosmetic in nature. They require correction to help patient overcome his feelings of social awkwardness.

Since **anaesthetic deformities** are caused due to loss of sensation resulting from nerve damage, they are rather difficult to correct. But these can be prevented by adequate precaution and care.

Surgical reconstruction of deformities in leprosy is a well established state of art involving established procedures. The reconstructive surgery is no more experimental. Integrated approach covering disciplines like orthopaedics, plastic surgery and physical medicine have made "tailor-made" operations feasible to suit the needs of a particular patient.

Timing the Surgery

The surgical skills for correction can be acquired with some practice but what is needed is the awareness—the awareness about the feasibility of surgery, suitability of a procedure and need of operation. A combined approach is essential here and a team of surgeon and physiotherapist alone can satisfy the need.

The course of disease normally influences the timing of surgery. The surgery for leprosy being elective, care may have to be taken to ensure good results. While selecting a patient for surgery, certain checks are required to be carried out to ensure: established paralysis (more than 1 year old); history of good response to the anti-leprosy drugs; absence of "reactions" at least for over six months; and whose skin is free from leprosy germs (particularly for cosmetic surgery like correction of nose, etc.).

> ***In post-operative period, injuries are sustained by patients because of their attempt to look and work like normal persons... as they tend to transgress their limit.***

Assessment of Patients

Aim of reconstructive surgeon is to make a patient occupationally functional and socially acceptable. Patient's motivation to accept surgery as a means of rehabilitation is important for the ultimate success of the surgical intervention. Reasons given by the patient for seeking reconstruction, assessment of psychological and

Surgeon
I.C.M.R.
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social needs, age, previous occupation, future needs—all such data is important for planning and selecting appropriate operative procedure.

After thoroughly evaluating pre-operative condition of the hand, the state of non-paralysed muscle needs to be ascertained to ensure its availability for transfer. The condition of joints also needs to be examined against contractures. All this is essential for the success of surgery.

Pre-Operative Physiotherapy

The pre-operative physiotherapy is essential not only to bring the part to be operated to a more acceptable state, but also to develop a crucial inter-personal relationship between physiotherapist and the patient. This is the time when the patient can discuss his problems more openly with the person who is going to be his benefactor. Later this information can be shared with the surgeon while he plans for his surgery.

During this phase, which can last from a week to a month or more, the patients are oriented to different exercises which they are expected to perform after the operation. During this period their corns, callosities, contractures are attended to. The part to be operated is made soft and supple with wax baths, soaking the part in water, giving oil massage. The patient's intelligence and his ability to perform a set of exercises is also assessed. This helps in opting for the appropriate operative procedure. Active participation of the patient is crucial.

Although the surgeon aims and aspires for perfection, he should take the patient into confidence and share with him the prospects and limitations in his case. The basic limitations in restoring his sensations needs to be explained to the patient. It will help to prevent later disappointments.

Post-operative care starts immediately after the operation is over and lasts till the patient is restored its functionality. The post-operative care is usually a time-bound programme. After the operation, any swelling or infection need to be carefully avoided.

When the stitches are removed a programme of exercises begins, depending on the nature of operation performed. This phase calls for close supervision from the physiotherapist and active cooperation of patient. Utmost care is needed because the patient is acquiring newer skills. Since a muscle transferred to a new place has to learn new jobs a conscious effort is needed at this stage. Later on the newly trained muscles integrate with subconscious and involuntary activity. This stage takes between 3 to 6 months to attain perfection. During this period patient needs re-examination at periodic intervals. Since old habits are likely to persist, a conscious effort is called for from the patient to practice new movements. Surgeon and physiotherapist both have to interact with the patient to achieve present goals.

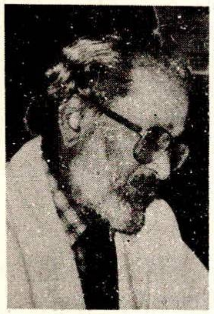
After Surgery What?

The patients usually carry wrong impressions. They are likely to think that surgical correction has 'Cured' them of the disease; and that they can stop anti-leprosy treatment. This notion needs timely correction. Anti-leprosy treatment needs to be continued till the desired state of "Inactivity" is reached. Deformity correction is different from cure of the disease.

In post-operative period, injuries are sustained by patients because of their attempt to look and work like normal persons. The patients generally tend to forget about their handicap and tend to transgress their limit. In the process they are likely to injure themselves. After the surgical correction the patients are more prone to injuries because their hands will be used much more than before. The patients would have to realise the limitations imposed by loss of sensation and take adequate care. This will prevent mutilations and injuries. It will give them lasting benefits.

19. Patient self-care and disability prevention in leprosy control programme

Dr. H. Srinivasan



Disability prevention necessary in Leprosy Programmes:

Multi-Drug-Therapy (MDT) is the greatest advance in the treatment of leprosy since the introduction of dapsone 40 years ago. However, MDT by itself will not solve all the problems of leprosy patients. Even now large sections of the public look upon leprosy as an affliction rather than an illness. Since the leprosy patient develops impairments, deformities and ulcers and becomes disabled on account of them in public perception leprosy is associated with such impairments. When the disease is diagnosed at an early stage, i.e. before the bacilli have invaded nerve trunks, MDT can prevent such invasion. Thereby preventing damage to nerves and also the impairments consequent to such nerve damage. But a large number of patients are diagnosed at a late stage and MDT cannot guarantee that it will prevent damage to nerves and the consequent impairments in those patients. Furthermore, there are a large number of leprosy patients who have already suffered damage to nerves to varying degree and they can develop deformities and ulcers. So long as leprosy patients develop and keep developing problems the public will not be convinced that the patient has been "cured" by MDT. Therefore disability prevention has to be an integral part of leprosy control activities. Only then can we expect public co-operation and participation which alone can make the programme successful in the full sense of the word.

> *A large number of patients are diagnosed at a late stage and MDT cannot guarantee that it will prevent damage to nerves and the consequent impairment in those patients. Therefore disability prevention has to be an integral part of leprosy control activities.*

Director
I.C.M.R.
Jalma Leprosy Institute
Agra.

Patient participation necessary for disability prevention

The physician's role in chronic disorders, though important, is rather limited. These conditions remain chronic because the physician is powerless to remove the cause or reverse the changes that have already occurred. The major burden of managing under these circumstances rests on the patients themselves who have to live with their impairments, and the patient's families and friends. In order to bear this burden it is necessary that the patients as well as their families and friends fully understand the problems they face. This is true for leprosy also. Leprosy patients face a life-long threat of deformity and disability; but with an intelligent understanding of the nature of this threat and with specific help from health-care personnel this threat can be met effectively.

The Problem

The medical aspect of the problem is that, as a result of leprosy, the nerves serving the hand/foot are destroyed and such damage is permanent and irreversible, except in the very early stages.

Because those nerves are damaged, the skin of the hand/foot becomes dry and insensitive; and muscle of the hand/foot may also become weak. The dry skin is apt to develop cracks. The insensitive skin is liable to develop wounds from cuts and burns and also suffer internal injury from normal or excessive use. The cracks, wounds and injuries are not painful as they are to a normal person. This is because of insensitivity. The patient does not bother about them because they do not put the patient in pain. Since they are not cared for, the cracks, wounds and injuries do not heal; they worsen, become septic and lot of tissues get destroyed. Chronic ulcers and contractures develop, worsening the disabilities of the patient. Sometimes the entire bone structure of the wrist or foot may be destroyed and cripple the patient.

The problem for the patient, therefore, is how to escape this dismal chain of consequences despite having damaged nerves. The solution lies in his continuos participation in a Disability Prevention Programme; and in the process develop "Disability Preventive Behaviour".

The goals of disability prevention

The goals of disability prevention are two: (i) to prevent new deformities and disabilities; and (ii) to prevent worsening of existing deformities and disabilities. These goals are achieved by the patient through developing "Disability Preventive Behaviour" (DPB). When the patient realizes that DPB is a way of protecting and preserving one's own person, the goals become attainable and the process of achieving them becomes meaningful and less onerous.

Basics of Disability Prevention Behaviour

1. Only the patient can protect and save her/his limbs. Others can help when they understand the patient's need. Otherwise they may hinder patient's efforts.
2. "Injury consciousness" is the psychological substratum for the development of disability preventive, i.e. self protective behaviour. It is the attitude based on the belief that any activity is potentially injurious until it is proven otherwise.
3. Skin care is self care. The skin will not crack if it is cared for and kept soft and supple. A well preserved skin preserves the hand and foot it covers.
4. For avoiding injury whether at home, at work or by accident, one should ask oneself before engaging oneself in any activity:
    - Is this activity likely to cause injury to my hand/foot? If so:
    - How can I avoid it?

One should also ask *after having gone through an activity:*

- Has this activity injured my hand/foot? If so:
- How can I avoid such injury in future?

Disability preventive behaviour gets established when asking these questions and modifying ways of carrying out injury causing activities becomes a habit with the patient.

5. Allow the injury to heal. The patient has to learn to recognize injuries by looking for them (inspection) and feeling for heat over swollen parts. The patient should also learn to manage minor wounds and cuts and simple ulcers, how to clean them, keep them covered and allow the injuries to heal.

Learning to live with insensitive hands and feet without damaging them is not easy, but it can be done. In any case it will be better than "living" as a cripple with mutilated, deformed and useless hands and feet.

20. Touching moments with leprosy patients in the hospital wards

Prem Pandit

Social Worker
New Delhi

After almost three long months, my husband had gone to Bhilai on a brief visit. On his return home as I opened the door the first person I enquired about was Nabi Beg. An old man of 50, bangle vendor who had slowed down his sales operations lately because of the problem with his eyes. He was operated in April this year for Lagophthalmos. A poor man, for whom it was difficult to pay even Rs.100/- which was the least we expected the patient to pay. In a quick flashback I recollected how in a brisk move we had collected some contributions from even the patients, who were camping at the Shakti Peeth for the 'Self-Care' Camp. Out of these collections we gave him MCR Sandals and Sun Glasses, besides cash towards his Operation Fees. As I handed over the amount and the gifts from the other patients, tears rolled down his cheeks. My husband could understand my anxious enquiries.

Coolly he said: "Not very encouraging news!"

"What!", I exclaimed utterly shocked.

Once again nonchalantly he explained: "Such things happen. Afterall its a big hospital!"

"But why?", I insisted. "I could understand such things happening when patients approach the Hospital routinely on their own. For the Camp cases so many of us were involved. At least twenty persons had made their contributions to Nabi Beg's Kitty, with high hopes and feelings. I'm really upset", I said in desperation.

"That only shows you're new to hospitals. Such things happen in big hospitals. After all even for the Hospital this was a new experience". Once again he was taking a casual view of whatever had happend. I was utterly disappointed with his responses.

"But it was not any hospital", I persisted. "It was our Hospital. It was a Hospital of all those hundred and odd volunteers who laboured to collect funds, to nurse patients. They have reasons to expect encouraging outcomes."

"Getting emotional doesn't help!", he remarked coolly and went in, leaving me behind.

I was disturbed. As I saton the sofa, I lost in recollections of those eventful four weeks. A few striking incidents rushed to my mind which reminded me of the depth of our involvement in the outcomes.

Wherever one went, the Operation Theatre, the Physio-Therapy Unit, the Patient Wards, one came across an atmosphere surcharged with emotions and feelings. I remember how while responding to one female patient one of our Workers had shouted loudly at her. She got so upset. She cried and cried. "Doesn't matter even if I die ... I shall never see his face again"..She declared to console herself. The incident had pleased me so much. I liked the uprightness of the patient. Later on when I met our worker, I narrated to him the strong reactions the woman patient had developed about his ways of handling things.

My mind soon jumped to a few other incidents. In Sector-I Hospital on the first two days when the patients arrived for their pre-operative physio-therapy, they were put up in a separate Ward. The Ward did not have an attached Toilet. They were served their meals not in their Ward, but in front of the kitchen by asking them to sit in a row. Seeing the treatment meted out to 'our' patients, gloom had descended on my mind.

However silver lining soon appeared. The patients themselves made noise about the discrimination. A Senior Officer came and reprimanded the staff. He was stern. He wanted these patients to be treated as any other patient. "We shall not tolerate any discrimination", he warned.

Immediately, the patients were shifted from the separate ward and accomodated on unoccupied beds in the General Ward. That evening they were served food in the Ward along with other patients.

Next day things became normal as far as treatment on par with other patients was concerned. We were happy.

As I sat on the sofa recollecting the events of the Camp, I experienced within me a certain relaxation — an antidote to the depression I underwent earlier.

My mind then rushed to patients in the Wards in Sector-IX Hospital.

Umashankar

Umashankar must be in his early forties. A picture of poverty, he was a hawker who sold Kerosene from door to door. He was anxious to set right his clawing fingers and eyes which had developed Lagophthalmos. But he had no money to pay for the Operation Fees. His wife had brought him to the Hospital with great hopes. When she came to me she was in tears. Umashankar, with all his problems still used to ride his bicycle with the Kerosene Drum on it, and earn a living for the family. His wife had brought Rs.100/- with her, as her contribution towards the Operation Fees. I assured her that her husband's operation will be 'taken-up'.

Since I had to return to Delhi for some urgent work, I introduced her to my husband. He too assured her saying: "There won't be any problem. I shall see you later". Before I left Bhilai I handed over a small note to my husband — as a reminder.

Next week when I returned and enquired about Umashankar, he was not there on the list of operated patients. On enquiry I learnt that my husband could not meet Umashankar's wife that day as promised. Next day when he reached the Hospital, neither Umashankar nor his wife were there to be seen. They had left the place the previous evening itself. Maybe in utter despair. I was displeased with my husband's slack handling of the case. I didn't have Umashankar's address either.

Vinod Kumar

Another young man, who was recruited for Police Training, came in for operation of his hand. While at training he was participating in a parade when the Instructor noticed his clawing fingers as he was saluting. Immediately his case was reported to the higher-ups. The Officer-in-Charge in turn referred the case to the Police Hospital. But instead of waiting for the Medical Report, the Officer discharged him from the training centre.

Later on the youngman fought his battle for over one year. Ultimately he had to give-up even though the medical reprot had shown him smear negative. Eventually the young man joined BSP. Now he is happy with his work. With great hopes he came in to get his clawing fingers operated.

Laxmikant

Laxmikant was a picture of confidence. His father worked as Civil Contractor. They had farm lands too. He had gone to Dubai on a workshop job. There he earned enough money. While in Dubai, he developed the disease. There he was hospitalised. Could not get satisfactory treatment though.

Two years back he returned home. Worked on farm lands of the family. He has plans of starting a Bakery. He has applied for Bank loans. The young man was anxious to get operated soon and then to launch his Bakery project at the earliest.

Sadly enough his medical examination revealed that he had developed Lepra reaction. His Operation had to be deferred. He lay down on hospital bed restless, always giving a melancholy smile whenever I enquired about him.

Shivaji Sharma

Shivaji Sharma must be in his late twenties. He was suffering from acute neuritis. The shooting pains which he suffered had made the life difficult for him. Our intervention with his employers helped him get admitted to the Hospital. The Employers (B.E.C.) — an Engineering Company — have been bearing the entire cost of his hospitalisation. They have kept him on sick leave. He needed blood transfusion. For want of the required group of blood, the transfusion was getting delayed. One of our Doctors donated his own blood. The case could be expedited.

During the second half of my visit I could see marked change in awareness amongst the patients. They had acquired a group identity. A patient who was lying on bed in the Orthopaedic Ward narrated how he managed to get a bed for one of "our" operated patients, whose bed earlier was spread on the Ward floor, for want of a vacant bed. He had kept a close watch on patients getting discharged. The moment he saw one getting discharged, he immediately called the Ward Assistant and requested her to accommodate on the bed "our" patient lying on the floor. Ultimately he saw to it that the patient was shifted to a cot. That patient's name was Dariyao.

Dariyao

Dariyao was in his late forties. He come from Nawagaon. He had one son. His one acre of dry agricultural land was not sufficient for the family's life support. He therefore worked additionally as a casual labourer.

Six years back he had observed a patch on his right thigh. He went to village elders who advised him to ignore it. But the patch started spreading. He also realised that while his whole body sweated the area of the patch always remained dry. He also experienced weakness in the leg. Once again he went to the village elders. They advised him to go to a local unregistered practitioner who diagnosed him by reading his pulse. His diagnosis was paralysis of the leg. The practitioner prescribed medicines (Syrup and Tablets) which was costing Dariyao about Rs. 40/- per month. He borrowed money and took the treatment for nearly 3 months. Not experiencing any improvement, once again Dariyao consulted another allopathy doctor— a private practitioner of Nandgaon, who diagnosed his condition as general weakness and asked him to reprot every 3rd day for treatment. During the visits he was given injections and some tablets. This was costing him about Rs.100/- per month. He never had any relief from this treatment. The patch was increasing.

The Doctor on seeing no improvement, one day took him on his motor-cycle to the Mission Hospital at Nandgaon, and arranged for his skin smear. This confirmed leprosy. He was depressed on hearing about the diagnosis. He developed fever. Even in this Mission Hospital none examined his nerves.

When he returned home he consulted the local PMW — Goswami. The PMW took his skin smear again and examined his nerves. He told him of the impending reconstructive surgery camp at Bhilai Hospital; and advised him to get his name registered for Footdrop surgery. The PMW arranged for his admission to the Surgery Camp.

On further questioning, Dariyao gave me some more information about his case:

Dariyao's footdrop occurred 8 months back when he was under treatment of the Private Practitioner, before he was taken to Nandgaon Mission Hospital for Smear Examination. For his admission to the Surgery Camp in Bhilai, he paid Rs.250/- as his contribution towards Operation Fees. For making this payment he borrowed Rs.100/- from one of his relations in the village. None from the community had taken interest in his case, ever since they heard about his being a leprosy case.

On return home, now, he proposed to resume his work as soon as possible.

He had no plans to improve his income through acquiring new skills. He considered himself too old to think of such changes at this stage.

He also narrated how bad he felt while he was lying down on the bed in the Ward. He saw four patients who came for post-operative check-up all the way from Dongargarh, were asked to come the next day because they reached late, after the surgeon had finished his round.

Surendra Kumar

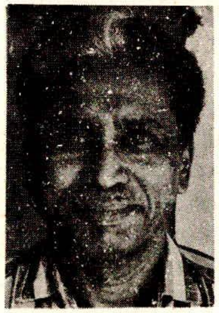
The young boy of 18, Surendra Kumar who was operated for his clawing fingers, however, pepped up my spirits. He greeted me with a broad smile; and narrated how happy he was feeling. He had come to catch up with the Camp programme by foregoing his annual examination of 10th class. He said: "Now once my hand gets alright, I can pursue my studies with confidence and peace of mind. He was not thinking of his earlier job of Basket Weaving. Now he appeared eager to study further.

My mind which was disturbed on hearing Nabi Beg's "not so encouraging" report earlier from my husband, regained some peace after Surendra Kumar's case came to my mind. His smiling face and his involvement with his future plans really had cheered me up.

