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# Psychosocial aspects of deformed leprosy patients undergoing surgical correction

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*Summary* A psychosocial study was conducted on 25 randomly selected leprosy patients undergoing corrective surgical procedures for their deformities. High anxiety and depression levels found preoperatively, reduced significantly after operation. Psychiatric assistance is needed for these patients in order to clear their psychic aberrations, create awareness, boost morale and to give self-confidence.

Only 50–75% of preoperative expectations were satisfied but that was only in 40% of patients. This calls for a preoperative counselling session with the patients to help them reach the realistic goals that they can achieve. They should be told what benefits surgery can offer them and be made aware of the problems which will persist after operation, such as anaesthesia and analgesia.

## Introduction

Leprosy predominantly affects the skin and peripheral nerves, which if damaged result in deformities of the face and extremities. It has been estimated that approximately 25% of leprosy patients are deformed. Patients with leprosy are very self-conscious of any deformity they have which they feel may advertise to others that they have or have had leprosy. The majority of these patients can benefit from surgery, and surgery is important in the overall rehabilitation of the patient.

Depression is the main psychological feature of patients with leprosy. A specific alteration in mood, sadness, loneliness, apathy and a negative self-concept is found. This may be associated with feelings of self-blame, self-disgrace or shame, self-punishing wishes and a desire to run away from everyday problems.

Anxiety is a common feature of many clinical states and it is reported to be significantly higher in leprosy patients. It is suggested that it creates worries, tension and irritation.[2]

Previous social and economic status are important factors in the rehabilitation of leprosy patients.[3] One study[4] concluded that reconstructive surgery helps leprosy

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patients, at least to some extent, to regain their cosmetic, functional, occupational and economic status in society.

The best results of surgery are obtained in patients with a positive outlook and having a favourable social and family environment, which aids resettlement and rehabilitation after surgery.

Various psychological aspects of leprosy are being investigated but there are few reports on deformed patients and even less on deformed patients undergoing surgery. This prompted us to undertake this preliminary study in order to find out the psychosocial status of the patients with deformities before and after surgical correction and also to assess:

1 The sociodemographic characteristics of leprosy cases who opted for surgical correction for the deformities.
2 The intelligence and personality make-up of these patients.
3 The depression and anxiety levels of these patients before and after surgical correction.
4 The expectations from surgery and its fulfilment after operation.

## Materials and methods

The study was conducted at the Central JALMA Institute for Leprosy, Agra. The cases were selected at random from the group opting for corrective surgery and a final sample of 25 patients has been included in the study. The cases were hospitalized for 1 or 2 days as many of them had travelled long distances. This was done to eliminate the effects of travel and exertion. The patients were assessed a week prior to surgery and then every 3 months for 3 successive visits.

The tools for collection and analysis of data are:

The examination, which aims to ascertain from the patients information regarding their sociodemographic characteristics and details of leprosy, duration, type of deformity etc., and also their expectations of surgery.

Psychological evaluation using:[5]

Beck's depression inventory; Taylor's manifest anxiety scale test; Thematic apperception test (TAT); and Wechsler adult intelligence scale test as modified and adapted to Indian situations by Ramlingaswamy (1972).[6]

### *Beck's depression inventory*

The inventory consists of 21 categories of symptoms and attitudes. Each category describes a specific manifestation of depression in a graded series of four to five self-evaluative statements. Numerical values of 0 to 3 are given to each statement reflecting neutrality to maximum severity. The tester reads the statements in each category while the patient follows from his own answer sheet and he is asked to circle the number of the statement which best describes him at that particular moment. The total score is obtained by summing up the scores of the individual's symptom categories. The inventory has been shown to be reliable, consistent and valid in several studies.

*Taylor's Manifest Anxiety Scale*

This scale provides scores for anxiety. The scale has a list of forty items. It is a self-administering scale and gives better results with individual testing rather than group testing. In a group situation the tester can also get quite appropriate results after establishing a good rapport with the testee. If the subject was illiterate, he was asked to hear and follow the statement. If the subject was literate, he was asked to read the instructions. So everyone could be included. Subjects were asked to tick 'true' or 'false' to whichever they agree. The testee should go through each item carefully. At the end of the procedure, a score is given for each correct answer and totalled. This scale is valid and reliable.

