Domiciliary and Field Work

DOMICILIARY REHABILITATION

(A 5-year follow-up study on self-employment of disabled leprosy patients)

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Introduction

This study is a continuation of a project started 5 years ago, a preliminary report of which was published in *Lepr Rev* (1976) 47, 295–305.

One of the common definitions used for rehabilitation is the one given by the National Council of Rehabilitation 1942 'Restoration of the handicapped to fullest physical, mental, social, vocational and economic usefulness of which they are capable.' The entire project has this definition as its background. In an attempt to classify rehabilitation the following steps may be considered:

1. Job placement { Same job
 Similar job
2. Domiciliary rehabilitation (self-employment)
3. Sheltered work { Without residential facilities
 With residential facilities
4. Pension scheme
5. Care homes.

This paper reports on our inferences in the second category which helps the patient become self-sufficient in his own community.

The method of operation

1. There should be a specific request for help.
2. The request should be reasonable, specific and workable.
3. The proposition is then analysed by the workers in full by home visits, interviews, on-the-spot observations and, if needed, training and counselling.
4. The final decision on the production unit to be given is made jointly by the investigator and the patient concerned.

With the approval of a small committee the unit is then bought, obtained, or made by the combined efforts of the patient and the investigator and handed over to him after

executing a bond. This bond specifies the person, unit given, cost involved, utilization and right of ownership until the cost is returned in full etc.

The follow-up work starts from the day the unit is given to the patient. For the first month the patient is visited every week, in the second month every fortnight and, unless more visits are indicated, from the third month onwards monthly. The visits are made with the specific intention of:

1. Observing and studying the improvement or change in the patient and his family's social and emotional status.
2. Making the patient realize that he is carefully observed.
3. Helping the patient in case of any avoidable deterioration.

The patient starts returning the capital investment after a pre-fixed period of time. Failure to make regular repayments is considered and dealt with firmly but sympathetically. However, only in the case of gross misuse may the option to withdraw the unit be exercised.

Material and results

The present study involved 60 patients who have been assisted during the period from July 1975 to June 1980. All these patients have been followed up for a minimum of 6 months and a maximum of 5 years.

MARITAL STATUS AND SEX

There were 13 female patients and 47 male patients, of which 32 were married, 21 unmarried, 1 widower, 5 widows and 1 separated.

DEFORMITY STATUS

Of the patients rehabilitated 80% had gross deformities. Some were without obvious deformities but had to be included because if no help had been given they could have become dependants of the general public (Table 1).

Table 1. Deformity pattern of the 60 patients

Deformity	No.	%
No deformity	4	6.7
WHO Gr. I (only anaesthesia)	8	13.3
WHO Gr. II (correctable deformity)	15	25.0
WHO Gr. III (un-correctable deformity)	33	55.0
Total	60	100.0

EDUCATIONAL LEVEL

Forty-five persons (75%) were either illiterates or had received only primary education, 15 (25%) were above secondary school level.

When rehabilitating patients, consideration must be given to the fact that certain occupations are done by specific castes, and neglect of this aspect has in some cases led to failure of rehabilitation because of the non-acceptance by the members of the caste concerned.

Table 2 explains the various types of trades given to the patients under this project and the cost of each unit.

Table 2. Hereditary occupation of the 60 patients rehabilitated

S. No.	Hereditary occupation	No.	%
1	Farming	22	36.7
2	Weaving	10	16.7
3	Unskilled wage labourer	5	8.3
4	Business (petty trades)	4	6.7
5	Sheep rearing	3	5.0
6	Pig rearing	2	3.3
7	Potter	2	3.3
8	Cobbler	2	3.3
9	Dhobi (village washerman)	2	3.3
10	Village priest (Hindu)	1	1.7
11	Basket maker	1	1.7
12	Smithy (artisan)	1	1.7
13	Non-specific *	5	8.3
Total		60	100.0

*Includes 5 patients who had no specific hereditary trade.

Table 3. Assistance given through rehabilitation project

S. No.	Trade	No.	%	Total cost	Average cost
1	Milking cattle	14	23.3	10,378	741
2	Capital for petty trade	14	23.3	3,800	271
3	Looms and accessories	7	11.7	3,530	504
4	Petty shop and capital	6	10.0	3,341	557
5	Sewing machine	4	6.7	2,822	706
6	Goats and sheep (unit of 6 per person)	4	6.7	2,760	680
7	Capital for cultivation (own land)	4	6.7	2,350	588
8	Animal-drawn cart	2	3.3	1,280	640
9	Cycle rickshaw	1	1.7	1,000	1,000
10	Public address system	1	1.7	1,797	1,797
11	Silk-screen unit	1	1.7	900	900
12	Unit of 2 pigs	1	1.7	360	360
13	Typewriting institute	1	1.7	2,455	2,455
Total		60	100.2	36,773	—

Milking cattle has been the most wanted aid, 23% in our area. This can be explained easily since the majority of people have farming as their hereditary trade.

A total of Rs. 36,773 was spent on 60 units which gives an average of Rs. 613/- per unit. The maximum amount spent on any one unit was Rs. 2,455/- and the minimum Rs. 50/- . So far 37% of the money spent has been repaid.

Of the 60 patients 32 (53%) have shown good progress towards becoming self-sufficient and come into the 'successful' group, Table 4. This was judged on 2 main criteria:

- 1 Changes in household articles such as clothes, utensils and type of house.
- 2 Regularity of repayments.

Changes in clothing are seen in the gradation of cotton, terry cotton and terene as they improve. In the same way utensils start from mud, to aluminium, brass, hindalium (a newly available alloy) and stainless steel. Houses start as mud huts with palmyra thatch which develop into grass thatch, later are replaced by country tiles, then factory tiles and finally concrete.