I got up from the sofa. Went inside. My husband was busy with his paper work at his table, perfectly at peace with himself, unperturbed by Nabi Beg's fate.

21. A stitch in time saves nine

Dr. S.L. Gude



In the process of treatment, episodes of "Reactions" and "Neuritis" signalled by feelings of numbness or tingling sensations in hands and feet, are a forewarning of oncoming disabilities and deformities. Skilful management of these episodes through providing rest to affected limbs, through splints; and through undergoing intense treatment with Prednisone, provides urgently needed succour to prevent setting in of anaesthesia. Such early prevention measures help control oncoming deformities like claw-hand; foot-drop; and lagophthalmos.

The problem of deformity of a permanent nature which stigmatizes the patient, crops up only when the forewarnings get neglected and patient remains without treatment for longer periods. The neglect results in loss of Eye-brows, wrinkling of Skin or the Face, elongation of Ear-lobes and Depression of Nose.

It is said—'A Stitch In Time Saves Nine.' Even a single 'surgical stitch' can be avoided if 'care' is taken to timely treat the early symptoms of sensationless drying skin, which when ignored generally leads to cracks, injuries and ulcers in anaesthetic hands and feet.

Patients with Multi-Bacillary disease practice Nasal Toilet with saline water. It is a simple but most effective practice of keeping the nasal passages and para-nasal sinuses free from crust-forming and mucoid discharge. These are likely to get infected by pyogenic organisms. Since the nasal septum and turbinates are thin bones and cartilagenous tissues lined with thin mucous membranes, possibility of infection from pyogenic organisms; and the infection leading to perforation of nasal septum and eventual collapse of nose is more common.

Danlep District
Co-ordinator
Durg & Rajnandgaon
Districts

The mucous membrane sheds innumerable leprosy bacilli in normal course of untreated disease; and remains the main source of infection to others. Keeping this part of the body clean helps to prevent spread of infection. It also protects the person from nasal deformity.

Nasal Toilet

Nasal Toilet consists of initiating free flow of Saline (0.9% salt water solution) through one nostril of the Nose and its outflow through the other. It can also be practiced by sucking the Saline water through the nose and allowing its outflow through the mouth. The Yoga exercise called 'Neti' performs similar function. The 'Neti-Lota' can be procured from any Yogashram.

Arresting Paralysis of Eye Lids

Eyes need to be protected with Dark Glasses or Goggles to prevent irritation to cornea from light, wind and dust. This is particularly necessary in cases with Multi-Bacillary disease who have paralysis of Eye lids— Lagophthalmos or Iritis and Iridocyclitis. Eyes affected by such anomalies are generally red. Watch for a red eye and be prepared to provide protection.

Protection of Hands & Feet

Hands and feet of Leprosy patients need special attention. Leprosy affects nerves which provide sensations to palms and soles; and motor power to muscles that move the limbs, fingers and toes. Loss of sensation is likely to surface in either of the five areas—Touch, Pressure, Pain, Temperature sense (sensation of Hot and Cold) or loss of Sweating which fine blood vessels control in palms and soles. Each hair on the skin is supported by a very fine muscle that moves the hair. One can notice this in situations when one feels frightened or gets angry or when one is subjected to extreme cold. Similarly a small sac which secretes the body-oil, is provided under the skin to keep the hair healthy. With loss of sweating and loss of the body-oil, skin becomes dry and tends to go dryer progressively. The dry skin hardens and thickens and eventually cracks. With loss of sensation and lack of pain, a person does not realise that such cracks or fissures tend to go deep and cause bleeding. The bleeding is the beginning infection, which causes trophic ulcers. Cuts and pricks or injuries to anaesthetic skin of palms and soles, are not experienced by the patient in the absence of pain. Patients walk with such wounded feet and keep on working with such sensationless hands. If care is taken to keep the dry skin moist and smooth with water and oil massage, the chain reaction set in motion by drying of skin for want of sweating and body-oil, can be arrested and also can be reversed.

Hydro-Oleo Therapy

This water and oil massage based treatment is called Hydro-Oleo Therapy. Patient needs to soak his hands and feet in a basin full of water for half an hour. The affected person can rub and scrub the feet to soften the hardened skin and remove the calloused skin surface at the same time. Immediately after soaking in water, some Vegetable Oil, Cream or Vaseline/Pomade should be rubbed into the skin of palms and soles to retain the moisture in the skin for longer duration. This procedure should be repeated three times a day if possible. The application of oil prevents the escape of water from the moistened skin and protects it from cracking. The purpose would be served better if socks are put on immediately after Hydro-Oleo Therapy to keep the moist and smooth condition of the skin well protected from dust and heat.

Post-Hydro-Oleo Therapy Exercises

Paralytic deformities need exercises after Hydro-Oleo Therapy to keep the joints mobile and to avoid stiffness. The exercises also prevent skin from contracting. Mobile clawing fingers can be corrected by surgery much easily. Stiff fingers and contracted skin would require extended periods of Physiotherapy. They also involve Complex Surgical Procedures for correction of deformities.

MCR Sandals for Protection of Ulcerated Feet

Microcellular Rubber (MCR) Sandals are specially made at the Shoe Units in Bhilai and Rajnandgaon Leprosy Control Units. This footwear protects the anaesthetic feet from hazards of injuries. It also prevents the breakdown of healed trophic ulcer scars and prevents recurrence of ulcers once they are healed.

"Resting"—the Best Healer

Those persons who have ulcers or wounds on anaesthetic hands or feet must get into the habit of resting their hands and feet till wounds are healed. Rest alone can help in healing the wounds.

Keeping Wounds Clean

Wounds can be kept clean, without sepsis and devoid of bad smell by using Betadine. 5 ML (one teaspoon) Betadine per litre of water can make active enough solution for this purpose. The amber colour of such solution resembles weak tea decoction. The colour of the solution disappears after use, leaving behind clear water. The colourless water indicates that the solution has performed its function. When Betadine is added to water in the Basin before soaking hands and feet, it performs multiple functions—Detergence, Disinfection and Deo-dorisation. Betadine applied directly to wounds by itself is the best and adequate dressing medicine.

22. Functional approach to hand surgery in leprosy

Dr. Satish Arolkar

*Surgeon,
Foundation for
Research in
Community Health
Bombay*

Correction of the hand in a leprosy patient is more than mere functional restoration. It is simultaneously a social rehabilitation. It relieves him of the deformity — a symbol of the outcast.

There is anaesthesia in the area of the affected nerve, quite often patchy and incomplete. It therefore, calls for a regional block. In the upper extremity a wrist block is quite adequate. An axillary block facilitates the uses of a tourniquet. Some of the patients requiring hand surgery, therefore, can be operated upon without either general or spinal anaesthesia.

Successful corrective surgery in Leprosy, in order to restore faith in the patient, depends on his co-operation. If the surgery is technically simple, less exacting post-operatively, in terms of man-days lost in physiotherapy, re-education, etc., patient's co-operation in the processes of rehabilitation becomes that much easier.

For the various methods available to the surgeon to correct a paralysed hand, the underlying principles are just two: (i) Static; and (ii) Dynamic.

Movement in the hand joints is ensured by local small muscles and distant tendons. In leprosy both the nerves responsible for innervating the small musculature of the hand get affected. Therefore fine movements get paralysed. The coarse movements conducted by long distant tendons remain intact. The result therefore is instability at the knuckle level or metacarpophalangeal level. This instability can be rectified by a 'static' procedure preventing excess "back-bending"; or extension at the knuckle level. It can also be rectified by a 'dynamic' method making use of the spared long tendons. The static method is simple. It not only stabilises the flail M.P. or knuckle joints but also restores the metacarpal arch so necessary to bring all five fingers together to scoop as in "rice-eating".

This technique can be conducted by any surgeon with an elementary knowledge of the hand. No sophisticated instruments are required. It can be done under regional anaesthesia by using axillary block as a tourniquet.

Care in the design of the skin & facia to be excised alone is essential. The elevated skin flap helps adjust correction under vision.

A single plaster shell for 3 weeks is adequate immobilisation.

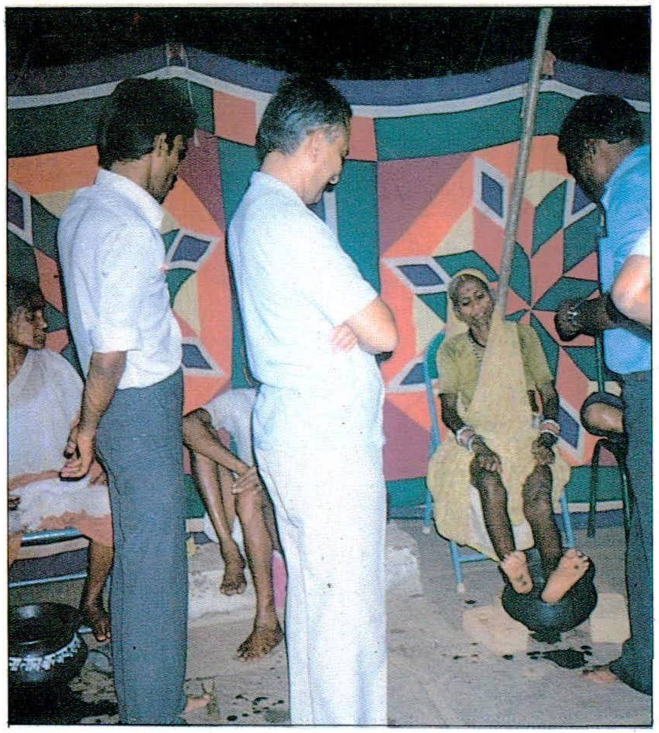
No re-education post-operatively is required as no tendons are transferred.

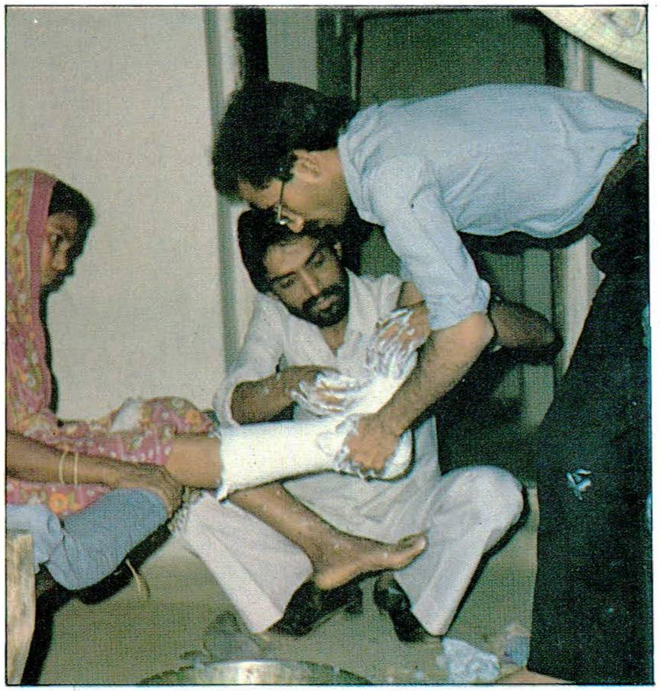
The principles underlying this technique were first explained by Dr Surendra Pandey of Lucknow. I have only redesigned the skin outline to streamline its advantages. Dr Pandey's method involves simple skin excision. Skeptics may point to its possible shortcomings by pointing to the eventual likelihood of stretching of the skin and argue that the method is not best suited for the manual labourer.

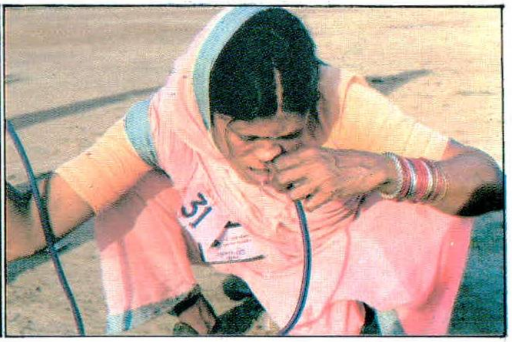
In such cases the CAR technique or Claw & Arch Reversal combination correction may provide the answer.

In this technique the spared long tendon is used to restore M.P. joint stability. Careful rerouting and attachments of the slips so freed under desired tensions, reverses the lost metacarpal arch simultaneously.

This surgery is also done under local anaesthesia, under an axillary block. No tourniquet, no special instrumentation except perhaps a tendon "tunneller" is used. No post-operative re-education is required as anatomy is least disturbed combining and using an extensor of the index finger compliments the procedure totally.







Disability Prevention

'Dread of deformities' no more! Your Cure in Your own Hands! ... Look up!! Measure upto the challenge!!! Week-long residential Self-Care-Practice camps convincingly carried the 'Look-up' message to right quarters: To the Patients, their families, friends and well-wishers!

Unhindered Access

Skin-Disease Diagnosis and Treatment Camps .... safe conduits for diagnosis and treatment of stigma-shy, leprosy-suspect cases. Scores of Cases came to the surface during such camps organised on a wide scale in the countryside. Nine Lepromatous cases in just one camp !

23. Leprosy treatment beyond "self-care"

Dr. P.R. Mangalani

Medical Officer
SADA Bhilai LEU
Bhilai

I was busy making notes on a Patient Card about a patient I had just examined. I was aware someone had come in, and had stood across my table in the clinic room. When he called me in a hoarse voice "Doctor", I looked up.

He was in his late forties, well dressed. I had never seen him before. Like a statue he stood in front of me and stared. From his expression he looked impatient to vent out his spleen. Totally stunned, I kept on looking at him without even showing him a seat. Even stretching of my imagination didn't provide a cue for the possible purpose of his abrupt entry into my room. When he had called: "Doctor", that too in a tense voice, I could make out he was in intense anger.

"Who was that 'Idiot' who shouted at my wife yesterday?" The well dressed man ventilated his anger.

Soon a reasonably dressed woman appeared in the Room. She was Veena Verma. She was staying just at a stone's throw away from the Clinic. We have been treating her since 1981.

At first she had complained of acute pain in her right hand. We had treated her for nutritional deficiency.

I did not know earlier that the man standing in front of me was her husband. The person to whom he reffered to as 'Idiot' was in fact one senior doctor. He was not in the employment of BSP. He was a specialist in leprology and happened to be in the clinic when Veena Verma came to Clinic yesterday. Because she could not give a coherent chronology and credible account of first symptoms and subsequent changes introduced in the treatment over past seven years the visiting doctor had lost his temper. Her husband was a regular BSP employee, entitled for free medical treatment; and courteous behaviour from doctors in BSP Hospital. He was upset because the visiting doctor had behaved rudely with his wife.

Veena Verma though was started with treatment for nutritional deficiency, soon could be diagnosed as leprosy patient when she came complaining about a big burn patch on her elbow which did not cause any physical pain.

By this time we had introduced multi-drug treatment for leprosy in our Dermatology Unit at Sector IX Hospital.

She was regular for first few months in her attendance. But whenever her pain subsided, she tended to discontinue the treatment. Her irregular treatment continued upto 1986. Then we shifted the leprosy unit at this new place. Though now we were closer to her residence, for more than a year she never showed her face. We didn't have her full record with us at the LEU. Because she appeared here as a fresh case in 1987. The senior doctor had lost his temper because neither he could lay his hand on the Case Record nor could the patient narrate important landmarks in her case in a coherent manner.

She was being treated last year sometimes with steroids and now mainly with Lamprene. As a result her skin had acquired almost chocolate colour. That had added to her anxiety for the past couple of months. The immediate provocation that had brought her to the Clinic yesterday in panic, was a shooting pain in her right arm.

I had not met her husband before. May be because he did not want to associate with the identity of his "leprosy-patient" wife in the public eye. I shuddered to think of a husband who could never show his face for consulting a doctor about his wife's disease. But could suddenly jump at his feet the moment he got a cue about her ill-treatment by the doctor.

Whatever way I may like to explain, the neglect to Veena Verma was a proven fact. Who is to blame for this neglect is a secondary issue at the moment. Because I know, how right from the word go 'neglect' becomes the order of the day for cases suffering from neuritis in our present methods of operation. These cases do not receive proper attention. It is not as easy to pass on the buck to the patient. This aspect of the disease somehow gets sidelined even under our health education programme. What is missing is adequate awareness.

We organised a major 'Self-Care' orientation in anaesthesia based problems like ulcers, etc. as part of the Aarohan programme in Bhilai. But even in Bhilai, neuritis based case management problems got side lined.

Veena Verma's case, in no way, is exeptional. Many more such cases can be cited. Let us take of yet another patient — Manikam. Manikam was a shop on his feet, hawking clothes in the streets. After noticing a patch on his abdomen, he consulted some private practioner. He took medicine for some time. The patch did not disappear. Instead more patches appeared on his body and also on his face. At this stage his case was suspected for leprosy. He consulted a private dermotologist. When he came to know it is leprosy, he panicked. He started a hide and seek game with his close acquaintances.

In the meanwhile he developed "Lepra Reaction" and gradually he turned into a Psychotic case. After he exhausted his savings on treatment; and started suffering financial hardships, he returned to his native place in Andhra Pradesh with the unsound mind.

I quote here a third case. Chandrakant an ambitious young man who/some time back noticed light coloured patches on his chest and his back. He consulted a few doctors who diagnosed it as allergy. They obviously treated him for allergy. After a few months Chandrakant developed intolerable pain in his limbs. He was admitted to a general hospital. There it was diagnosed as leprosy. Before he could overcome the initial shock, he had alredy developed deformities in hands and feet. The deformities came on him so sudden. He showed himself to various doctors. But did not get any satisfactory treatment.

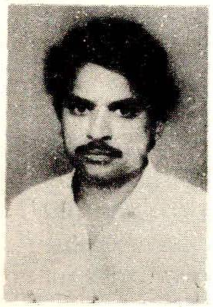
All this goes to show that due to lack of early and proper diagnosis of the neuritis type of cases, and timely treatment of complications that arise out of incorrect diagnosis and consequent wrong treatment, the patients do suffer. These are lapses in management of the disease. Most of the neural cases initially give symptoms akin to nutritional hunger. In the absence of experience in leprosy diagnosis, the practitioners do not take simple tests either to check on the loss of sensation; or care to feel the nerve inflammation.

The need of the day is to think seriously about not only the treatment of leprosy patients but management of the disease mainly in the context of lepra reaction, and other complications arising out of the treatment, including health education. Recently I heard of a case from a neighbouring LEU where the Para-Medical Worker, when confronted with a severe reaction case on his Pulse-Day visit, left steroid tablets with the patient alongwith the pulse dose. Not knowing the complications it might cause, the patient consumed these tablets almost daily. By the next pulse date when the PMW met the patient, he was bleeding through several erruptions on his body, almost looking like a burns case.