*Thematic Apperception Test (TAT)*

The TAT consists of a series of pictures with people and objects in ambiguous situations. The person is asked to describe what he thinks were the events that led up to the situation in the picture and what he thinks will be the outcome.

*Wechsler Adult Intelligence Scales (WAIS)*

The test presented here is an adaptation of the Wechsler Adult Intelligence Scales to suit Indian situations. It consists of eleven sub-tests, namely, information, comprehension, arithmetic, similarities, digit span, vocabulary, digit symbol, picture completion, block design, picture arrangement and object assembly. Of these the first six form the verbal scale and the last five the performance scale. Picture completion and picture arrangement tests have been modified. Digit symbol, block design and object assembly remain the same as in the original WAIS. The age range for the scale is 15 years and above. The items for each of these tests were scored and the points summed up to give the 'raw score' for each test. The 'raw scores' were then transformed into weighted scores according to the manual.

## Observations

The general sociodemographic information is given in Table 1. Of the 25 patients studied 18 were in the 15–35 year age group and 23 had suffered from leprosy for 1–5 years. Twenty-three patients had tuberculoid or borderline–tuberculoid leprosy and 2 had lepromatous leprosy. Twenty patients came from rural or semi-urban settings. Only half of the patients had received primary or higher education, others were totally illiterate. Eleven patients were farmers and labourers; 6 (24%) were without work. Fourteen of the patients were married. Family size was medium (4 to 6 members) in 15 cases. Ten patients had an average socioeconomic status. Family atmosphere was congenial in 18 (72%), manageable in 3 and hostile in 4. Eighteen patients came from nuclear families and 7 from joint families.

Of the deformities operated on, 19 patients had claw hands, 4 had foot drop and two had collapse of the nose. In 11 cases multiple deformities were present which were

**Table 1.** Sociodemographic data of the cases

| Item | Data |
|---|---|
| Age | 15 to 30 years, 15<br>31 to 50 years, 8<br>Above 50 years, 2 |
| Sex | Male, 20<br>Female, 5 |
| Type of disease | T/BT, 23<br>LL, 2 |
| Duration of disease | 1 to 10 years, 21<br>Above 10 years, 4 |
| Type of deformity | Claw hand, 19<br>Drop foot, 4<br>Collapsed nose, 2 |
| Extent of deformity | Single, 14<br>Multiple, 11 |
| Religion | Hindu, 18<br>Muslim, 7 |
| Cultural status | Rural, 14<br>Semiurban, 6<br>Urban, 5 |
| Education | Illiterate, 12<br>Primary, 5<br>Above primary, 8 |
| Occupation | Farmer/Labourer, 11<br>Housewife, 4<br>Nil, 6<br>Others, 4 |
| Marital status | Married, 14<br>Single, 9<br>Separated, 2 |
| Family size | Small (1 to 3), 2<br>Medium (4 to 6), 15<br>Large (above 6), 8 |
| Nature of family | Nuclear, 18<br>Joint, 7 |
| Family atmosphere | Congenial, 18<br>Manageable, 3<br>Hostile, 4 |
| Socioeconomic status | Low, 15<br>Average, 10<br>High, 0 |

subsequently operated on but have not been included in this study. The psychological characteristics of these cases are shown in Table 2.

As revealed by the psychological projection tests (TAT), these patients had a tendency to blame their surroundings—family and outside, for their shortcomings, indecisiveness and failures. However, these patients were realistic, conforming and had a creative nature. Most of the patients accepted their social set up and evaluated themselves to be good and

**Table 2.** Psychological features of cases

| | | | |
|---|---|---|---|
| IQ | 15 Below normal | 8 Average | 2 Above average |
| Anxiety | 11 High | 9 Moderate | 5 Nil |
| Depression | 9 High | 9 Moderate | 7 Nil |

**Table 3.** Anxiety and depression levels before and after operation

| | Anxiety | | Depression | |
|---|---|---|---|---|
| Level | Before operation | After* operation | Before operation | After operation |
| Nil | 5 | 15 | 7 | 15 |
| Moderate | 9 | 5 | 9 | 7 |
| High | 11 | 5 | 9 | 3 |

*9 months postoperatively.

