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# Impact of Reconstructive Surgery (RCS) among Leprosy Patients: A Social Appraisal

*Debajanee Lenka, Amarendra Mohapatra  
and Chittaranjan Kar*

## Abstract

Reconstructive surgery (RCS) has made a significant improvement in deformities and disabilities management among leprosy patients. However, it seems that due to existing misconceptions that is hereditary and not curable regarding leprosy still lead to concealing the disease, therefore the patients hesitate and unenthusiastic to avail these facilities. This study was carried out in Sonepur district of Odisha with 60 RCS has undertaken leprosy patients. Out of 71 operative patients during 2000–2012, only 60 patients were alive and interviewed, in this study entire universe was used without any sampling. A semi-structured questionnaire was administered to assess their understanding, better quality of life (QOL) after reconstructive surgery. Nearly, 98.6% could meet their expectations to some extent, another 1.6% failed to get their expectations. Among all the RCS patients only 33.3% changed their profession to avoid further risk in their life after surgery. This study concludes that Reconstructive surgery plays a vital role to bring for leprosy patients into their normal life and lead their life in this open society of today. The result implies a motivational message for the deformed leprosy patients to come forward and depicts to encourage the surgeons to counsel the patients towards reconstructive surgery, which will reduce stigma in due course.

**Keywords:** leprosy, stigma, RCS, QOL, knowledge, acceptance

## 1. Introduction

Leprosy is a chronic infectious disease caused by *Mycobacterium leprae* (*M. leprae*). It is a micro-organism which has a predilection for soft tissues of a human organism like skin and nerve. Now leprosy is known as a common cause of non-traumatic peripheral neuropathy worldwide [1]. This *Mycobacterium leprae*, the causative agent of leprosy, was first discovered by Hansen in 1873. Therefore leprosy is also known as Hansen's disease and considering it the first bacterium to be identified as causing disease in human [2].

The transmission of *Mycobacterium leprae* always occurs through upper airways and manifested as skin lesions with reducing sensation including nodule, pigmentation, and patches on some portion of the body. These lesions can affect any part of the body as a nasal bridge and oral cavity [3]. The above said causative agent of leprosy, *Mycobacterium bacillus*, is associated with a prolonged incubation period

between initial infection and development of skin reactions. The incubation period of leprosy is 5–10 years but it hardly takes 20 years to have appeared as skin patches, deformities, and disabilities [4].

The extent of social stigma aggravates due to the blind believe or the misconception that leprosy is not curable and is hereditary. The crippled limbs (finger and feet) add fuel to fire of social stigma.

Reconstructive surgery to correct deformities in leprosy has made dramatic and revolutionary changes in the lives of affected patients [5, 6]. Nevertheless, leprosy patients are still hesitating to avail these benefits of reconstructive surgery due to many reasons [7]. The existing reasons associated with leprosy lead to take delay treatment and concealment of disease in society.

Since history, the misconceptions about leprosy being a hereditary disease, lead to increase the level of stigma related to death and mutilation due to its existing attributed causes like deformity and disability. This misconception also leads to prejudice, discrimination and social exclusion which are resulting in infliction of congenital suffering on leprosy patients, which can have serious repercussions in their personal and professional lives [8].

Government integrated Reconstructive surgery unit in the health care system to reduce stigma, which caused due to misconceptions, and to eliminate leprosy burden in different states of our country with the help of PPP (Public-private partnership) program including Government and non-government organizations Contemporary to Govt. The non-government organization has put more efforts. NGOs had handled 1076 surgery cases whereas Government hospitals had done 921. Maharastra has performed a better result in comparison to other states with 495 RCS by both Government and NGO. The recorded data on Reconstructive surgery has been given below (**Table 1**).

**Table 1** shows that among 35 states all across India, Maharastra has performed well at both Government and NGO level, i.e., 39 and 456. Next to Andhra Pradesh NGO has performed 487 RCS. In Madhya Pradesh, the government has done 122, whereas 91 was performed by NGO. Similarly, Odisha has performed very nicely in Government level, i.e., 248 RCS in 2013–2014 and Chhattisgarh has performed as well in same Government level with 234 RCS than 5 in NGO. In NGO level the performance of RCS is far better than Government. In Uttar Pradesh, 235 RCS has carried out in NGO and 33 in Govt level. But some states have not performed satisfactorily in both. Thus, it gives an idea of RCS (1786) has been well performed in NGO level.

### 1.1 State

The present research has been conducted in Odisha, consists of 30 districts. Among these districts, seven designated surgical units have been inaugurated in few districts for leprosy RCS. These districts are Berhampur, Dhenkanal, Koraput, Sonapur, and Cuttack, etc. In Odisha 10 government institution and 5 NGOs have been recognized for performing RCS. In Odisha, the number of Reconstructive Surgery performed by the Government is 262 in 2012–2013, 248 in 2013–2014 and 307 in 2014–2015 (end of March) whereas NGO has not performed any RCS.

**Figure 1** the NGO-LEPRA Institutional Based Rehabilitation (IBR) is working tirelessly on post rehabilitation of RCS patients and provides free footwear and skill development training. The health staffs of this IBR have taken endeavour to aware the people about the system for early diagnosis and available Government facilities for leper patients.