There is one more dimension of case management. It falls in an area requiring combined operation of the local community and the treatment providers. One youngman—a landless labourer—a M.B. Case under treatment initially ignored the symptoms of neuritis. He worked on earth work jobs. When properly diagnosed, he required bed rest for at least one month. Local community came to his rescue. They paid for his to and fro travel costs to Raipur. Arranged for his indoor admission at RLTRI Hospital; and provided sustenance for his young wife and her child, since the patient remained out or work.

24. From Donagarh to Dongargarh

Suresh Soni and Harjeet Arora



Chairman
"Peedit Sweekar Samiti"
Dongargarh.

"Suresh Bhai, didn't I tell you? ... Now you've seen it with your own eyes!" ... murmured Bhayyaji the Chairman of the Temple Trust, just as I entered his shop where he was sitting along with three-four other Members of the Trust. He had specially sent for me. I was rather puzzled, not knowing the context of Bhayyaji's remark. Before I could ask, he explained: "They have money for hiring Maruti Cars and Video Camera Units ... and no money for feeding the poor?" ... I could immediately make out what Bhayyaji was hinting at. I was a member of the management committee of the Trust and was instrumental in making the Trust donate Rs. 3,000/- for the 10-day Mixed Group Residential Camp being held in Dongargarh. Today was the 1st day of this camp. About 500-600 villagers and more than 200 leprosy patients from the surrounding villages, some of whom were to join the Camp, had poured in the town from all directions, amidst deafening slogan shoutings, and drum beats, through processions. The town was taken by utter surprise. A video-shooting Maruti Van was moving in the vanguard of the procession recording the moods and musings of all that was on the move in the bearably hot November afternoon.

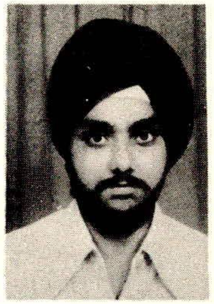
"But Bhayyaji, we are the hosts", I explained as I was settling down in a chair. "Different agencies are participating in this event. Just as there is government there are other people from Delhi who have experience in providing Patient Education in long duration residential camps". As I was explaining, Bhayyaji's man brought us tea. While sipping tea I continued: "These agencies wanted us to play hosts to the patients. They never expected us to meet their expenses. We're spending on food for the patients alone."

"If they had money to spend on cars and Camera Units, they could have as well spent on feeding the Patients", Bhayyaji interjected. "Why waste Trust funds? What would people say who donate to the Trust?"

"But Bhayyaji, they never approached us because they didn't have money for feeding the patients", recalling earlier discussions I explained. "It was we who wanted to join hands and feed the patients as the village people had done in the surrounding villlages. Isn't that true?"

It was almost half an hour before Bhayyaji could cool down.

Such reactions from the townsfolk were but natural. They had their own ways of looking at things. In their eyes certain things did mean extravagance. In a way they were right. Let's see the way the PWD Engineer — Vermaji — responded that evening. None had invited him to the meeting. He came; and sat through the discussions of his own. We were considering how to organise the campers' feeding gracefully, as well as economically. After examining various alternatives without changing the Menu, we brought down the cost estimates from Rs. 18/- to Rs. 12/-. The tenor of our discussions must have influenced Vermaji. Without coaxing by anyone, he announced contributions for one day's feeding costs (Rs. 1,500/-) from his Office Staff. If persons like Vermaji viewed the Maruti Car or the Video Camera Unit as extravagance, one need not be surprised.



General Secretary
"Peedit Sweekar Samiti
Dongargarh.

Like Bhayyaji, Mr Verma also got in tune soon with the Camp organisation.

All that was happening at the Camp was a totally strange experience for the prominent citizens of the Town. They had always imagined leprosy patients in dirty, tattered clothes, with deformed limbs and ugly looks. They were wonderstruck to see amongst patient ranks strong and sturdy persons, hardly distinguishable from other non-patients. Their clean and tidy ways of living at the Camp impressed them so much. Their mixing together with other villagers and leprosy workers without any reservations was a spectacle unthinkable for them. Invariably they sent in their family members in the evenings to the Camp-site to move about and see things for themselves. One day even Bhayyaji visited the Camp in the morning. He waited to see how campers—the patients and the non-patients—sit together and eat their lunch. He did not join the lunching group though. In the evening he sent in his wife and other women folk and children from his family to visit the Camp. As days passed the Camp visits became a festive occasion for the people. Perhaps it was because they were seeing the patients in a more acceptable form. It opened new vistas in their understanding of leprosy. Young men from the Town got together and started supplying milk, fruits, sweets, soap, etc. as voluntary gifts.

We had reports from different village centres earlier about the 'rise' of patients in the estimation of the village elders during the previous week—before they were brought to Dongargarh for a Central Camp. Garlanding of patients at the hands of village elders; receiving patients in a festive style—with drum beats; local Rich persons giving shirt lengths to those patients who just could not afford to bring clean, untorn 'spare' as the organisers had anticipated; feeding them free of cost with a generous heart; all such reports did not fall beyond credibility limits of the townsfolk now. However what we heard about a reception given by one Village Headman from the Bor Taalab area, first sounded just incredible. But it was found true. Here the village headman and his wife literally washed the feet of 20-25 patients whom they had invited for lunch. They did it in the true Chhattisgarhi style of traditional hospitality. It was difficult for us to reason out the underlying motivation. But soon such reprots became common place. Gradually they trickled through different layers of the town; and resulted in bringing the townsfolk including our Bhayyaji — closer to the cause of leprosy patients. To Bhayyaji Maruti Van no more remained an 'issue'.

It did not take us long to realise that Bhayyaji's sharp reactions earlier, actually reflected his displeasure at our indulgence in defiance of the traditional leadership. Once the camp was over and accounts were finalised, our cost effective management of feeding, came in sharp focus and earned us acclaim even from the old stalwarts. This pacified the uneasiness caused by the youthful defiance earlier. "Peedit Sweekar Samiti" — the committee which managed the Camp, acquired new respectability in the eyes of even the 'old guards' like Bhayyaji.

What the Camp left behind for the people of the area was a new role' for the non-patients community, a new understanding' of the 'disease', and a 'new image' for the patient.

People not only saw, at least in a large majority of them, clean and respect evoking persons, but also sensed the depths of their longings for company, for good life, for healthy living. The youthful amongst the patients were prepared to pay the price for making extrovertness the hallmark of their life. They revealed their patient identity without any fear. They played together. They shared their hopes and fears. The way they responded to practicals of 'Self-Care' — in order to confront the onslaught of anaesthesia, did leave behind lasting impressions. A few amongst the patients effectively played the roles of the 'Teacher', and the 'Educator'. It was an unforgettable experience.

Within two-three months, yet another camp came our way. It was organised at Purena under the same banner of "Peedit Sweekar Samiti". New insights gained at Dongargarh Camp were put into practice here far more convincingly. Management initiatives were seen vastly diffused. A new Worker-Patient-Village leader combine emerged on the camp management scene. We didn't wait for Trust to make donations. Contributions came forth in 1 or 2 kgs. of Rice but from a larger multitude.

We returned from Purena with new awareness of combined strength, with redoubled faith in ourselves and our capabilities.

Yet another two months and the new awareness of 'strength' burst its seams, when it came to parading the "new-patient-identity" openly in the streets of Bhilai. In a specially charted passenger Coach, flaunting Patient Badges on their breasts, conscious of their inner strengths, 62 patients joined the famous Solidarity Run' — Marathon of Bhilai, on 4th April; and jostled together with non-patient civilians in a mood of gaiety and new awareness.

The Coach returned to Dongargarh from Bhilai during late night hours leaving their 'ill-person' identity behind for all time to come.

25. Leprosy control from across the drawn lines

Dr. T.P. Sharma

Director
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Bhopal.

National Leprosy Eradication Programme is being developed and implemented on new lines in Rajnandgaon, more particularly in Dongargarh; and subsequently in Durg. It opens a new chapter in a highly stigmatised sphere of "health". Our limitations in providing effective preventive or protective cover to the community at large against leprosy is one of the factors that explain perpetuation of stigma about this disease. But let us not gloss over the fact that this is just one amongst the many other factors that have escaped our attention. It a sphere of public health where social image of the disease and its cure remains a major stumbling block, group methods of work should have remained a logically sound strategy. A diamond is cut only with a diamond. Recent experiments in community participation in the two districts of Madhya Pradesh underline the scope for renovation of our methodologies.

> *The problem of worker motivation and slack supervision was not so much related to administrative design and procedure It was embedded more in the "secluded" style of functioning of the control system at the outreach*

Problems confronting the programme are menifold. These appeared insurmountable. In the administrative parlour it was lacklustre field worker motivation; and slack as well as narrow-vision-supervision. At the patient level it was fear of ostracisation; and oscillations in the patient response, who needed early diagnosis and regular, uninterrupted treatment. At the community level it was the social resistance to reinduction of non-infective and cured leprosy patients back into the social mainstream. All these were but outward manifestations of the problems that confronted the delivery system in leprosy. The basic problem, however, revolved around the "Fear" of the disease deeply ingrained in the mind of the community, including that of the medical profession.

Whereas the Programme design talked about concerted attack on all these problem fronts, we could do precious little because at the operational level it tended to work only in a piecemeal fashion.

The problem of worker motivation and slack supervision was not so much related to administrative design and procedure. It was embedded more in the "secluded" style of functioning of the control system at the outreach—totally cut off from the social mainstream. Rather subdued by social and professional value systems. Symbolic of this is the "Road-side Clinic". It connoted secrecy as well as social distance. The 'distance' nurtured by professional circles is only obverse side of the same coin. How to put an end to this 'seclusion' was the crux of the problem that confronted the administrative design.

How to overcome the problem of "seclusion"? Can it be resolved by formal integration of the control system with general health? The administrative opinion has remained divided on this issue. The controversy over whether the vertical system would be more effective or the horizontally integrated one tends to develop into an academic debate in view of the basic character of the problem—the problem of seclusion at the periphery.

There is no point in advocating horizontal integration of leprosy control with General Health on a formal basis. Formal integration would pose more problems than what it would solve. How the problem could be tackled at an informal level was illustrated effectively in the district of Durg. Here Intensive Therapy under MDT was planned and executed under joint auspices of the community, the district administration and the health administration.

As we have seen, community participation helped accomplish a task in just over two months which would have normally taken more than two years. Maybe integration attempted here was on an ad hoc scale, but the joint campaign did involve integral man power operations at an informal level.

Reaching the drugs expeditiously to the patient was but one of the objectives. Genuine patient care which included problems posed by reaction and nerve involvement cases, required more concerted application of combined energies. Such combined application, in turn, creates demands on high degree of field worker motivation and also on an inclusive style of supervision. These are critical factors to ensure prevention and arrest of deformities as well as disabilities. Dongargarh Block in Rajnandgaon District has handled the task in a superb way. Here worker motivation is found at its best because distances between the field worker and the patient on one hand and the field worker and the general public on the other have narrowed down to almost zero level. Even the distances between the patient and the community are withering away fast. It is the social environment of this nature that is found more conducive to promotion of "integration" which is simultaneously informal and functional.

That this can happen within the distance conscious' administrative system by itself carries conviction to an otherwise cynical mind.

We are used to working in such integral fashion during the 'campaigns'. Our campaigns, besides being ad hoc in character, represent "one-shot" approaches. Whereas the highly stigmatised field in leprosy requires release of social forces on a continuing basis. Notions of authority and authority-centred hierarchy, run right through the organisational design. We may have to give a serious thought to examining the scope for non-hierarchical accommodation of community participation on a continuing basis.

A comparative look at the manifest difference in quality that field worker motivation and perceptive as well as inclusive supervision make at the periphery, is convincing enough. But in terms of assessing feasibility of induction of such inclusive methods and ensuring measurable outcomes, which is mainly the administrative concern, it calls for studies in depth.

In the sphere of Leprosy—more so because of its social denominators—qualitative aspects of field work are of significance to performance appraisal. The fact that only a few workers could bring about a high rate of voluntary reporting of fresh cases cannot be subordinated to our concern for measurable outcomes. It has been observed that only field workers with effective rapport with the community and the patient, have succeeded in maintaining higher rates of patient attendance on 'pulse' dates. The character of influence underlying voluntary reporting of fresh cases has further underlined the qualitative dimensions of field work. For genuine qualitative appraisal, additional data on mode of case reporting acquires added significance. Fresh case reporting based on patient to patient communication or community leader to patient communication, will be more valuable for eventual integration of health services at the delivery point.

From the reports on patient showings at the Bhilai Corrective Surgery Camp, patient or community contributions towards the Operation Fees and field response to such insistence on collaborative effort were indicative of qualitative aspects of field work and of the depth of field worker involvement. Such indicators need scrutiny before their integration in administrative procedure is taken up.

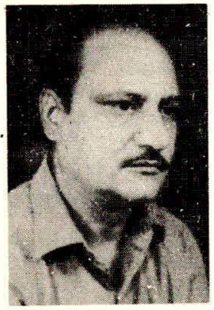
I am told that deep, qualitative and inclusive involvement of the field worker in 'patient care', is proving helpful in giving new content and vision to "patient-care-centred-supervision". For the first time the system has started paying concerted attention to anaesthesia based problems of the leprosy patients which tend to keep them locked lifelong in the disease psychosis.

The new focus on prevention of deformities has highlighted the need for continuing community involvement. Because it is their involvement alone that holds promise of bringing about qualitative change in field worker responses. If these trends are allowed to progress further, the day may not be far off when the leprosy programme would be in a position to fix its eyes on more august preventive aspects — goals which hold promise of segregating leprosy from the 'dread' of deformities.

26 डोंगरगढ़ का पथ प्रदर्शन

डॉ. जी. पी. मिश्रा

जिला कुष्ठ अधिकारी,
जिला राजनांदगांव



१७ मार्च, १९८७ का दिन। डोंगरगढ़ में (राजनांदगांव जिले में) चल रहे राष्ट्रीय कुष्ठ उन्मूलन कार्यक्रम को एक नई दिशा पर मोड़ने का प्रयास। क्या था वह प्रयास? एक अजीबो-गरीब विचार को अपनाने की हलचल थी। वह विचार था सेवा के माध्यम से समाज शिक्षा (Community Education through Comprehensive Services) लेकिन इसे पेश किया गया था एक सवाल के रूप में। कुष्ठ रोग के बारे में समाज की समझ काहे से बदलेगी? ज्ञान के बढ़ावे से या संवेदना की गहराई से? क्या ज्ञान संवेदना बढ़ायेगा?

दूसरी समस्या थी कार्यकर्ता को अखरने वाला उसका अकेलापन। इसे उठाया गया था दिसंबर १९८६ में। खटिया में हुये कार्यकर्ता प्रशिक्षण के दौरान। ''मीलों-मील सायक्लिंग करते गांव पहुंचते हम। कोई पानी के एक ग्लास को भी नहीं पूछता। यह दयनीय स्थिति कौन दूर करेगा हमारी?'' नया विचार कहता था: ''केस **डिटेक्शन** के काम से बाहर निकलो। जासूसी, अकेलेपन की जड़ है।'' मुश्किल था अपनाना इस विचार को। लेकिन आसान भी न था उसे ठकराना या भुला देना।

यहां से खोज का प्रारम्भ हुआ। पहला कदम था कुष्ठ उन्मूलन और जन भागीदारी की कार्यशाला। यद्यपि कई दिनों पूर्व से ही इसकी तैयारी शुरू की गई थी, पर कितनी सफलता मिलेगी, मिलेगी भी या नहीं कोई आश्वस्त नहीं था। न कार्यकर्ता न ही मार्ग-प्रदर्शक। बस धुन थी एक खोज की। इस खोज में शरीक हुये अलग-अलग श्रेणी के करीब ४० कुष्ठ कार्यकर्ता और आसपास के गांवों के ७०-७२ प्रमुख व्यक्ति—पुरुष और महिलायें। वह शरीक हुये जन- भागीदार के रूप में। दस दिन तक साथ रहने की उनकी मान्यता थी। कार्यकर्ता और जन-भागीदार एक परिवार की तरह मिलजुल कर रहे। पूरे कार्यशाला परिवार में कुष्ठ के प्रसार संबंध में विविध मत थे। एक मत दूसरे को काटता रहा। परिणाम स्वरूप कुष्ठ के पूरी तरह ठीक होने के संबंध में समझ बनने की बजाय बिगड़ने लगी। कोई कहता कुष्ठ पापों का फल है और कोई उसे तालाब में नहाने से होता है बताता। कोई कहता छूने से होता है। कुल मिलाकर निष्कर्ष निकला कि कोई नहीं जानता कुष्ठ रोग फैलता कैसे है। यही विवादास्पद स्थिति कुष्ठ मुक्त मानने के संबंध में भी थी। विकृति के रहते व्यक्ति रोग मुक्त नहीं माना जा सकता। यह लगभग सभी की मान्यता थी। किन्तु इसे झुठला दिया श्री प्रेम लाल ने जो रोग मुक्त थे किन्तु उनके हाथों में थी विकृति।

विवादस्पदता तो बढ़ी लेकिन साथ रहकर काम करने की उत्तेजना और बढ़ती गई। समाज के साथ मिलकर जगह-जगह चर्म रोग निदान शिविर लगाकर कुष्ठ का निदान शुरू हुआ। आम लोगों के सामने निदान करने से समाज की झिझक टूटती गई। ऐसे विश्वास नहीं होता था। लेकिन एक ही शिविर में ९ एम.बी. **केसेस** मिले। धीरे-धीरे यह बात स्पष्ट हो गई कि कुष्ठ से घृणा कैसी? विचार मंथन चलता रहा। और चलती रही नई समझ की बढ़ोत्री। यह भी आम लोगों की तरह एक रोग है और उसी तरह फैलता भी है जैसे दूसरे रोग। यह भी स्पष्ट हुआ कि जिस तरह माता की बीमारी ठीक होने पर भी दाग रह जाते हैं वैसे ही विकृति भी रह सकती है। यद्यपि यह जरूरी नहीं।

साथ-साथ चला विकृति के मुकाबले का सिलसिला। विकृतिग्रस्त दो महिलायें और एक पुरुष जिन्हें मालिश की जरूरत थी, जिन्हें अपनेपन की आवश्यकता थी सामने आई। धीरे-धीरे उभर आई अपने हाथों मरीजों की मालिश करने की प्रेरणा। दो महिलाओं ने बिना हिचकिचाहट के विकृति ग्रस्तों की मालिश की। जन-भागीदारों की झिझक टूटी। साथ ही टूटी झुलझुलाहट से भरी विवादस्पदता।

एक नया विश्वास कार्यकर्ताओं में जागा कि सेवा में उन्हें समाज साथ देगा। सेवा के माध्यम से अकेलापन दूर होगा। जन-भागीदार और समाज के कुछ लोग साथ हुए। सफलता मिली और कदम आगे बढ़े।

पहला कदम उठाया एक कार्यकर्ता श्री एस.एम. नायडू ने। वह थे एन. एम. एस खैरागढ़ के। वह प्रेरित हुये कि वह भी अपने क्षेत्र में ऐसा ही शिविर लगायेंगे और समाज में संवेदना का नया दौर शुरू करेंगे। खैरागढ़ में शुरू हुआ एम.डी.टी. का सघन कार्यक्रम। जन-भागीदारों के सहारे हौंसले बुलन्द हुए थे नायडू के। समाज का खुल्लम-खुल्ला पेश आना और कार्यकर्ताओं की टीम पर आधारित सेवा प्रदान करना, यही रहा नायडू के काम का स्वरूप।

यहीं से उत्पन्न हुआ नया विचार। क्यों न एक ही सेक्टर के अलग-अलग सेवा केन्द्रों में (Service Delivery Point) प्रतिमाह पूरे दिन के लिए सेवा प्रदान करने का यही प्रयास जारी रखें। इस जीवन्त उदाहरण से हमारे पीड़ित भाई बहनों के साथ समाज के विशेष और साधारण हर वर्ग के लोग समय व्यतीत करें और दूर करें उनके मन के भीतर छिपा भय, दुख, असहायता। पीड़ितों की आप बीती सुनें। अपने गुनाहों के लिए पश्चाताप करें और प्रायश्चित भी। ताकि भविष्य में कोई भी कुष्ठ पीड़ित न हो, शीघ्र ही जांच और इलाज हो।

इस विचार से सोमनी सेक्टर के ग्राम मनकी और ग्राम सोमनी में एक दिवसीय शिविरों का आयोजन किया गया।

इन शिविरों से एक और बात सामने आई। एक पीड़ित श्री जैताराम जिसके पैरों में घाव थे, उसने अपनी दवा और पट्टी अपनी पगड़ी में महीने भर के लिए सुरक्षित रखी थी। कार्यकर्ता ने अपना फर्ज पूरा किया। मरहम पट्टी, कपास कुछ दे रखा था जैताराम को। किन्तु उपचार तो दूर रहा था। लाभ कुछ नहीं?