**Table 4.** Clinical expectations before and after operation

| Level of Expectations (%) | Before operation | After operation* |
|---|---|---|
| 76 to 100 | 14 | 3 |
| 51 to 75 | 6 | 10 |
| 26 to 50 | 4 | 9 |
| 0 to 25 | 1 | 3 |

*9 months postoperatively.

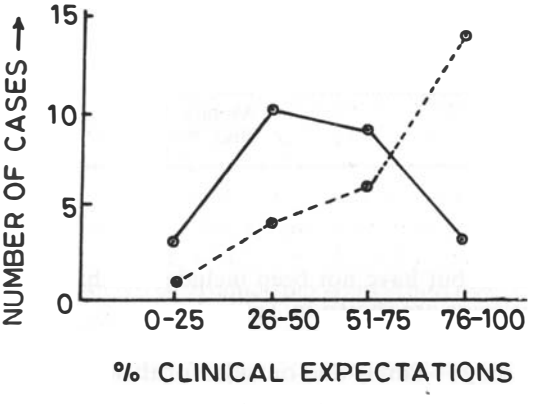


**Figure 1.** 'Expectations' before operation and the fulfilment after surgical correction. – – –, preoperative; ——, postoperative.

ambitious. They were frustrated with life and were in an unhappy and hostile mood. They preferred to withdraw themselves to avoid unfavourable or hostile situations.

Table 3 shows that before surgery 11 (44%) of the patients had high anxiety levels, the number came down to 5 (20%) postoperatively. Depression also cleared up in 32% and in 24% the high levels of depression disappeared.

Table 4 shows the expectations for improvement (before operation) and the expectations fulfilled after operation. Fifty-six per cent expected miraculous results and presumed that all their expectations were going to be fulfilled. However, after a third follow-up interview, it was found that only 50 to 75% of the pre-operative expectations were fulfilled and that was in only 10 (40%) of the patients.

## Discussion

Leprosy deformities act as an advertisement proclaiming the presence of the disease and failure of treatment. The clinical cure is different from a bacteriological cure or clearance. In addition to producing physical disfigurement and functional incapabilities, the deformities are usually associated by the public with infection which is often not true; in fact many of the deformed patients are not infectious. Surgery is important in the overall care of such patients and is part of the rehabilitation programme.

From the series reported here, some interesting observations have been made:

1 A male predominance in the series probably suggests that being an earning member and also male means patients get better attention within the family. This may also be due to the sex ratio seen for leprosy itself where males have been found to be more affected than females.

2 Patients with borderline–tuberculoid leprosy comprised 92% in contrast to 8% lepromatous. This is due to the fact that borderline leprosy patients get paralytic deformities more often. There were more claw hands because ulnar nerve involvement is more common.

3 Patients with a shorter duration of the disease were much more interested in getting rid of the deformity compared with cases of long-standing disease.

4 Sixty per cent came from the low socioeconomic strata. It was not clear whether it was because of deformity that the social status was low or because this reflected the general trend of the patients attending the hospital.

5 There were more married patients (56%), mostly from medium-sized families. These patients appear to be better motivated and well supported. In 72% (18 cases) family atmosphere was congenial which was a positive factor towards their rehabilitation.

6 It is often stated that leprosy causes psychological problems which manifest as symptoms. In our series we found that 20 patients (80%) had moderate to high anxiety levels preoperatively. This may be a sum total of the effects of deformity and the anticipation of surgical operation. A surgical operation stands as a major threat to anyone who has to undergo one. This is particularly so in leprosy because of its chronicity and the social stigma attached to it. The lack of awareness about these operations also contributes because they are not routinely performed in a general hospital.

Postoperatively anxiety disappeared in about half the patients and in others the level was reduced. As anxiety affects the personality and life style of the patients, it would be

worth evaluating anxiety levels well in advance of surgery to establish the true levels of anxiety without the additional effects of anxiety-reaction developing in anticipation of surgical operation. The high levels of depression were also reduced after operation, as shown in Table 3. These are the two psychological benefits the patient gets, in addition to the correction of deformity and restoration of functional abilities.