Another group of 9 patients (15%) come under the group 'fairly successful'. That is to say they have shown improvement in one of the criteria but failed in the other. The column 'no change' has 13% of the patients. These still have their units, but they have neither paid back the money nor shown any visible improvement in their living conditions.

Table 4. Period after rehabilitation and present status

Period (years)	Successful	Fairly successful	Change	Failure	Total	%
4-5	5	2	4	4	15	25
3-4	5	2	Nil	2	9	15
2-3	11	4	Nil	5	22	37
$\frac{1}{2}$ -2	11	1	2	Nil	14	23
Total	32 (53%)	9 (15%)	8 (13%)	11 (18%)	60 (100%)	100

The column 'failure' has 11 patients (10%) who have shown further deterioration even after issue of a production unit.

Eleven patients who come under 'failure' were analysed further to see why they deteriorated, the following are the details of these cases.

- 1 The patient was evicted from his house by the Highways Department since he had built it on Highways property.
- 2 The patient was given a draught bullock and a cart which he could use for transporting vegetables, as he had done in the past, from villages to the town market. When he developed a foot ulcer, he left the cart and the bull at home and went away to a distant hospital and was admitted there for a number of months. During this time his wife and children, and also the bull, almost starved. On his return his cruel attempt to make the starved bull work killed it and the patient sold the remnants of the cart.
- 3 The third patient was a farmer by profession. After he developed leprosy he was trained as a weaver in a care home. On leaving he was given a hut and loom near the hospital and arrangements were made for him to have orders from the hospital for table mats. The hospital was also to supply the raw material. The patient was then able to sell the finished product to the hospital at the market price. But he was unable to adjust to the new discipline of weaving, probably because his hereditary trade was farming. (It is significant to note that in a similar case the patient who was a weaver by caste was given a house and the same facilities, and he was one of the 'successful' group.)
- 4 This patient was a small-scale smuggler of liquor etc, but now said that he wanted to settle down in life. He was given a capital of Rs. 50/- to buy some bundles of firewood and a few litres of kerosene oil. This he could sell to the slumdweller, of whom he was also one. However, his decision to reform seems to have been halfhearted, he later disappeared and we lost contact.
- 5 The fifth patient after rehabilitation developed some heart complications and so he was advised not to use his unit, namely a sewing machine, so he returned the unit and now he is under constant medical care.
- 6 The sixth patient was given a jutka (passenger cart drawn by a single horse). He was not successful, apparently, because he had changed his religion from Hindu to Islam. He was rejected by both communities, which led to his downfall.
- 7 This patient was given 2 cycles for hire and some tools and spares for a cycle-repair shop. This was a second attempt to help him but the patient sold off the cycles and the spares once again. It was clear on analysis that he did not have the aptitude to become self-sufficient.
- 8 The eighth patient was given capital for seasonal business. He was doing well and within a year had a running capital of Rs. 1,000/- but then he became too ambitious and took a 'short cut' to double his capital. He was cheated and lost everything.
- 9 The ninth patient failed because he used up the capital he was given for his shop instead of using the income. He was originally a paid employee who did not have any business experience, but as he was insistent he was given the opportunity of running a shop on a trial basis.

- 10 The tenth patient who was also assisted in business failed due to a conflict with his siblings in his large joint family. Seven family units lived in the same house, enmity developed and he was finally thrown out.
- 11 The eleventh patient died 5 weeks after rehabilitation and so did not get a chance of improving. He was put under failure because this was a wrong selection. He was over 60 years old when he was assisted.

This analysis shows that there cannot be any general rule to give reasons for failure but it does offer some guidelines in selection. It would appear from the analysis that age is a risk factor to be considered.

Discussion

Domiciliary rehabilitation, followed up for a period varying from 6 months to 5 years, shows that there is a chance of about 68% of patients becoming self-sufficient and independent or at least substantially improved. Patients thus rehabilitated are able to retain their place in the society.

There are a number of government projects which give assistance to such causes, e.g. loans for cultivation of lands, starting a small poultry unit, purchase of cows for small farmers, but these facilities could not be used in our project because the patients we assessed were found to be in such desperate and urgent need that they could not wait for the time it would take to obtain government aid.

Rehabilitating a patient in a light-engineering workshop which makes precision tools under a sheltered situation, comes to c. Rs. 40,000/-50,000/- per workplace. But these small self-employment schemes in a rural area cost an average of Rs. 600/- per workplace. Against this of course it could be argued that the former category are materially better off, but often are not well integrated into the local community. Domiciliary rehabilitation avoids the possibility of patients being colonized in artificial groups.

Once patients are successfully rehabilitated, especially if they remain in their own village, they are no more dependent on the institution or anyone else, and so are able to retain their self-respect and be useful citizens of the country.

Conclusion

This project gives us an insight into the minor details of practical problems and advantages of organizing a self-employment scheme in a rural area. It demonstrates how important certain aspects like hereditary trade, previous experience and aptitude are in making rehabilitation successful. It also explains how financial stability correlates with the so-called stigma attached to leprosy. It is interesting to note that patients who were on the verge of becoming outcasts from society due to 'stigma' become well-adjusted and accepted in the same society, once they are able to earn sufficient money. Financial independence would appear to be a most important factor in reducing the stigma.

We feel we must stress the importance of the factor of careful selection of the type of assistance given, and very meticulous follow-up home visits by members of the rehabilitation team. Indiscriminate handing out of aid can only result in large losses and an increased number of failures.