एक दिशा मिली कि सिर्फ रस्म पूरी नहीं करना है। हमें सेवा करनी है। स्वयं की सेवा पीड़ित स्वयं कर सकें ऐसा बनाना है हमें पीड़ित बन्धुओं को।

सोमनी और मनकी में उभर आयी और एक नयी ताकत। दोनों एक दिवसीय शिविरों में कुछ पीड़ितों ने उनमें बसी कुष्ठ रोग सम्बन्धी जानकारी की गहराई का अनुभव करा दिया। यह गहराई कुष्ठ कार्यकर्ता के ज्ञान को भेद रही थी। ज्ञान के साथ-साथ उनमें अनुभव की प्रखरता थी। समझने का आसान ढंग था। फिल्म, स्लाइड, पोस्टर, आदि आडम्बर की उन्हें जरूरत नहीं थी। समूह में शामिल दूसरे पीड़ितों के सहारे रोग निदान करते-करते समझाने की सहज शैली थी। क्यों नहीं अपनाया जाये इसी शैली को? शिक्षा के इसी प्रभावी माध्यम को? यहीं से हुआ प्रादुर्भाव "पीड़ित बने शिक्षकों का" (Patient-Turned-Educator)।

नये तजुरबे। नये साधन। समस्याओं को सुलझाने की नित नई कोशिश। यही रहा आगे बढ़ने का तरीका। नये तजुरबों को अपने काम में अपनाने का ढंग। अपने मामलों को नये ढंग से सुलझाने की लगन। इसी लगन से निकला एक नया प्रकल्प।

क्यों न सभी एम.बी. केसेस को एक जगह १४ दिन रखकर गहन चिकित्सा (Intensive Therapy) दी जाये। सभी कार्यकर्ताओं और मार्ग दर्शकों ने तय किया और १६.११.८७ से कार्य प्रारम्भ हुआ। पहले पांच अलग-अलग गांवों में पांच दिनों तक, पीड़ितों को रखा गया, उनके साथ कार्यकर्ता भी रहे। गांव वालों ने किया खाने-रहने का प्रबन्ध। फिर २०.११.८७ से सभी मरीज और कार्यकर्ता डोंगरगढ़ आने को थे। एक समिति का गठन नागरिकों ने किया, नाम दिया "पीड़ित स्वीकार सेवा समिति।" फिर इसी समिति ने किया सभी के खाने और रहने का प्रबन्ध।

पांच अलग-अलग कुष्ठ निदान केन्द्रों के ग्रामों में शिविर पांच दिन तक लगे थे। उसी के साथ एक-एक गांव में उप शिविर भी लगा रहा। आसपास के ग्रामों से कुष्ठ पीड़ित, (एम.बी. केसेस) और कार्यकर्ता वहां पांच दिन तक रहे।

टीम लीडर अपनी टीम के साथ पीड़ितों के साथ उठना बैठना, खाना पीना करते थे। ग्राम वासियों से एक लगाव हो गया था सभी का। आखिर पांचवे दिन हुआ बिदाई समारोह। दुखित मन से ग्राम

वासियों ने अपने स्वजनों मेहमानों को भावभरी बिदाई दी। गाजे बाजे, जुलूस के साथ सम्मान सहित उन्हें मुख्य शिविर स्थल डोंगरगढ़ तक पहुंचाया गया।

यहां एक नई दिशा मिली, पीड़ितों को भी कार्यकर्ताओं को भी। क्यों विकृतियां आती हैं, क्यों पैरों में घाव होते हैं। क्यों नहीं हम उन्हें रोक लें होने से? इन प्रश्नों का उत्तर यहां मिला? डा. गुडे के मार्ग दर्शन में तथा श्री खान पी.टी. और अन्य कार्यकर्ताओं के सहयोग से शुरू हुआ, जल-तैल पर आधारित उपचार का दौर, दिन में तीन बार।

कार्यकर्ताओं ने देखा, पीड़ितों ने अनुभव किया कि साधारण जल-तेल उपचार में भी असाधारण क्षमता है उनके अंगों को विकृतियों से रोकने की। एक और नई राह मिली, मरीजों की सेवा की। किन्तु यह सब कुछ विशिष्ट लोगों के मार्गदर्शन में होता रहा था।

कार्यकर्ताओं में उत्साह **जागृत** हुआ एक नया आत्मविश्वास आया। क्यों नहीं यह शिविर हम स्वयं आयोजित करें। क्या जरूरत है मार्गदर्शकों की?

जनवरी ८८ आई। कार्यकर्ताओं ने एक जुट होकर निर्णय किया कि ग्राम पुरैना में मोहारा और डुन्डेरा सैक्टर के पीड़ितों का शिविर लगाया जाये। इस हेतु सारा सहयोग आसपास के सभी ग्रामों के ग्रामवासी करेंगे।

पीड़ित स्वीकार सेवा उप-समिति पुरैना का गठन हुआ और दिनांक ६.२.८८ से शिविर ५ अलग-अलग स्थानों पर शुरू हुए। पांच दिन पांच स्थानों पर उसी तरह उप-शिविर हुए और फिर मुख्य शिविर पुरैना में प्रारम्भ हुआ १२.२.८८ से २०.२.८८ तक।

यह शिविर कई **दृष्टिकोणों से महत्त्वपूर्ण रहा।**

पहला तो यह शिविर केवल शासकीय कार्यकर्ताओं और ग्रामवासियों के प्रयास से हुआ। दूसरा इसमें केवल शासकीय और ग्रामवासियों द्वारा एकत्रित राशि तथा धनधान्य उपयोग किया गया। शासकीय राशि की केवल उतनी ही गिनती की जो साधारणतया उपलब्ध हो सके।

किन्तु इस शिविर की सफलता पूर्व में नवम्बर माह में किये शिविर से अधिक रही। क्योंकि यहां स्वयं पीड़ितों ने स्वीकारा कि उन्हें आशातीत लाभ हुआ है। ग्राम वासियों और पीड़ितों के बीच की **दीवार टूट गई। यह पहचानना कठिन था कि कौन पीड़ित भाई है और कौन अपीड़ित। सभी एक रस हो गये थे। इस शिविर से** कार्यकर्ताओं का आत्मविश्वास उभरा।

फिर बात आई कि क्यों न हम सब मिलकर अपने अन्य साथियों को भी यही राह दिखाएं, यही सब सिखाएं और इसकी पूर्ति के लिए कुष्ठ नियंत्रण इकाई कवर्धा से कार्य आरम्भ करें।

कवर्धा के सभी कार्यकर्ताओं की एक बैठक हुई। दिनांक ५.४.८८. से ९.४.८८ तक आयोजित किया गया एक शिविर। खुद ही **शिक्षक खुद ही के प्रशिक्षार्थी। "सेवा करो और सीखो"** In-service Training को In-group Training का नया स्वरूप दिया गया।

डोंगरगढ़ की सफलता, पुरैना का दिल फुलाने वाला अनुभव, दोनों के किस्से और उनकी चर्चा यहां भी फैल चुकी थीं और इसी से प्रेरित होकर ग्राम खैरबना के कार्यकर्ता अपने अन्य सहयोगियों सहित आगे आये अपने यहां के सेवा शिविर के आयोजन की और सफलता की तमन्ना लेकर।

ग्राम उपरवाह में भी तीन दिवसीय स्वरक्षा शिविर का आयोजन केवल ग्रामवासियों के सहयोग से सफलतापूर्वक किया गया।

मार्च १९८७ से आरम्भ हुई खोज यात्रा का सार यह था कि कुष्ठ का कष्ट केवल दवाओं से मिटाना संभव नहीं। उन्हें सेवा चाहिए, अपनी सेवा अपने हाथ है यह विश्वास चाहिए। और साथ चाहिए समाज का। उस समाज का जो आज तक उनके और उनके सेवा दाताओं के बीच दीवार बन कर खड़ा रहा। उस समाज का साथ उन्हें चाहिये जो हमेशा उन्हें अनजाने ही रोकता रहा उपचार से।

समाज ने भी एहसास किया कि अनजाने ही क्यों न हो, उसने कितना बड़ा अपराध किया है पीड़ितों के साथ। और उसी अपराध का प्रायश्चित है ऐसे ''सेवा शिविर''।

26. Path finding in Dongargarh

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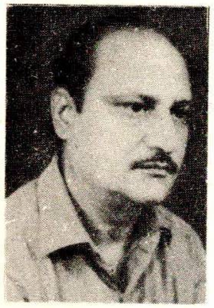


The Date—17th March 1977. Place—Dongargarh, district Rajnandgaon. Efforts were on to explore more effective ways to promote community education for leprosy eradication. Indeed, we were bitten by a strange thought, a new idea—community education through comprehensive service. The idea was presented in the form of a query. What will help change the attitude of the community towards leprosy?... Width of knowledge or depth of sensitivity and feelings? Does wider sweep of knowledge increase sensitivity?

Feelings of loneliness experienced by the field workers was another problem that was hovering high on our thought world. The problem was raised during the workers' training at Khatia, in December, 1986. "We reach villages after cycling miles and miles. Nobody offers even a glass of water. Who will improve our lot? What will help pull us out of this pitiable situation?", the workers had asked. Once again the new thought offered a strange reasoning: "Your spying role is the root cause of your loneliness! Withdraw from the case detector role!" It was difficult to accept the new proposition. Equally difficult was to push it aside, to ignore it as absured. "Let us explore and find the truth ourselves." This was our response.

This camp was organised only with the effort of Government workers and the villagers. Secondly the amount spent on the camp came solely from the Government funds and from the donations made by the villagers.

The search began in all earnestness. As a first step a ten-day Workshop was organised. A Workshop on Mobilization of Community Resources for Leprosy Eradication. Although the preparations had started a few days in advance, neither the Workers nor the Resource Persons were quite clear about the outcome. None was sure if at all clarity would flow in. Our obsession was for search! About forty leprosy workers of different categories, resource persons, and 72 social communicators from villages around, both, men and women, joined in. Basically it was an exercise in togetherness—a novelty for the workers as well as the Social Communicators. They were determined to live together like a family, for ten long days. They differed in their notions and beliefs about how the disease occurred, how it spread. In certain cases the beliefs clashed, or mutualy squared each other. No wonder common understanding on how to eradicate leprosy remained elusive. Some believed leprosy was a curse of God. Whereas others thought of it as prone to spread through common bath in village ponds. Yet others believed: it spread through skin contact. In the ultimate analysis it became clear that none knew about how it was transmitted. Similar divergent beliefs prevailed about its "cure." No patient was considered completely cured unless his deformity disappeared. But such notions were questioned by persons like Prem Lal. He was completely cured and yet had continued 'clawing' of fingers.

The controversies kept on mounting. So was the excitement of living together, working together. With the support and co-operation of social communicators, work on diagnosis of leprosy started right in earnest through, once again, a novel medium of Skin Disease Diagnosis camps organised at different places. The camps were an 'open' affair. Yet none hesitated in coming forward. "Openness" became an order of the day. By and by it became clear that there was no need either to hide or to spite leprosy. This idea gained ground. With it grew a new understanding about this disease. Once spite gave way, hesitations crumbled. This disease. was accepted as any other disease. Participants argued, developed their own analogies, arguments to prove that persistence of deformities after cure was nothing more than marks left behind by Small Pox. Gradually common understandings gained ground. What really gained weight was "openness" in diagnosis, and sturdy defences of their changed behaviours.

Alongwith it, began the battle against the 'dread' caused by deformity, almost a war on 'fear'. Two women and one man, three disabled/deformed cases appeared on the scene. These three cases had suffered 'neglect'. Care after cure had not reached 'two' of them. Whereas the 'third', still an 'active case', had developed anaesthesia. All the three were starved of affection and 'care'. Massage sessions started. First at the workshop. Then on open platforms in the midst of villagers' large gatherings. By and by the workers realised the magic spell of massage sessions. Fear was on the run. Villagers came forward and started massaging the patients with their own hands. Two women workshop participants massaged the patients suffering from deformity and neglect without any hesitation. The event almost pierced through the walls raised by 'fear'. It helped the participants in getting rid of their hesitations. Now the workers realised the meaning of the picture: "Gandhiji massaging Purchure Shastri". What a force this weapon wielded in changing attitudes of people.

A new hope and faith dawned on the workers. They realised: society would support them if they approached through the medium of service. They could experience the strength of the antidote for their feelings of loneliness. Service brought them friends and sympathisers. Workshop participants and some persons from the general public, some respected persons from the society, all worked together leading the massage sessions to resounding success. Indeed, it turned out a major step forward.

First follow-up step was taken by a worker Mr S.M. Naidu, a NMS stationed at Khairagarh. Motivated by his experience during the workshop he organised a service-camp in his area. It was a bold bid. A new era of public sympathy and active co-operation dawned. Out of this camp started the MDT programme in Khairagarh. People's participation boosted Naidu's courage and confidence. First MDT Intensive therapy programme on the total initiative of the NMS became a reality.

From the success experience of Naidu, was born a new idea. Why not organise one day duration 'composite service' camps at the Drug Delivery Points (DDPs) in different NMA (Para-Medical Worker) areas. Once again NMA Chandrakar's area was chosen because of his capacity to take initiative and to provide sustained follow-up. The experiment started. Under this experiment a 'composite team' of treatment providers and people from both middle and higher classes of society, spent time with patients, listening to their woes in an attempt to remove fear from each other's minds. In the process people also realised how their wrong notions about the disease have played havoc with the patients. In a spirit of seeking forgiveness for their wrong doings they came forward with hands out stretched for sustained co-operation.

Such one day camps on experimental basis were held in villages Manki and Somni, in Somni sector. During these camps one more aspect of patient-suffering came to light.

A patient named Jeta Ram who had ulcers on his feet was given ointment and bandages and medicinal powder by our Physio-Therapist on previous pulse date - one month back. The patient was very old. His wife at home was blind. No wonder the patient had kept the medicines and bandages issued by the P.T. safe inside his turban for the whole month. No doubt the Physio-Therapist had fulfilled his obligation by issuing requirements for bandaging ulcerated wounds. But this did not materialise actual treatment. The suffering patient remained devoid of the treatment.

This incident raised a fresh issue. Doing routines of the job unimaginatively did not produce results. Merely completing the rituals is not service. Rendering the service in a manner that generated a sense of responsiveness in the patient was more important. Workers' attention was forcefully drawn towards outcomes of their service inputs.

In Somni and Manki we experienced a new sense of strength. These one day camps opened before us a panorama of patient's capabilities. Depth of their knowledge about leprosy, in some cases, surpassed our understandings. It developed a sense of respect for the patients. Besides knowledge, there was depth of feelings and experience too. Their method of explaining things was simple, facile and effective. They needed no posters, films or slides. No elaborate preparations required. Their style was simple. But far more effective than our cumbersome methods. Playing the symptoms present on other patients in the group, articulating their 'cure' experiences and early hesitations. It all meant effective communication. Why not adopt such 'patient-experience' based methods of education which were an effective medium? From here emerged the concept of "patient-turned-educator" for conducting group discussions. Using patients in community education became an attractive proposition for our workers.

New experiments were leading to new experiences and to uncovering of new resources. With passing of time new techniques for solving our problems started emerging. A belief developed: the only way to march forward is to experiment and to adopt new experiences for solving problems. The belief had taken deeper roots. This spirit opened a new chapter and a new proposition came forward. Why not give Intensive Therapy to all MB patients by keeping them together at one place for fourteen days? Drug distribution plus education. All the workers and also the resource persons endorsed this plan. Work on the new plan started on 16.11.1987.

To begin with, the patients were brought together from surrounding villages for five days in five DDP villages. The workers also stayed with them. Learning through mutual exchange of experience followed. The villagers made arrangements for their boarding and lodging.

While organising the DDP centred five camps, simultaneously sub—camps of two-days duration were organised in Central Villages. In these villages, too, the leprosy workers and MB patients under MDT stayed together and ate together.

In the process team leaders, workers and patients developed emotional attachment with the villagers. The group was expanding day after day. In the end, on the fifth day a farewell function was arranged. With heavy hearts the villagers bade a fond farewell to their guests. They were seen off to Dongargarh camp through local send off ceremonies accompanied by music and processions.

Then on 20.11.1987 all the patients and workers came to Dongargarh for a central camp. Drumbeats, processions, slogan shouting workers and patients paraded the streets of this township. A strange spectacle for the townsfolk. Here at Dongargarh a new committee had been constituted by the towns people. It was named as "Peedit

Sweekar Sewa Samiti". It was this society who were to make arrangements for boarding and lodging for all the patients and the workers for the remaining ten days of the Intensive Therapy.

Through this new exercise in togetherness the patients as well as workers received a new direction. How deformity occurred? How and why ulcers occurred on feet? Could we prevent them? Various questions relating to deformities were raised and answers to these questions were searched. With the guidance of Dr Gude and help from our Physio-Therapy Technician, Mr P.T. Khan, other workers learnt new methods of preventing and treating these deformities. Thrice a day Hydro-Oleo Therapy practicals were organised during the camp. These exercise turned highly motivating influence on patients as well as workers. Both realised that the simple processes of hydro-therapy had a great potential for preventing occurrence of deformity. Thus they came to know about newer ways of serving the patients. This was possible only because of valuable guidance provided by the specialist.