The study confirms the findings of Dean (1983),[7] that surgical procedures may well result in even less psychiatric morbidity. Therefore true rehabilitation including reconstructive surgery must be a part of the leprosy control programme; it is also essential that, in addition to medical and surgical care, these patients get some form of psychiatric counselling in order to dispel their psychic fears, boost their morale and bring self-confidence to them. For many of the patients, surgery will help to contain the psychological problems, by replacing a stigmatizing lesion with a socially acceptable one. Patients think that if they are questioned about the lesion, they can say they have had an operation or an accident and show the scar as proof.[8]

After corrective surgery only 50 to 75% preoperative expectations are fulfilled and that in only 40% of patients. This needs researching. The surgical procedure can result in the correction of deformities and restoration of some functions. The operations have their own limitations and not all delicate functions can be brought back by available techniques. Moreover the presence of anaesthesia in extremities or the lack of olfactory sensibility in the nose persists, which is frustrating for many patients. Our results reflect the importance of preoperative counselling to develop realistic postoperative expectations and therefore better psychological adjustment.

It is suggested that before corrective surgery is undertaken, a proper discussion should take place with the patients about their problems, and the benefits and limitations of surgery. This will help to improve patient cooperation and motivation and also reduce the frustrations of either side. The postoperative goals should be more realistic for the patients and this should be explained to them like any other cosmetic surgical procedure.

Well-motivated patients for surgery will improve overall results and increase the number of satisfied patients. Health education should be part of such a programme so that anaesthetic extremities are prevented from injuries and mutilation. Sensory functions are restored in a number of cases after operation when the operated extremity is put into use, but it can take several years and is influenced by many factors.

It therefore seems essential to include surgical reconstruction in a programme of rehabilitation designed to assist these patients to return to society as useful members. The surgical correction of deformities in leprosy is most rewarding and indispensable for the rehabilitation of the patients who have been deformed due to the disease.

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## Aspects psychologiques des lepreux difformes subissant une reparation chirurgicale correctionnelle

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*Résumé* Une étude psychologique de 25 lépreux choisis au hasard qui devaient subir des réparations chirurgicales correctionnelles de leurs difformités fut entreprise. Avant l'intervention, les taux d'anxiété et de dépression étaient élevés et après l'intervention, ils avaient baissé de manière significative. Ces patients ont besoin d'une aide psychiatrique pour soigner leurs aberrations psychiques, pour provoquer une prise de conscience, améliorer leur moral et leur donner confiance en eux-même.

50 à 75% des espérances pré-opératoires furent satisfaites mais uniquement chez 40% des patients. Une consultation avec les patients avant l'intervention s'avère donc nécessaire pour les aider à atteindre des objectifs réalisables. Ils doivent prendre connaissance des effets positifs d'une intervention chirurgicale et des problèmes qui persistent après l'intervention comme par exemple l'anesthésie et l'analgésie.

## Aspectos psiquico-sociales de los pacientes leprosos deformados sometidos a correcciones quirurgicas

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*Resumen* Se realizó un estudio psíquico-social en 25 pacientes leprosos seleccionados al azar sometidos a intervenciones quirúrgicas para la corrección de sus deformaciones. Se encontraron elevados niveles preoperativas de ansiedad y depresión que bajaron de modo significativo después de la intervención. Es necesaria la ayuda psiquiátrica para tales pacientes para despejar sus aberraciones psíquicas, despertar la consciencia, estimular el ánimo y para que recuperen la confianza en si mismo.

Solamente se satisficieron entre 50% y 75% de las expectaciones preoperativias, pero esto fue en solamente el 40% de los pacientes. Esto indica la necesidad para una sesión preoperativa de asesoramiento para ayudar a los pacientes que establezcan metas realistas de que sean capaces realizar. Se les debe informar los beneficios que ofrece la cirugía, y se les puede alertar de los problemas que persistirán después de la intervención, como la anestesia y la analgesia.