A new enthusiasm and self confidence developed in the workers. Why not organise these camps ourselves? This was their reaction. We can organise such camps on our own, was the confident response. Do we need guidance from outside any more?

Approached January, 1988. The workers unanimously took a decision to hold one Intensive Therapy Camp in village Purena for the patients from Mohara and Dhundera Sectors. Workers from other areas joined hands. With the unreserved co-operation from the villagers of all nearby villages what came about was a splendid spectacle — the dream world of tomorrow.

Here a Purena Branch of Dongargarh's 'Peedit Sweekar Sewa Samiti' was formed. From 6.2.1988 onwards five DDP level camps were organised at different places. The main Central Camp was organised in Purena from 12.2.88 to 20.2.88.

This camp turned out significant from several angles.

Firstly, this camp was organised only with the effort of Government workers and the villagers. The amount spent on the camp came solely from the Government and from the donations made by the villagers. The Government funds used for the purpose also remained well within the limits of what was normally available for such occasions.

This camp was more successful than the camp held previously at Dongargarh during November. Here the participating patients admitted that they were benefitted more. The dividing line between the patients and the villagers had completely vanished. It was difficult to recognise who was the patient and who was not. They all mixed together without any reservations. This camp having been organised entirely through workers' effort increased self confidence of the workers.

The success experience of Purena led to yet another idea. Why not guide the counterparts of these workers in other LEU's? A decision was taken to make a start from the LEU Kawardha.

A meeting of all the workers of Kawardha was held. Eventually a training camp was organised from 5.4.88 to 9.4.88 where they themselves functioned as teachers as well as trainees. 'Learn through Service' was the motto before the campers. The in-service training in Kawardha was imparted in the shape of "in-group training."

The news of success of Dongargarh camp followed by the heart-warming news of Purena camp, reached Khaibarna. It inspired the workers to organise a service-cum-training camp there with the co-operation of other workers.

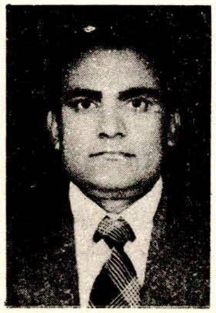
Success begets success. Now it was from Khairbana to Uperwah. Yet another successful three days "Self-Care" camp was organised in the village Uperwah with the help of villagers. Here, too, villagers made arrangements for the stay and food of all the campers.

The journey commenced in March 1987 in search of effective methods brought forth rewarding outcomes. Most significant of these outcomes is the strong awareness of our inherent capabilities. We now realise: Leprosy cannot be eradicated by drugs alone. The patients need service and a new understanding from the society. A change in the attitude and outlook of the society. Society's traditional attitudes have all along functioned as a barrier between the patients and their helpers. Unintentionally this attitude has resulted in preventing patients from availing the treatment during early stages of the disease.

Now the society also realised that though unintentionally, it has faulted. The community action in the form of support to "Service-Camps" which we witnessed during the year is indicative of the new moods of repentence and of a new desire to undo the damage.

27. This happened in Durg: exercise in community participation

Dr. S.L. Gupta



Anti-Leprosy activities were limited to only leprosy staff till 2 years ago. These were failing to make any dent on the enormity of the task of community education. Several wrong notions and beliefs about this disease still persisted in the society. Indeed, to overcome this lacuna, what was called for was not so much the education but the re-education of the community. Community's involvement in the processes of re-education which were emerging on the horizon of leprosy in Madhya Pradesh, tended to show a way out in overcoming the limitations of staff-centred approaches.

Limitations of staff-centred activities, also, were becoming obvious in the State where a bold experiment was underway to introduce new Multi-Drug Therapy through replacing old Dapsone-based monotherapy. Effectiveness of the new drugs depended upon rigid compliance of the treatment regimen. It meant time consciousness and also regularity.

Government of India guidelines required MDT to be administered through circuit planning which required almost one year to complete the Intensive Phase in one Control Unit with a population of about 4 lakhs. This was challenging enough task for the staff as well as for the well wishers of the programme in the community. Ensuring rigid "patient compliance" and regular attendance over one full year at the Drug-Delivery-Points (DDPs), month after month, as envisaged under the GOI guidelines, required to sustain undiluted worker motivation round the year.

> *The new experiment saved government approx. Rs. 9,000/- to Rs. 10,000/- per circuit (Rs. 3,000/- to Rs. 4,000/- on petrol and oil; and Rs. 6,000/- to Rs. 7,000/- on D.A. to workers). Coverage of one Block for Intensive Therapy involved two and half circuits.*

District Leprosy Officer
Durg

We thought it necessary to meet the challenges by involving the community in the Leprosy eradication programme. Shri R.K. Verma—the NMS of Berla Block-took the lead in organising the Intensive Therapy Residential Camp from 2.11.87 to 15.11.87. He was anxious to prove his worth to higher-ups in the department because, he had not received his seniority promotion that was due to him while others received it. With the help of Janapad Chairman and through involving other community leaders, he managed to provide cost-free meals to all the 101 patients who stayed at the camp site throughout the 14 days.

In due appreciation of the initiative and daring of the NMS, the Director, PH & FW, M.P. announced a Prize of Rs. 101/-to Mr. Verma.

Berla Camp ensured sure attendance of patients for the daily Drug Delivery in the presence of the Doctor. Besides, the camp provided a golden opportunity to promote education of the patients regarding the prescribed drug regimen and about involved "Self-Care" of the ulcerated hands and feet. It also ensured coming closer together of the patients and the community. Instead of ostracising the patients, now the community was engaged in providing "care". To the community it meant overcoming wrong notions and unfounded beliefs about leprosy. They gave respect to the patients, intermingled with them. This meant a totally new experience to the patient as well as the community. In no small way it worked the same way for the Field Workers as well.

The new experiment saved government approx. Rs. 9,000/-

to Rs. 10,000/- per circuit (Rs. 3,000/- to Rs. 4,000/- on petrol and oil; and Rs. 6,000/- to Rs. 7,000/- on D.A. to workers). Coverage of one Block for Intensive Therapy involved two and-a-half circuits. There are 4 Blocks in one Leprosy Eradication Unit.

Under the GOI Circuit Plan, it would have taken three-and-a-half months to cover one Block with the new drug. What required three-and-a-half months, was completed under the Intensive Therapy Camp within just 14 days. Expeditious delivery of drugs to the patients in itself was a yeoman service.

The message of rapid control of infectivity through bringing together large number of patients for delivery of the "new" Drug spread to other areas in the District. Community leaders from these areas, who visited Berla Camp, worked as catalysts. With some spadework by the LCU staff, the idea of Leprosy eradication through community involvement, gathered momentum.

Next Camp at Arjunda came about with a big bang. As against 5-Sector coverage at Berla, 16 Sectors were covered in Arjunda. This ensured expeditious treatment to 401 MB cases. Whatever provisions community leaders brought forth for feeding such a large gathering of patients, when converted in its rupee equivalent, the amount would come to a staggering figure of Rs. 1,00,000/-.

Arjunda Camp, organised during 7th to 20th of December 1987, was marked by one more innovation. Here patient education covered "Self-Care" in a far more cogent form. Daily practicals of Hydro-Oleo Therapy (HOT), introduced during the camp, exerted highly motivating influence on ulcerated patients. These exercises gave them a sense of confidence about controlling the damaging influence of anaesthesia. The ulcerated patients practiced the HOT exercises thrice a day, throughout 14 days.

Active participation of the local Block Development Officer and his staff in camp organisation was yet another redeeming feature of this camp.

Intensive Therapy at Arjunda proceeded on different lines. A striking feature of organisation of MDT in this area was intense involvement of the PHC staff in both preparatory as well as the implementation phases.

Last of the series of Intensive Therapy Camps in Durg district was organised at Bemetra, from 17.1.88 to 30.1.88. The Camp at Bemetara besides covering all other previous features of community participation, added a few new dimensions. Food for 261 patients came from 27 villages, two or three villages grouping together to feed the campers on different days.

Keen interest taken by the Sub-Divisional Officer and the local MLA remained the salient feature of Bemetara Camp. They worked day and night for construction of latrines, bathrooms, and for ensuring food and water supply to the campers.

Daily cultural programmes arranged through participation of local talents was a special feature of Bemetara. Here local community donated sets of 1 Lota, 1 Thali, 1 Dress and 1 Chaddar to all patients and a pair of MCR chappals to the needy patients. Expenditure personally incurred in favour of this camp by the local MLA, ranged in the neighbourhood of Rs. 40,000/-.

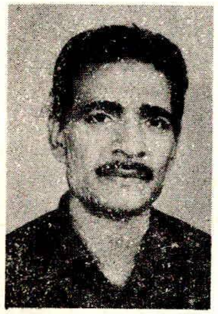
Dalli Rajhra Mahila Samaj helped the programme by organising skin disease diagnostic camps. Three such camps were arranged by the Mahila Samaj during 1986-87.

It has now decided to organise 6 more such camps during the year 1988-89. It also distributed 50 pairs of MCR chappals; and has decided to distribute another 60 pairs during the current year.

A team of District Leprosy Officers comprising Dr. Tripathi (Gujarat), Dr. Chopra (Himachal Pradesh), Dr. Burnswal, Dr. Hameed and Dr. Shrivastava (Uttar Pradesh) who were attending training at RLTRI, Raipur, visited two DDPs on pulse days. They were highly impressed to see local community mixing freely with leprosy patients. In a radio talk given by these DLOs — AIR — Raipur, they highlighted the significance of community involvement to eradication of Leprosy.

28. Pivotal role of PHC in the follow-up to MDT intensive therapy

Dr. K.L. Bhandarkar



*Medical Officer
PHC, Dhamdha
Durg.*

Fear Removal' is the only effective treatment for leprosy. The fear dwells in the minds of patients and the general public. It could be seen even in the minds of doctors in certain cases. The 14-day ."Intensive Therapy" (fully residential) Camps organised through community participation in certain areas of Durg during November-December 1987, indeed helped in minimising the Fear. It also facilitated "image lifting" of the leprosy control programme in the eyes of all the patients, the general public and the doctors who had the advantage to observe the process of conscious intermingling of patients and non-patients.

Preparatory to Intensive Therapy, a Survey for identification of new cases was conducted by involving Multi-Purpose Workers of Dhamdha PHC.* As a result the case-load increased from 712 to 827 in the Block.

December-January was the coolest month of the year, even then attendance at the Drug Distribution Points (DDPs) was about 70% to start with. This shot up to 95% in just 2 days. The increased attendance level was maintained till the end of the I.T. phase, thanks to the bright image developed for the new drugs under MDT, and also because of the change in psyche created by the Residential Camps organised by the Community.

Once the intensive phase was over, it was the turn of "Pulse" on fixed dates, during fixed hours and at fixed points. It was a task which called for planning and coordination with other general health personnel.

Maintaining high levels of patient attendance at DDPs on Pulse Therapy days, once every month through contacting the patients just one or two days in advance, is a strenuous piece of work if it is to be shouldered by the Leprosy Field Worker (NMA) alone. Generally the Patients are spread over 20 to 25 villages in one NMA area (Sector). Besides the stress and strain involved in maintaining high attendance, the reluctant cases pose yet another problem. In both these spheres, team-work of MPWs* (Male & Female), Village Health Guides and trained Dais (the traditional Birth Attendants) and the NMAs would play a crucial role in relieving stress and in making the drug regimen compliance a functional reality.

In each PHC there are some villages with abnormally high bacterial load. A village in Dhamdha PHC—Pendri—with a small population of about 423, has 23 cases on the LCU Register with the prevalence rate shooting up to 54 per thousand population as against the average of 7 or 8 in the rural areas of Durg. Villages like Pendri need a close surveillance. This could be ensured through winning the confidence of villagers 'through organizing repeat skin diagnostic camps, thus helping cases which remain in hiding to come out and move closer to treatment.

Another equally important aspect of control work relates to follow-up of cases with deformity and anaesthesia based disabilities. Co-operation of general health Field Workers could be of considerable help in controlling and preventing damage to limbs of Leprosy patients. But then it would be reasonable to expect reciprocity from the NMAs (Non-Medical Assistants) and the NMS (Non-Medical Supervisor) of the Leprosy system. They would have to come forward and extend helping hand in general health programmes.

In monthly staff meetings leprosy staff should remain present to orient the general health staff regarding detection of leprosy cases; and to exchange notes with them regarding their own problems in the field. They

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*Primary Health Centre

*Multi-Purpose Worker

could also inform about the dates of Pulse Therapy and give lists of problem (leprosy) patients in villages covered by respective MPWs.

Whenever the MPW visits a house, he could very well enquire with the community about leprosy and about the regularity in drug dosages by the patients. If there is any problem, he could note it down and inform the concerned NMA.

Just as in 'Global Eradication of Small Pox', 'Zero Targets' could be developed for groups of school children. The children would do a commendable job in searching out early symptoms of leprosy in schools. General Health Workers who even otherwise approach schools for their own work could be of help in identifying leprosy cases in early stages.

BCG vaccination is being routinely administered in PHCs under the UIP (Universal Immunization Programme) for children from 0-1. This 100% immunization programme will help in providing diagnostic orientation in Leprosy to mothers. It should therefore, be made obligatory on the NMAs to remain present in immunization sessions in villages, more particularly to bring children of Leprosy "contacts" to these sessions.

29. Community in action: the focal point for integration

Dr. B. Devangan

Medical Officer
P.H.C.
Gundardehi Block
Durg

A broad-based meeting convened by the Chairman of the Gunderdehi Block Janapad marked the formal beginning of organisational work for the camp. Invitees for this meeting included Chairman of the Gram Panchayats in the Block, the Members of the Janapad, Women active in social, cultural and religious life of the community, prominent citizens, Medical Officers of the PHC and Health Workers of the General Health System. The idea of bringing all M B cases together in a Residential Camp was first mooted at this meeting, and a formal Committee — 'Gunderdehi Leprosy Eradication Samiti'-was set up with sub-committees responsible for looking after various facets of the Camp life.

Prior to such formal organisational effort, considerable spade-work had gone in during the previous month. Though the patients attended the Camp from 7th to 20th of December, collaboration from local organisations like Rotary Club, Women's organisations working in the field of Development of Children, Business organisation like Indo-British Fertilizers Ltd., the District's Agricultural services set-up, etc. were the real backbone of educational activities. The message of introduction of a new effective drug could be spread far and wide largely through the training programmes organised under the aegis of these local organisations.

Medical Officers and the Health Workers of the PHC were on their feet throughout the month of November, assisting the NLEP field workers in updating the Registers of MB cases for administration of MDT; in expediting the Survey-detection of new cases and in the preparation of Patient Cards.

Out of 439 M B patients on the Treatment Register, 402 joined the Camp. Total responsibility for their feeding and stay rested on the shoulders of the local Samiti. It was a massive mobilisation effort. It involved collections in kind as well as in cash. It also meant lining up the manpower required for smooth operation at the Camp. In terms of Rupee equivalent, the local resources mobilised for this purpose amounted to not less than Rs. 125,000/-.

Looking at the massive release of people's energy during the organisational processes of the Camp, one question often came to my mind: Why did the people work so hard with no frown ever to be noticed on their face? What made them remain active almost 12 to 14 hours a day without any respite? Were they out to please their local leaders? Were they currying favours with the influential officers of the area who mattered in moving their papers faster? Were they out to please the Doctors in the General Health System to ensure earnest and prompt attention in health matters to their kith and kin? A cynical mind would be inclined to give the answer in the affirmative to all these questions.

But I asked myself, were they right in jumping to such sweeping conclusions? My own answer to these questions, however, would have been in the negative. Not because I formed the flesh and blood of the organisation for the Camp. But because I too, had worked as other people did. When I ask myself: Did I work to please someone else — my bosses in particular? The answer that comes to my mind is both 'Yes' and 'No'. Initially, during November when I worked for the camp preparatories, I was meeting a 'service' obligation. I was on the look out for a pat on my back from my bosses. The systems-man in me was active.

But once the Camp started functioning, and I witnessed the phenomenon of patients and non-patients mixing together without any reservations, a phenomenon so difficult to believe unless seen in person, intense questioning started disturbing my mind. My hesitations which were hiding somewhere deep down, about the infectivity factor in leprosy treatment started causing uneasiness. My professional and departmental service roles apart, I realised, I was a social being as well. Why couldn't I discard earlier my self-preservation concerns in common with the other multitude in theCamp? What was preventing me from presenting myself to leprosy eradication work? As the other multitude was engaged in doing now without looking out for favours? Was it the 'systems-man' in me bound only by the defined job charts? Didn't I have any obligation towards the leprosy patients who have been subjected to endless wrong by the society for no fault of theirs? Was it only because I was a 'systems-man'?

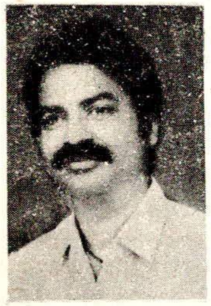
The answer, perhaps, was 'yes'! This 'answer' emerges more forcefully today, as I am once again back in the saddle, trying to ride the system horses. Once again leprosy recedes in the background. The usual concerns or salary scales, incentives, duty charts common to departmental ways of thinking take their precedence.

Leprosy becomes a problem once again to be tackled within the four corners of hierarchical norms of working. Problems posed by salary differentials, difference in mobility facilities and monetary incentives, grapple us once again. Leprosy or no leprosy: it hardly matters to the mind! One may feel sad about these faces of work life. But they are the reality.

Mind fails to find a way which will help pool manpower resources in the gigantic task of mobilisation in the interest of leprosy eradication work. A sad thought makes room in the mind: so long as we remain hidebound to notions of formal integration of the leprosy control system with the one operative in general health, the solutions would remain as elusive as ever.

30. Inching towards high-rise credibility*

Nehru Sharma and Jitendra Kalchuri



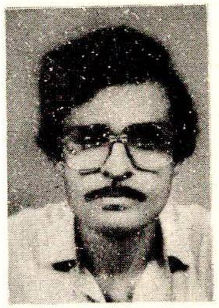
In our work life of over a decade we had rarely seen leprosy patients engaged in discussions with other patients. They generally led an isolate's life. Whatever social life they have had remained confined either to members of their own families or to close circle of friends. This was our experience about group life around leprosy patients. Why did they shun group life with other patients? It was difficult for us to reason out. But we knew for certain it represented a common pheno-menon.

No wonder expression to emotional hang ups of these patients remained supressed.

However in recent months we have been observing a perceptible change. Patients spending time together, gossiping whenever they meet at Drug Distribution Points and engaging themselves in lively discussions, is becoming a common sight. We consider this development as a major 'breakthrough' in patient's otherwise despair ridden, closed, circumscribed, personal life.

We checked these observations about the breakthrough with our other colleagues. They, too, were inclined to share our assessment. The real import of these changes is in fact a reflection of community's overall changing appreciation of the disease with particular reference to its curability; and their eventual movement toward rejection of old notions of patient centred life-long hazard of disease transmission.

The fresh and substantive in-flow on new cases at Drug Distribution Points (DDPs) in recent months, we are tempted to relate to the 'breakthrough'. In Dongargarh Block, for instance, during the past three months out of 93 fresh-case reportings, 44 were M.B. cases. Source of influence that lay behind this 'inflow' helps explain the phenomenon of the breakthrough! Out of these 93 fresh-case-reportings, 40 came through Patient to Patient communication (17 MB + 23 PB); 23 on Patient's own initiative (12 MB + 11 PB); 18 accompanied the social communicators from their respective villages (10 MB + 8 PB); and only 12 (5 MB + 7 PB) through contacts of Health System Workers. The Health System Workers in this case included Community Health Volunteers (CHVs), the Multi-Purpose Workers (MPWs) of the General Health System, and the Healthy Contact Surveillance visits of Para-Medical Workers of the Leprosy System.



It is worth noting that these reportings over a three month period ending March, 1988, far exceed the number of cases reported over one full year in the past. Moreover, the 'steep' increase in the rate of reportings noticed in Dongargarh is not observed in the remaining three Blocks of Rajnandgaon Leprosy Control Unit.

We are, therefore, inclined to view the changing pattern of influence behind fresh-case-reportings, and its steep rate of increase as two sides of the same coin—Group Method of work (as distinct from the 'individual' centred 'clinical' approaches) adopted in Dongargarh on a vigorous scale over past one year. The simultaneity of earnest, and authentic interactional involvement of the three arms of Leprosy Control Triangle - the Patient and his family, the Social Communicator,

Non-Medical Supervisor
Dongargarh Block
Rajnandgaon LEU

Health Educator
Rajnandgaon LEU

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*Free style rendering from original in Hindi and the Treatment Provider—in promoting 'responsive action' underlined the method.

The phenomenon of 'responsive action' manifested through Social Communicators expecting the Patients to present themselves 'clean' before the society; and the Patients expecting respectful treatment in return, can be cited as one of the many forms of such 'action'. Similarly Patient-Social Communicator combination creating demand on Treatment Providers for timely delivery of composite service which is directed towards 'Patient Care'—far beyond the 'pill-popping' practices, and the Treatment Providers, in turn asking the Social Communicators to provide for feeding and other arrangement for the Mixed-Group Residential Camps during the Mass Service Sessions, is yet another form of this 'action'. Fairplay practised while promoting 'responsive action' during the interactional process, generated a new climate wherein mutuality of genuinely reasonable expectations thrived.

As a result of these practices in the field over a period, the Mixed-Group-Residential (MGR) Camps turned out a most convenient instrument for articulation of the mutual expectations and practice of mutually compatible roles.

The latest in the series of the MGR Camps was organised in the month of February to demonstrate 'composite' character of the 'Service' in a 'responsive action' setting. This was synchronised with 'Intensive Therapy' under MDT for the remaining two Sectors in the Dongargarh Block. The Camp operated in two stages. First six days at the DDP and its surrounding villages, and the remaining eight days at a central point—Purena.

Here, the 'three arms' of the Leprosy Control Triangle stayed together round the clock, absorbed in learning pursuits, shared responsibilities, tuned their listening to heartbeats of each other, endeavoured to develop understandings about mutual urges and aspirations, and accommodated their roles in the major task of removing misconceptions about leprosy, its occurrence, transmission and "Cure". It was a heart-warming exercise in Community Education through 'responsive action.'

Whatever happened during those eventful 14 days at the Camp needed to be seen to be believed. What the well motivated, determined team of Field Workers did during this camp, no formal authority could have ever ordained us to do. Not having known the depth or our determination, even an ardent ideologue would not have dared to hope his dream world come so true. We entered the 'Camp Arena' with our hang-ups, prides and prejudices, fears and apprehensions—still sticking to us, though unknowingly. But bound together by a certain deep rooted determination to transcend our previous performance levels, attained during the Dongargarh Intensive Therapy Camp under the guidance of Resource Persons, we worked at our best. We were anxious to show: we can do better unaided by the 'resource persons'.

With passing of those morale boosting 14 days in close proximity, we lived to merge our separate identities almost into one. It would be of interest to see how such merger of identities through accommodating distinct but complementary roles, resulted in building a vibrant image of "credibility" for the Control System. We quote below two events to underline this march towards high rise credibility:

Taran Das*

That evening Taran Das (a patient at the Camp) was sitting with a group of patients and was talking a lot against the treatment he received earlier in a non-governmental Hospital which offered specialised services in leprosy.

Taran Das complained that he was treated very badly there, so much so that nobody even touched his body during the medical examination.

He was asked by the other patients as to why he did not go to the right place (meaning the Leprosy Control Unit) for treatment in the beginning. This remark upset him.

Am I not attending the 'Unit' now? Am I not taking Drugs regularly?', he asked. "I don't see much of improvement even here!" he explained.

Others in the group gave an analogy of a watch that is not functioning properly. In such a case it has to be taken to a good watchmaker for repairs and one has to be regular in winding the key every 24 hours. Also, it has to be reported to the watchmaker if the watch shows a wrong time.

To illustrate this point someone from amongst the group advanced a watch that had stopped working.

Fortunately enough because of the treatment at the Camp, Taran Das noticed hopeful improvements subsequently. It was observed that the clawing trends in his fingers started abating, they were becoming straight. The fingers had started getting perspiration which in itself was considered a marked improvement. One day on his own he remarked: "My hands are showing improvement".

Surja Bai

It was the first day of the MGR Camp for Intensive Therapy. A woman in her early fifties with clear signs of nodular leprosy, walked into the campsite with a rolled-bed on her head and a rolled up newspaper in her hand. Her name was Surja Bai. She had come all the way from village Pondi in the neighbouring district of Bilaspur. The Newspaper in her hand had brought to her the news of this Camp.

She was taking medicine from a local NMA (Non Medical Assistant) for the past several years. She was not regular in her treatment though. Partly because of her disillusionment with the treatment; and partly because of the irregularity of visits of the local NMA.

Surja Bai's husband—retired as a driver from Government Service. Surja Bai lived with their Son, who too, was working as a driver in a Government office.

None of the family members, however, accompanied her to the Camp. Though they had given her all encouragement to proceed to Purena—the Camp headquarters.

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*Both excerpts produced from Recorded Tapes

Her admission to the Camp was a problematic proposition. She did not belong to Rajnandgaon District. The matter was referred to the local Camp Organisation Committee Members. They were expected to make arrangements for not only her meals and stay, but also to ensure her regular attendance in future, during the 'Pulse Stage' drug distribution.

Surja pleaded with the Committee Members to send her the drugs for subsequent months by Postal Delivery. Since this was not permissible, a compromise formula was worked out.

Surja's parental family belonged to a village in the neighbouring Block of the same LCU. She assured the Committee about her regularity in taking medicine every month at her parental home.

The Committee Members allowed her to join the Camp. She showed exemplary behaviour while at the Camp; and endeared herself to other Campers.

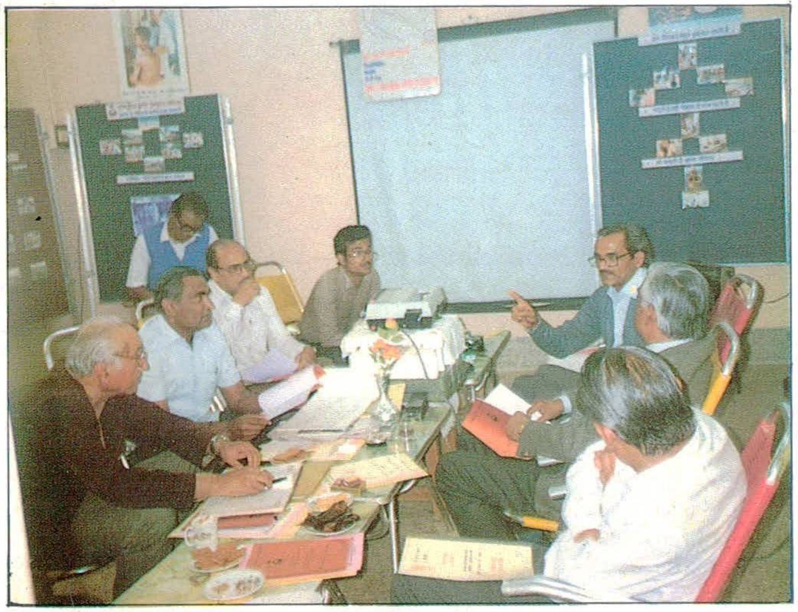
Surja Bai, as promised has been regular on the three subsequent "Pulse Dates."

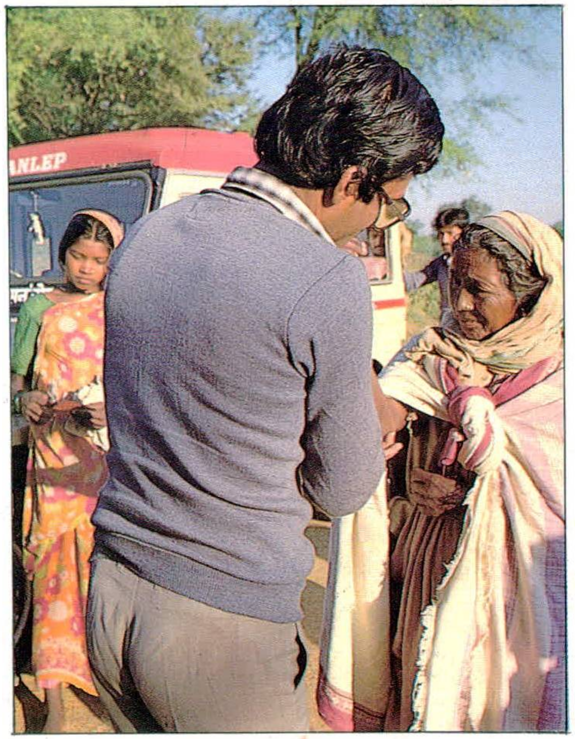
We are inclined to attribute the new trends in "fresh-case-reportings in Dongargarh to the dynamics involved in the promotional efforts of "responsive action" and the consequent emergence of high-rise credibility. Even the field workers' intense involvement witnessed during the Camp is a product of the mutually satisfying self-acquired roles, performed on a sustained basis by all the three arms of the triangle.

No wonder, therefore, on 20th February, when it came to parting of company on the concluding day of the camp—we felt as though we were holding on to a new legacy of merged identities which would hold us together under a nostalgic spell for months to come.

This was succinctly brought home by the Collector, Rajnandgaon, while addressing the campers on the concluding day. The sum and substance of what he was driving at the fact was that we all had worked unlike conventional government servants, by discarding the usual aura of authority and by adopting new (Yaachak) role; risking and working on our own steam, with our own hands on the steering wheel. It was a clear manifestation of what the Resource persons had earlier visualised as a practice in 'delegation upwards'—a new way of working rather alien to governmental administrative systems.

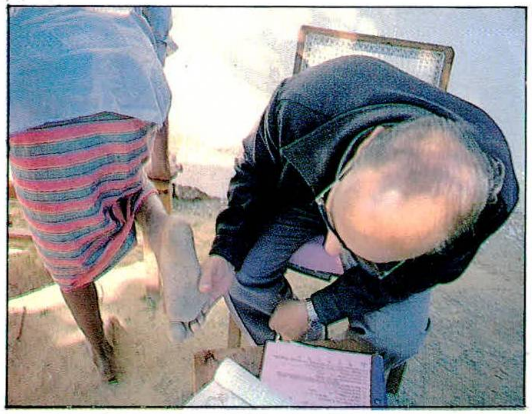
On 29.2.1988, in the quiet of the evening hours at the village Khalari, the entire group of workers who had worked at Purena hardly 10 days ago, once again met to recall the events and to take stock of whatever happened during those heart-warming camp days. In our midst were a few others who could not attend the Camp earlier. The occasion turned out as a forum for exchange of notes. Workers of all hues from DLO to the Field Worker, vied with each other in narrating the events and in exchanging their experiences. A few selected narrative accounts are reproduced hereafter with a view to share with co-workers elsewhere the flavour of the "product" of 'responsive action' which we ourselves relished so intensely during those eventful 14 days.





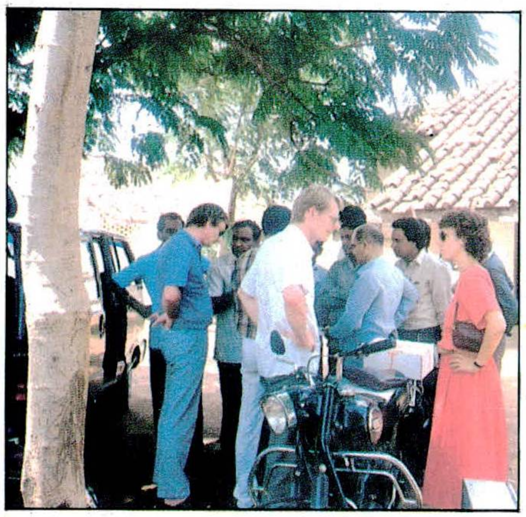
Drug Delivery With A Difference

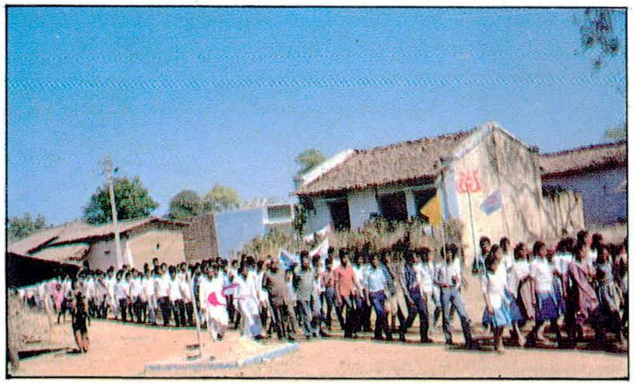
Bhilaians rejoiced at the dawning of a new era of Freedom from Fear of Leprosy under MDT. Thanks to high credibility of Drug Delivery System! Safe Storage ... Supervised Drug distribution ... Strict adherance to Delivery Schedules ... Well designed Blister Packs to ensure patient-monitored 'Regimen Compliance' ... Facility for short-cycle-feedback on performance ... 'Top' to 'Bottom' permeation of concern for 'Patient-Care'.

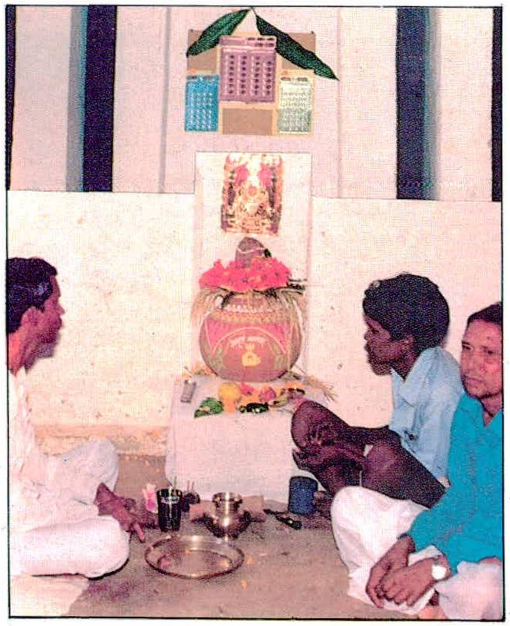


Stigma .... On Retreat

Regularity of Medication and tracking the influence which brings the patient to treatment in Fresh-Case Reporting ... a twosome appraisal tool ! In Dongargarh Block out of 44 MB and 49 PB fresh-case-reportings over past three months, 40 showed-up through patient to patient communication; 18 through Social Communicator-channel; and 23 through patient's own initiative.







30.1. Panchayat ghar without a light

B.L. Kose

*Health Educator
Bhilai SADA LEU
Bhilai*

We faced problems while organising a camp at the DDP (Drug Distribution Point) level. In fact Bilhari was a totally new place for us. Never before had we organised camping activities here. One of the Field workers was to reach Bilhari to-day, one day before the camp started. About 9 patients were to reach the Camp site in the night.

Later in the night the DLO and myself reached the Panchayat Ghar where the camp was scheduled to be held. We are anxious to know if the Field worker had faced any problems. To our utter disappointment none was to be seen at the Panchayat Ghar; not even our Field worker.

We then proceeded to Mohan's house. Mohan was our Jan Bhagidar (Social Communicator) from Bilhari. Mohan, too, was sleeping. We found our Field worker sleeping in Mohan's house. According to the Field worker, out of nine patients only one had turned up. Since the Bulb was missing and it was dark in the Panchayat Ghar, he had made arrangements for the Patient in the house of another villager.

We expressed our displeasure at the slackness in preparations for the Camp; and enquired with Mohan if we should shift the Camp site to a nearby village. We had selected Bilhari because the patients from surrounding villages favoured this place. Mohan felt bad. Because the slackness was not intentional. He assured us that all arrangements would be made the next day.

Next day when we reached Bilhari, we found all arrangements in order. The light fittings were there. The cultural group activities were well planned. We were surprised at the briskness. It appeared Mohan was on his feet early in the morning. He convened a group meeting and explained the objectives of the Camp. The people showed interest in his ideas. With great enthusiasm they came forward to render help.

Whenever we organised a small camp like this in a village, we anticipated support from villagers. The villagers generally finalised arrangements in a group meeting. In such meetings, on occasions, we had seen the villagers splitting into two groups, one in favour and the other against.

While organising a camp a Cheepa we faced such problems. Soon we realised that it was mainly a local problem.

Our Survey had indicated that 16 M.B. and 35 P.B. cases were to be brought together at Cheepa from 6th to 12th. But for want of unanimity amongst the villagers the preparatory arrangements for the Camp had remained in the doldrums for some time.

With our intervention, an agreed proposition was worked out. The arrangements for six days were divided into two segments of three days for each group. Immediately Sanwalra and Kotdar brought to us cash contributions of Rs. 24/-. They collected rice and other necessities adequate to feed the Campers for 3 days. Nothing was found wanting in the arrangements. They had distributed duties to different groups. Every evening the groups used to meet together and sort out their problems.

We saw that such intense involvement of villagers in hosting the Camp, brought them closer to patients. It was a thrilling spectacle to watch villagers taking the patients to their homes and treating them for Tea and Pan-Supari (Betel leaves) on their own initiatives.

Even the way the cash collections of Rs. 24/- came in, appeared quite interesting. Daya Ram had given 2 kg. Rice and Rs. 5/- in cash. Patel Ramsukh made a similar contribution. Ramacharan gave 1.25 kg. Rice and Rs. 2.25 in cash. There were even smaller contributions. But when

Amar Singh announced Re. 1/- in charity, there was big hulla gulla in the meeting. The group objected to his using the word "Charity". They did not accept his Rupee. On the contrary they extended an invitation to Daya Ram to visit the larger Camp at Purena to understand the difference between "Charity", "Alms" and "Cooperation".

My patients' list increased gradually. In the beginning I had fourteen cases. Then the number increased to sixteen and now it is 26. It is worth mentioning here that I did not motivate anyone. They joined the Camp on their own.

The additional 10 M.B. cases opted for this place as a second thought. They joined here instead of moving to places earlier suggested by them.

Lingering Influence

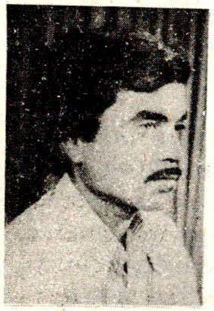
In Dev Katta, I met a very old friend of mine. He used to be my classmate in the village school. After completing his studies he became a teacher in Dev Katta school. Since then we had rarely met. Somehow he heard that I am working with the Leprosy Eradication Programme; but did'nt have clear information about the nature of my work. When a camp was organised in Devkatta under Mr. Kalchuri's guidance, he was a regular visitor there and observed Mr. Kalchuri at work. He was highly impressed by what he saw.

Subsequently, when I visited Devkatta on a pulse date, he met me and was all praise for Mr. Kalchuri. He went a step further and expressed his desire to work with us during his summer vacations. From his previous experience of working at the camp he knew that this kind of work brought immense mental satisfaction.

There is another person like him in Bilhari. Mohan is now completely involved in this kind of work. He is prepared to work in any part of India and is willing to travel at his expense to the camps. At the Bilhari camp, he became our right hand man. The credit for the camp's success goes to him.

30.2 The Morose Patient*

B.S. Bhatnagar



Para-Medical Worker
Mohra Sector
Rajnandgaon LEU

"One day I noticed a patient sitting quietly in a corner. According to other patients he was a 'Khallori' (a Scheduled Caste). I strongly disapproved. 'We all are equals and should mix freely without any reservations', I said. I also noticed a few ulcers on him, which made him look unclean and unhygienic. This might be one of the reasons for his sitting aloof. I cleaned his ulcers and bandaged the wounds. This brought about an improvement in his looks and also in his attitude towards others. Soon afterwards he was seen sitting amongst the patients talking freely."

"As a general practice the patients cleaned and bandaged each other's ulcers. But in this particular case I helped the patient in order to remove his feelings of estrangement and discomfort. As others came to know about this incident, my behaviour was subsequently debated in a small learning group during the camp."

"Discussing such matters in small groups always helped convey important messages effectively about cleanliness and personal hygiene. By doing so we came closer to each other and mixed freely. We made it a point not to apply any force or give any instructions in matters of personal cleanliness. They themselves understood its importance through group discussions. They realised that those who did not observe cleanliness raised barriers in free mixing."

"Patients used to come to common meetings meant for larger group sessions punctually at 8 AM as a routine. To start with they would clean and decorate the place with Rungoli. Then take medicine, followed by dressing of wounds."

"During the camp days, the high standard of cleanliness was evident not only in the camp and the surrounding areas, but in the entire Purena Village. This was happening entirely on villagers' own initiatives. They had cleaned and whitewashed the exteriors of their houses as is normally done on festive occasions like Diwali."

"Today an interesting incident took place. A patient from a nearby village came two days late. I noticed this but kept quiet. However in my presence other patients questioned him. They also told him that he missed two days of learnings which dealt with MDT treatment and hydrotherapy.

The newcomer looked unclean and was wearing dirty clothes. The other patients prevailed on him to take a cold water bath. He was also told to go back home and bring clean clothes. He went home and returned with clean clothes."

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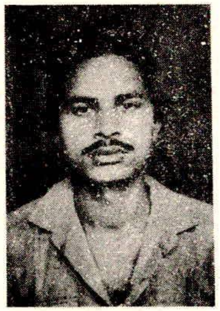
*Nine write-up that follow, based on free style rendering from the recorded tape: Original in Hindi.

30.3 Bhawani's shirt

Ram Gopal Thawait



"One boy—a patient named Bhawani was wearing a torn kurta. He was asked by other patients as to why he was wearing such a kurta. Why did he ignore the early instructions of the Organisers? The boy got irritated at these comments. In a rage he completely tore off his kurta into pieces. I was watching this scene. It made me nervous for a moment. I feared a flare up resulting in a fight. But nothing of this sort happened.

"Quietly the boy took out a new shirt from his bag; and wore it to the utter surprise of all."

"Someone from amongst the small group asked Bhawani: "Instead of tearing off the shirt couldn't you have given it to a poor and needy person?"

"It was so bad that even a beggar would not have liked to wear it", replied Bhawani in a lighter vein."

"For some time Bhawani remained quiet. Then all of a sudden he got up and demanded: "Let me go and inspect the cleanliness and tidiness of others."

"While he was inspecting one of the patients—a Kotwal, Bhawani told him that his shirt was dirty. The Kotwal in a fit of anger retorted: "Your shirt was equally dirty. Since you had brought a spare shirt, you changed it. I don't have a spare shirt."

"Prompt came Bhawani's reaction: 'While taking bath you could always wash it and dry in the Sun. Kotwal did not relish this advice either."

"All the same next day we saw the Kotwal wearing a well washed shirt."

"Soap was in great demand in the Camp. Those who managed to get it, used it generously for washing and bathing. Whereas others kept on asking for soap and hair oil, but could not get it. The Kotwal came to me and asked for soap. He wanted to wash his clothes. He could not manage to get soap so far, as there was no soap available in the stocks. I offered him my soap. Toiletries for the camp were donated by the villagers. The stocks needed replenishments."

"The patients had already selected six persons from amongst them as their leaders. Potdar and Preet Ram—two of the six, today took a round of the camp to see whether the variously agreed points regarding cleanliness were observed properly or not. This included nail cutting, mending of torn clothes, washing of bed sheets, keeping shoes and chappals, at a safe distance from the beds."

"None took offence at this inspection."

Panchu

"A patient from Chheepa by the name of Panchu was very poor. So much so that he used to ask for left over food in the village for his family. Before coming to the camp he borrowed Rs. 20/- from someone and bought rations which would last 4-5 days for his family."

"He used to do voluntary work at the camp, fetching water, cleaning utensils and serving food, etc. In the camp a helper was required on daily wages to do the miscellaneous errands. Panchu being a camper could not have been paid cash for the work he was doing there. But impressed by his sense of devotion some of the campers suggested that his wife should be engaged on daily wages to do these jobs."

"Panchu took this suggestion in a different light. It appeared the suggestion had hurt Panchu's ego. He outright rejected the offer. Although his wife and children often came to the camp to enquire about his welfare, he did not like the idea of his wife working in front of others on payment."

Para-Medical Worker
Charbhata Sector
Rajnandgaon LEU.

30.4 Ramkali

Savitri Tiwari

Para-Medical Worker
Dhundhera Sector
Rajnandgaon LEU.

On 7th February, Ramkali was brought to the Purena Camp by her elder brother — Tularam, who was a known Pandavni style singer. No one from her husband's family accompanied her. In fact her journey to the camp, in a way, was facilitated by a three year old PB patient, Punki– Tularam's daughter.

When Punki accompanied her mother to the Dongargarh Leprosy Clinic a few weeks back, she had seen a patient being examined who had symptom on her body which, according to her, resembled the ones on the body of her father's sister—Ramkali. Back home Punki's mother spoke to Tularam. As a result Tularam brought Ramkali to Purena Camp.

After examination the Doctor declared her to be a Leprosy Case (MB).

As soon as she heard about the diagnosis, I noticed tears rolling down Ramkali's cheeks. In a choked voice she muttered: "What will happen to me now? Why has God been so unkind?" Her disease was in somewhat advanced stage. This made her all the more depressed. She was trying her best to bear the shock.

As she was in the midst of the shock, and was wondering about how she was going to reveal this to her husband, and others in the family at Balaghat, she overheard someone amongst the people around say: "Look! She's Ramkali. She is a superb singer." She looked up and noticed a few persons gazing at her. Expression on her face underwent change. She collected her bag and proceeded to the place where others were staying.

After 14 days at the camp, she was a totally changed person. She talked to other patients, mixed freely, and sang to the delight of other camp inmates. She was conscious of being a good singer. She got the much needed recognition at the camp. The cordial atmosphere in the camp; the warmth underlying the medical treatment, and the special attention she received, brought forth a tremendous change in her attitude towards her disease.

Next day she participated in the cultural programme organised for the evening. She sang to the great delight of other inmates and villagers. The programme was so interesting and absorbing that none of us could leave it halfway. It was based on the epic Ramayana. The group presenting the programme was playing drums and a variety of other locally available musical instruments. Tularam, brother of Ramkali, was the main singer. Ramkali's contribution was superb. All the villagers and patients enjoyed the programme so much that nobody thought of going to bed till it lasted. They remained there from 9 PM to 2 AM next morning.

On the day of departure when prizes were being distributed for different best performances, at the hands of the Collector, Ramkali received the 'Best Patient' prize. She was lustily cheered by one and all.

While taking leave she mumbled: "I wish I'd stayed here longer!"

Donated blankets

A pleasant afternoon of November. It was concluding day of the Community sponsored Intensive Therapy Camp at Dongargarh. One Donor from Delhi had sent cotton Blankets for free distribution amongst poor Leprosy Patients. The blankets were 45 whereas the number of patients at the Camp was 92.

Respective Para-Medical Workers were requested to prepare selective lists of relatively more needy patients from their Sectors.

Workers thought it imprudent on their part to prepare such lists. They considered it a risky device. Because it involved displeasing 50 per cent of the patients. According to them, those not included in the list were sure to be displeased.

Ultimately the task of preparing the list was entrusted to a committee of 5 representatives of the Patients — with a suggestion that they should evolve a criterion first for judging a deserving patient; and on that basis prepare the list.

For more than 40 minutes the 5 Representatives struggled hard to evolve a criterion which was acceptable to all the five. Finding the task difficult, they adjourned and put the decision-making responsibility back in the lap of the organisers.

The organisers pondered over the problem and in the end decided to refer the matter to the good sense of the general patient community. All patients were called in a meeting. After presenting the problem before the gathering, the organisers requested them to think about those others whose need for the blanket was more reasonable than theirs. It was suggested that those patients who were willing to surrender their own claims in favour of needier patients, should stand up and withdraw their names.

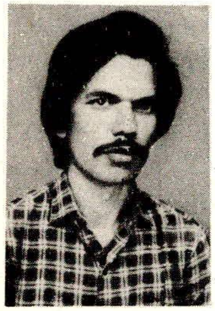
What followed in its wake was a heart-warming spectacle. One after the other they got up to withdraw their names. Amongst them were those who presented a picture of poverty. And yet without hesitation they declared—"My need for the blanket is not as pressing. I withdraw my name".

When it came to women patients, the scene turned much more touching. Tears rolled down many eyes when two old women in their tattered sarees, stood up one after the other and announced: "I forego my claim".

As a result of the large-scale withdrawals, 23 Blankets remained surplus with the organisers. Posing yet another problem!

30.5 The sarpanch and his "Kodhis"!

Bhimrao Khatarkar



Para-Medical-Worker
Dhundhera Sector
Rajnandgaon LEU.

"Today a strange incident took place. Seepar Ram—the Sarpanch from village Purena, visited the first phase Deokatta Camp along with one of his friends. As he was moving about in the camp, talking to his friend, some patients overheard him refer to leprosy patients as "Kodhis"—in the derogatory term with which the leprosy patients were generally referred in this Region. Seepar Ram was explaining to his friend how exacting it was to make arrangements for the big camp of "Kodhis" being organised at Purena from 12th February onwards."

"Patients at Deokatta were very much agitated at this demeaning reference by Seepar Ram. They held a meeting in the evening and requested LEU staff to cancel the plan of holding the Central Camp at Purena wherein Seepar Ram was to the Organiser Role. They were prepared to strive hard and make alternate arrangements at village Khilari, instead. The camp atmosphere got surcharged with emotions."

"The situation was saved by tactful, timely intervention by some elders from Deokatta. They defined the term "Kodhi" as one who shirked his responsibility towards the society by refusing or neglecting regular medical treatment. "How could it apply to you? You are leaving no stone unturned to get yourself cured. If anyone called you "Kodhi" he must have run out of his senses. He must be a mad person", they consoled."

"The tactful intervention of the elders—the local MLA and his son saved the situation. Tempers were cooled. The elders arranged a song party afterwards. It all ended on a pleasing note."

"Even otherwise, Seepar Ram always took a condescending view of the leprosy patients. He was involved in making arrangements for the camp not so much because of his love for them. But largely because of his mother's insistence."

"We had observed him bring his own Tumbler for drinking water whenever he came to eat. For similar reasons he had disapproved of the practice of serving meals on 'Paatas' with plastic sheet coverings. For first two-three days he rarely mixed with the patients. It was only after the grand gala cultural night wherein patients, both men and women, outdid performances given by non-patient villagers, that he started moving about amongst patients."

"In fact after the cultural programme evening, the patients had gone high up in the estimation of other villagers. Villagers took patients to their homes either for eating "Paan" or for "Tobacco-chewing". Some even invited them home for tea."

"On the concluding day, however, when the District Collector joined the patients for the common lunch, Seepar Ram did not bring his separate Tumbler; and drank water from the one commonly used for drinking purposes by the campers."

Censored message

"Stormy scenes were witnessed today on three different occasions, but almost on a common theme. Surprisingly our co-workers got involved in the subsequent heated exchanges. To start with one issue was under debate in an informal group discussion of patients, social communicators and a few villagers. The latter group included the Sarpanch of the village who after participating in the DDP level camp previous week, had taken a firm stand against his village people and had allowed bathing of patients in the common village pond against the villagers' wish."

"He was agitated today because one of the visiting doctors, had advised the group about not allowing persons with ulcers to bathe in common village ponds. A hue and cry was raised by the Sarpanch about his earlier deception by the workers."

"The house, however, appeared divided on this issue. One group maintained: when cattle could wallow in the pond, when all types of dirty things could be washed with impunity, what difference did it make if a person with an ulcer took bath? This group made themselves bold and even questioned the wisdom of the doctor. Arguments and counter arguments followed."

"In the end though the Sarpanch stood convinced about his earlier action, some of our co-workers got agitated at the contradictions inherent in our approach which this incident had brought to the surface. They were disturbed over the contradictions. More particularly with regard to 'transmission' of the disease and 'infectivity'. They pointed to a paragraph in one of the Health Education pamphlets to illlustrate their point. The particular portion talked about an infectious type of patient who through his breathing, sneezing, and coughing transmitted millions and millions of bacteria. They asked, didn't this mean talking with two mouths? If what was written in the pamphlet was correct, then why did they waste their energies on persuading villagers to mix with the patients without any hesitation? Why did they encourage their colleagues to sleep with their beds in close proximity to those of the patients? Were they not cheating the village people and the patients? And also the Workers?"

"At this stage, some of the patients, too, joined in the discussions. They asked if they were infectious, why did the Organisers call them to this camp? A strong chorus of protests came from this section. They were disturbed emotionally. Tempers ran high. Practically everyone was on his feet. They even objected to a reference in the Certificate given to 'cured' patients by Leprosy Hospitals. There it was stated: "now he (the patient) can take medicine at home." They wanted this reference to be deleted because it put others into a category who needed compulsory social segregation."

"Waving the particular pamphlet in the air one of our colleagues appealed to all others to tear off the objectionable portion from the pamphlet then and there. What he himself tore off was the entire pamphlet. Others followed suit. A verdict was given. Something within us was up in arms. It was far more powerful than logic."

"The action taken in a fit of emotional upset was to the liking of one and all. All got up to go even though the formality of group discussion as part of the training session was not over."

31. From Dongargarh to Bhilai

Pandit Patankar

Consultant
Community Action
DANLEP
New Delhi

When it comes to dealing creatively with a knotty problem like leprosy, what helps most is not generation of new ideas, but escaping from dysfunctional hangovers of old ones. The journey from Dongargarh which started in March 1987, essentially has a character of an escapade in this sense, casting away the dysfunctionality of old ideas. A classic example of how a dysfunctional hangover persists and stalls progressive movement towards meaningful action can be cited here.

When does a person with M.B. history, ceases to be an 'infectivity risk' to others? It is a simple question which interests both the general public as well as the patient. Since long it has been crying for an answer. Is it when he has a negative smear? How does a person in the street or let us say in the neighbourhood of the patient, know when the patient goes negative on his smear? What does that person in the neighbourhood do when he is not aware of the smear results? Then what about the 50 per cent plus M.B. cases, who are on regular treatment of MDT despite negative smear? Should a man in the street discriminate between these two? And how? Should he shun social contacts with this person with leprosy history? Further hair-splitting would lead us to increased uncertainties in our responses.

'Mixed-Group-Residential' . . . camp in its design and organisation simulated "In-Group" social setting of the envisioned tomorrow. A setting where the patients lived a free soul satisfying social existence in company with important members of the village communities.

The paradox of these uncertainties becomes sharper when we pronounce from house tops the phenomenon of natural immunity against this disease amongst 98 per cent of the humans. The uncertainties becomes more perplexing when we say 99.9 per cent bacterial 'kill' takes place just with first few doses of MDT amongst the balance 2 per cent who get infected. If both the pronouncements about natural immunity and the instancy of bacterial kill are sound and true, how is it that a patient who has been regular in taking daily doses of MDT successively for 14 days, and has maintained a commendable record of treatment compliance subsequently, still remains suspect as an 'infectivity-risk'? Deductive logic gives the answer: "He certainly cannot". And yet uncertainties hang on. How do we explain these uncertainties to the person who remains under constant threat of social ostracisation? None has explained so far, which of these patients are really an infectivity risk, the person under treatment with negative smear or the one with positive smear; or both? And how? Yet the 'infectivity-risk' mania persists. Not amongst the laymen but amongst the para-medics and even the professionals. Thereby crippling their potent capacities to deliver effective services to leprosy patients. This is what we mean when we talk of need for escape from dysfunctional hangovers of old ideas.

I call it a 'hangover' because we persist under its spell with no convincing evidence at our command. In the day-to-day life none of these patients who are regular on treatment have ever posed 'infectivity threat' to others. At least we do not possess scientific data to say that it does. And yet we are lethargic in putting to use such a potently powerful tool. I am told that now in the post-'Aarohan Month' phase in Bhilai voluntary reporting of new cases has increased more than hundred per cent.

Since March '87 in Dongargarh, we decided to escape the rigours of these uncertainties by considering all those who have completed 'Intensive Therapy' under MDT, and have maintained a reasonably regular record of medical treatment subsequently, as persons with no 'infectivity risk' to the community. Indeed, on this basis, we built the entire structure of the (now famous) long duration 'Mixed-Group-Residential' (MGR) Camps like the one conducted in February this year at Purena. These camps brought together the patients (M.B. Cases), the prominent villagers (whom we called in Dongargarh as Social Communicators) and the full range of control unit staff — right from the DLO down to the Para-Medical Worker. These are the 'Three Arms' of the 'patient-care-triangle'. The Camp in its design and organisation simulated "In-Group" social setting of the envisioned tomorrow. A setting where the patients lived a free, vibrant and soul satisfying social existence in company with important members of the village communities. These latter in turn, underwent a new experience of 'scare-free' social proximity with those whom they had feared and rejected earlier. What better learning experience we could think of for the workers as help in crystalising the goals of the overall leprosy eradication progamme?

The personal as well as professional growth of the Field Staff, in the process of organisation of such camp, was in evidence in a subsequent get-together, where a critical review of the Purena Camp was undertaken. We had earlier in November '87 presented the 'MGR Camp Model' to a select group of the LEU staff in a Laboratory-cum-Workshop at Dongargarh. By way of a Feedback on how they performed at Purena while working on this model, they reported: "What you wanted to do earlier at Dongargarh, but could not do, we have done here in Purena". I must confess: Purena camp was the most satisfying experience in this journey we had undertaken since March, 1987.

Yet another escape from the hangover of old ideas, or to put it by using a behavioural science 'cliche', the required unlearning, was attempted during the year long journey. This related to materialising 'patient-care' in leprosy—to mutual satisfaction of the patient as well as the delivery system. In leprosy, patient care is not only not episodic, it essentially remains dependent on or is governed by the presence of positivity in the social environment. It is these factors of positivity that set scale to the degree of positivity of the patient response. The community forms one of the major factors in either hindering or facilitating free-flow of 'medicare' or for that matter any form of other care to leprosy patient in this sense. The conventional bilateral, 'medicare' based clinical model of patient care, therefore, has remained inadequate. The most heart-warming patient behaviours witnessed during the camps like Purena, provided convincing proof of the need to look upon the Community as a critical medium for effective translation of 'medicare' into broader aspects of 'patient care'. It was seen that medicare and patient care were two different concepts in leprosy. The patient care delivery required a triangular setting. The patient, the value infuser in the community and the treatment provider, formed the triangle for patient care.

The real snag in operationalising this 'Triangular Model' was not the absence of community response. The snag lay in the style or pattern of response seeking practiced in a governmental system. It carries an hierarchical flavour. In the MGR camps the community played a 'major partnering role. This was well demonstrated when decision for admission of Surja Bai (a patient who belonged to another district was seeking admission for MDT in Purena) was referred to the local committee of the villagers. The issue whether the governmental system would accommodate and assign such a role to local community and be able to adjust with it, does arise in a long-term perspective. Such adjustment is likely to be perceived as a threat. What happened if the patients and the community indulged in 'unreasonable expectations' from the Field staff? Doubts of this nature haunt the Field workers who obviously worked under resource constraints and pre-patterned delivery of services?

Events in Dongargarh, however, proved that such apprehensions were nothing more than the hangover of the 'old idea'. We did escape from its spell. 'Responsive Action' involving mutuality of expectations came our way quite handy as a safeguard. Only the old idea wherein the delivery system was conceived as a transaction between givers' and 'takers' in their fixed roles needed to be discarded. The 'giver' and 'taker' roles were required to be made interchangeable. They need not be statically seen as 'agency' specific. We could see, how the day the Field Staff played the 'Taker' role in Dongargarh (the 'Seeker' or 'Yaachak' role) a totally new field dynamics developed. That day the community 'Arm' of the triangle acquired pro-active dimensions, it started shaping itself into a medium of 'patient care' in leprosy in Dongargarh area. The 'Seth' in the Sabdi Bai's case and the role he played that morning on the 'Pulse' day, was symbolic in this sense. Judging from the quality and character of field responses in certain areas in Dongargarh the 'Seth's behaviour', in no way, could be termed as 'exceptional'.

The role-exchange transaction, the switchovers to "Seeker" role; and the manager role did not remain restricted only to the 'treatment providers' and the 'community'. The patients too, were drawn in the process of 'role-exchange-transaction' equally significantly. To begin with as part of the 'responsive action' they were expected to remain clean if they anticipated 'acceptance' and 'respect' from their social setting. Indeed, cleanliness formed priority number one activity of a 5-point programme that was devised to highlight the scope to promote transactions in roles or in exchange of the role functions. The programme covered — (i) Cleanliness (Swachhata); (ii) Respect or Social Acceptance (Samman); (iii) Relay of Affection or Warmth (Lagaav); (iv) Composite Service (Samagra Sewa); and (v) Endeavour (Nirdhar or Prayaas). The three arms of the patient care triangle were to implement this 5-point programme while developing work in villages. In the wake of this programme, during the year, a vide variety of actions and interactions flowed in giving rise to sharpness of mutually transacted expectations and shaping of consequent 'roles'.

All said and done, escape from the hangover of the old idea about 'patient-role' remained a slow-scaling down process. The old idea visualised primarily 'Taker' roles for the patients. Even imagination did not stretch to a point where escape from this old idea could be considered feasible. How could a patient play a 'giver' role? Developing a 'delivery system' to promote and develop new, socially meaningful 'giver' roles for the patients sounded ludicrous. It sounds ludicrous because scant attention has been paid to the identity needs of the patients. Medicare, under the old idea was seen as the beginning and the end of the function of the delivery system. Escape from the hangover of such understanding of the function of the delivery system, appeared a hard nut to crack.

Medicinally centred service formed the focal point of the delivery system. The functions of Survey, Detection, Case holding, Surveillance, etc. which were visualised for the system, inadvertantly created an impression amongst the patients' mind that the system was installed to advance the community interest of protection from infection, rather than to cater to patient needs.

First attempt of escape from the restricted view of the function of delivery system was made during the Community Resource Mobilisation Workshop of March, 1987. It marked the beginning of search for an escape route. Fieldworkers were asked to go to villages not for case detection work. A proposition was made that they should not-spy on the community in this fashion; and in the process expect the community leaders to play 'informer' roles. The suggestion sounded ludicrous. But credence was given for search of an alternative function. The focus of vigilance shifted from 'detection' and 'surveillance' to 'service'. Skin Disease Diagnosis & Treatment Camps came handy in the pursuit of the search for alternatives.

Patients were seen as potentially better educators. Articulation of their experiences turned out as better channels of education on matters pertaining to the disease. This was just the beginning of an understanding of the capability potential amongst the patients. Eventually, a new awareness developed that they are valuable to the delivery system as active partners.

Simultaneous with this awareness, discarding of the Case detector role by the Fieldworkers had created a void in Role functions of the Fieldstaff. As a result of this 'void' a gradual process of transfer of Role functions commenced. Field worker was giving up something that was hurting to the patient and patient was taking over something which was soothing to his ego. A role transaction was taking place.

In Dongargarh, during the November '87 Intensive Therapy MGR Camp, thanks to special emphasis given by Dr. Gude on Hydro-Oleo Therapy based 'Self-Care' service, the system developed new insights into preventive aspects of work in leprosy which proved critical factors in changing perspectives on 'system-function'. The system could see an equally vital function beyond bacterial control. Anaesthesia did not die with bacteria. Tremendous interest got developed not only amongst the field staff, but within the patient community. The way the latter evinced keen interest in 'Nose & Mouth Toilet" and in 'Ulcer Treatment' exercises as part of this new therapy, marked a major successful escape from the old idea of 'medicare' centred delivery system. Perhaps for the first time the patient experienced something concrete and worthwhile being attempted to arrest his downhill drift to disintegration. 'Medicare' was generally perceived by the patients as a system primarily devised and developed to protect the community from infection of the disease. The new therapy, therefore, for the first time gave him a new hope. This was critical for the process of 'role-taking' by the patients which had commenced earlier in the 'patient-turned-educator' programme.

For the first time new crystalisations started materialising about the functions and objectives of the delivery system. The system at the operational level could visualise new possibilities of freeing the 'disease' of its dread; and lifting the patient to his unsullied, rightful place in the society. As Shri Pradeep Singh says in his introductory remarks, Sabdi Bai represented the patient of tomorrow — assertive enough and striving to satisfy his/her own identity needs while simultaneously at peace with the community around, being assured of positivity of its response symbolised by the 'Seth'.

Leprosy plays havoc with patient's mind. The patient, therefore, can be aptly described as a 'soul-lost' person. Reviving his faith in himself and putting him on his feet so that he becomes aware of his capabilities and potentialities, is all that should be expected of the new enlarged delivery system. Shaping a 'giver-role' around the patient was all that important. Why underestimate his potential to 'give back' to the society; to the 'likes' of him who needed help? He can extend his hand to put up a workshop for the handicapped. What makes us doubt these possibilities? The doubting Thomases within us remain active because we have focussed our attention on only destitutes amongst the patients.

In Bhilai bold experimentations were undertaken to identify and shape 'giver' roles for the 'patient'. To recognise them wherever these were already being performed. An effort was made to present to the public that patient whose competency to play the giver' role remained at least on par with others in the normal (non-patient) society.

Special attention was focussed on two types of patient groups in Bhilai. One category represented the "strong" and the "sturdy" who represented the majority. Some of them were already playing the 'giver' roles but were on the sly. Then there were those who were eager to play such roles but were physically handicapped. The programme in Bhilai covered both these categories. Escape was sought from the old idea of focussing attention on that segment of patient population which capitalised and thrived on its destitute image.

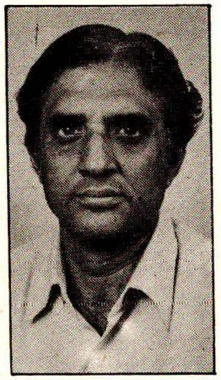
The former group indeed played a stellar role in improving the overall image of the leprosy patient in the eyes of the general public. It was observed that this group had a potential to function as a 'lever' to lift those docile and subdued ones at the one end of the axis, and the shy and slippery ones at the other end.

Experimentation in Bhilai remained centred on search for a delivery system which primarily met patient needs beyond medicare'. In the process the weaknesses of the existing system in attending to patient problems created by anaesthesia and nerve paralysis came to the surface. The problems appeared essentially organisational in nature which could be overcome with application of administrative mind.

We tried to relocate services for Reconstructive Surgery in leprosy at a General Hospital. The perspectives which prompted this experimentation were informed not so much by the concern for multiplication or diffusion of these services. It was governed by an awareness that unless these were developed with adequate social or community supports, they would never satisfy their prime justification — promotion of expeditious "In-Group Absorption" of persons with leprosy history.

It is gratifying to note that social supports so hitched on to these services open up a new vista of social action which effectively grapples with wider issues of social stigma that are haunting the sphere of Rehabilitation work. One of the broad-based programmes widely canvassed in Bhilai, therefore related to promotion of "mixed-group-work opportunities" in the existing work set-ups. Bhilai Mahila Samaj was bold enough to invite 10 cured Leprosy patients (women) at work at their 'Gloves Manufacturing Workshop'.

Prospects of promoting organised but not independently institutionalised social action to uproot stigma have emerged brighter after Bhilai programme. In this sense Bhilai does not mark the terminal point of the journey which began at Dongargarh. Indeed it marks the launching of it anew in a new vehicle which will by fuelled and propelled by community action.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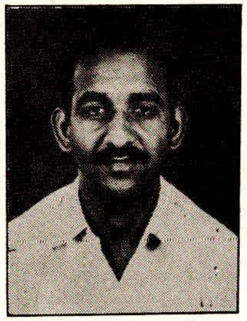
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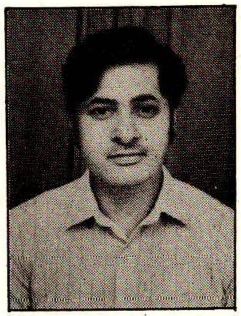
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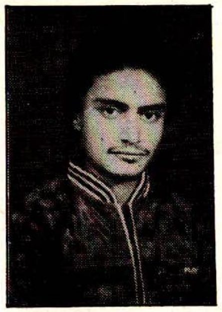
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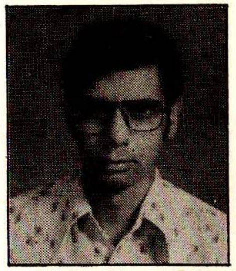
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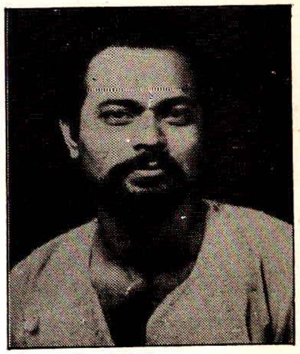
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Patron,
Samagra Prayas Aarohan Samiti
Bhilai
Bridge between Samaroh Organisers and
Trade Union Functionaries
Bhilai Steel Plant

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Heart Warming Nursing Care of
Corrective Surgery Patients in the Wards.

A. Chacko
Senior Staff Nurse Bhilai Hospital
Meticulous care of corrective surgery
patients

Dr. Rakesh Chhabra,
House Surgeon,
Diligent pre and post operative care
in Hospital Wards
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Mahesh Chaturvedi
Artist, P.R.O. BSP Bhilai
Ever willing competent helping hand for
organising exhibitions & drawing-
painting competition. Member of the
Panel of Judges children's art
competitions.

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President
Grameen Mahila Mandal
village Risali-Bhilai –
willing worker amongst village women

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Physio-Therapist
In-charge of the Physio Therapy Unit,
Bhilai Hospital. Valuable services
rendered in post-operative physio-
therapy to corrective surgery patients.

Dr. G.L. Gupta
Specialist
In-charge Orthopaedics, Bhilai Hospital.
Untiring surgery hand for corrective
surgery patients. Deep commitment to
work in the field of Leprosy.

Gulab
Dresser, Bhilai Hospital
Patients carried memories of his 'Service
with Smile'.

Dr. M.L. Jain
Specialist In-charge
Burns Unit, Bhilai Hospital
Plastic Surgeon
Known to patients for warmth and
competency. Doctor with few words
with enduring smile

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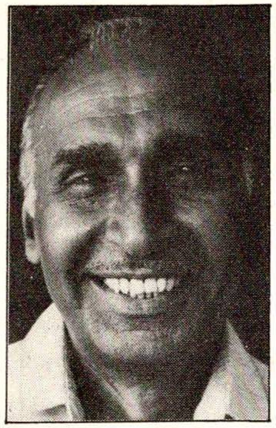
Philanthropist, kind hearted adopter of
corrective surgery patients

Dr. D. Jha
House Surgeon, Bhilai Hospital
Valuable help rendered during pre and
post operative stage for corrective
surgery patients. Active organisational
role in other activities of the Aarohan
Samaroh.

A. Joseph
Senior Staff Nurse, Bhilai Hospital
Warmth of nursing care in wards
remembered by corrective surgery
patients.

K. Kamalamma
Senior Staff Nurse, Bhilai Hospital
Prompt attention to corrective surgery
patients in wards.


Tina Patankar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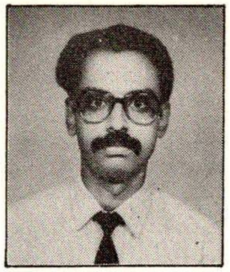
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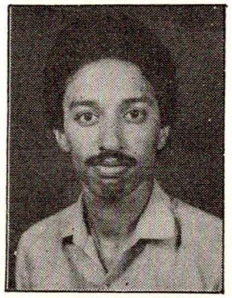
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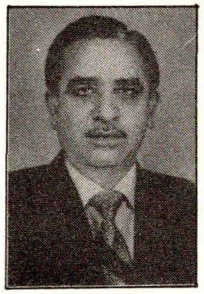
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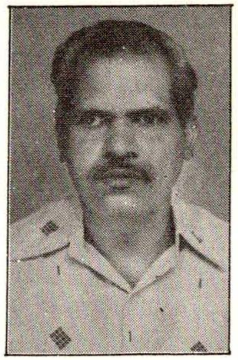
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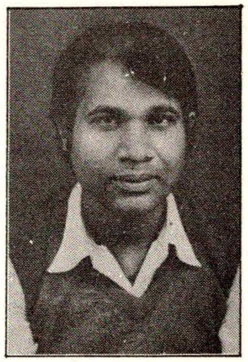
Pramod Yadav

P. Kumar
Asst. Nursing Superintendent Bhilai Hospital. Compassionate supervision winning hearts of patients in wards.

Kuldeep Kumar
B.K. Industries, Bhilai
Member of a known philanthropic family adopter/donor for corrective surgery cases.

Himanshu Mishra
In-charge, Video Unit PRO Bhilai
Rendered invaluable service by covering out-door video shooting of Aarohan programme; and by briskly supplying visually edited ready to view tapes.

Abhay Newalkar
Social Worker
Voluntarily offered services for the entire duration of the self-care camp held at Gayatri Shakti Peeth. Endeared all for his infective smile.

Tina Patankar
Specialist DANLEP Video Unit New Delhi. Young smart lady with smile. Spent long hours behind the video camera in Operation Theatre day after day, to record corrective surgery operations by the visiting as well as the Bhilai Hospital surgeons.

Shivdas Ramteke
Dresser, Bhilai Hospital
Endeared all patients by ungrudging services.

Papa Rao
Artist,
Medical and Health Services BSP
Valuable help in putting up exhibitions

H.R.V. Rao Kandi
H.S. Mechinist
Machine Shop BSP
Volunteer Specially released by the management to organise Aarohan programme. Rendered behind the scene valuable services.

Laxman Swamy
Theatre Assistant
Bhilai Hospital,
Meticulous nursing care of the patients in the ward.

Mool Chand Shah
Patron
Industrialist, Simplex Industries, Bhilai,
Chief Guest, Samaapan Samaroh on 29th April, 1988.

Mrs. Gayatri Soni
Social Worker
Volunteered her services for the duration of the camp. Valuable silent organisational work for "A Rupee For New Life" programme.

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Secretary, DANLEP.
Diligent handling of Manuscriupt Development for the Publication—"An experiment in Community Action" Personal attention poured into otherwise tedious and strenuous work of preparing repeat drafts.

Dr. M.C. Tayal
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In-charge Anaesthesia,
Head of Department, Bhilai Hospital
Painstaking services, highly appreciated by visiting surgeons

Anil Vashisht
Cameraman Video Unit PRO, BSP, Bhilai
Ungrudging services for outdoor video-shooting of Aarohan programme.

N. Vishwanathan
Section Officer Finance, Specially released as volunteer by B.S.P.
Pillar of strength. Diligently handled accounts keeping for numerous volunteers working for "A Rupee for New Life" programme. Firm handing of a delicate mission.

M.M. Wadhwa
Physio-Therapist
In-charge P.T. Unit, Bhilai Hospital,
Accommodated with understanding extra-rush of cases from corrective surgey camp.

Pramod Yadav
Photographer, PRO Office, BSP,
Still photography for the Aarohan programme handled with great understanding.

Incongruities Consigned to Flames

- Alms giving to Beggars: heaping indignities!
- Social isolation of children of Leprosy patients: trampling the scientific spirit.
- Hesitations to work with "cured" but physically disabled: self-preservation at others' cost.
- Objections to sharing General-Ward-Beds with infectivity-free leprosy afflicted persons: hurting insensitivity.
- Disinclination to eat & drink with infectivity-free persons: shaming civility.

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