In Odisha many studies have been conducted on leprosy, its stigma and how does it affect man and women, its community perception and knowledge about its

Sl. no	State	Inst. recognized for RCS		RCS performed	
		Govt.	NGO	Govt.	NGO
1	Andhra Pradesh	1	9	0	487
2	Arunachal Pradesh	0	0	0	0
3	Assam	1	1	0	16
4	Bihar	2	2	21	64
5	Chhattisgarh	1	2	234	5
6	Goa	1	0	0	0
7	Gujrat	3	0	136	0
8	Haryana	1	0	0	0
9	Himachal Pradesh	0	0	0	0
10	Jharkhand	2	3	10	47
11	Jammu & Kashmir	0	0	0	0
12	Karnataka	5	4	34	106
13	Kerala	0	2	0	0
14	Madhya Pradesh	2	1	122	91
15	Maharastra	9	8	39	456
16	Manipur	1	0	0	0
17	Meghalaya	0	0	0	0
18	Mizoram	0	0	0	0
19	Nagaland	0	0	0	0
20	Odisha	10	5	248	0
21	Punjab	0	0	0	0
22	Rajasthan	1	0	2	0
23	Sikkim	1	0	1	0
24	Tamilnadu	2	8	1	106
25	Tripura	0	0	0	0
26	Uttar Pradesh	3	2	33	235
27	Uttarakhand	1	0	15	0
28	West Bengal	9	2	18	90
29	A&N Island	0	0	0	0
30	Chandigarh	1	0	0	0
31	D&N Haveli	0	0	0	0
32	Daman and Diu	0	0	0	0
33	Delhi	2	2	5	83
34	Lakshadweep	0	0	0	0
35	Pondicherry	1	0	2	0
Total		60	51	921	1786

*No. of RCS performed in different states of India 2013–2014 (NLEP progress report on 2013–2014, dt.26/8/2015) [9].*

**Table 1.**  
*Institutes and No. of RCS cases operated state wise.*





**Figure 1.**  
*An IBR of lepers at Sonepur.*



**Figure 2.**  
*Lepers at Kustha ashram.*

treatment, etc. But no literature is available on patients' perception after surgery. So the intention of this work is to explore the patients' perception regarding post RCS and its consequences. This study is conducted in Sonepur district of Odisha; the LEPROS A society office at Sonepur has a rehabilitation center for leprosy patients. They did help me in getting the old patients contacts.

The aim of this study is to assess the patients' socio-psychological condition and their acceptance in society after reconstructive surgery.

**Figure 2** depicts about the lepers of Kustha Ashram in Sonepur district, Odisha. It has been established in the year 2001 by the Government to facilitate the isolated deformed and disability lepers from society. Government supports the patients to rehabilitate them by supplying footwear, cloth, food along with pay pension, widow pension and compensation for surgery who have undergone for RCS.

## 2. Methodology

The study area was selected according to the highest prevalence and annual case detection rate of leprosy in Odisha. In the year 2009–2010, the highest ANCDR was 41.7% of Sonepur district in comparison to another endemic zone of Odisha. During this study, the record of surgery patients reported that 71 had undergone for surgery of six different blocks of Sonepur district. Out of these RCS patients list, only 60 RCS patients were alive and included in this study, which is the universe

sample of this study area. In this work above age 60+ and below 15 year leprosy patients, non-RCS patients in leprosy were excluded. This study was conducted in three phases like pilot study, main field work-1, and main fieldwork-2.

In Pilot study, which was conducted for 4 weeks to interact with patients, health staffs like MO, DLO and Paramedical health staffs who were working in leprosy. A semi-structured questionnaire was developed and examined various tools for the assessment of RCS patients. In the first phase of the main fieldwork, data pertaining to the demographic profile of the patients and their household and the quality of life were gathered from reconstructive surgery leprosy patients.

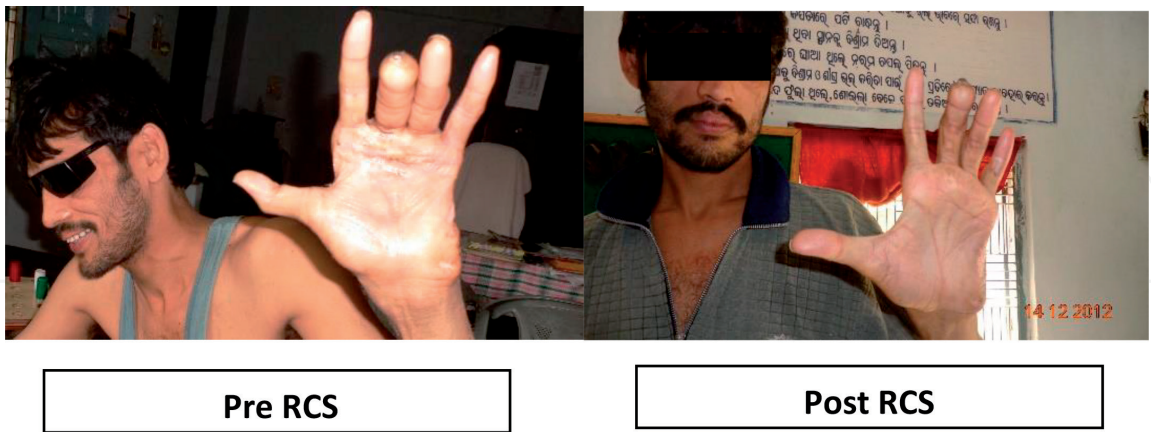
In the second phase of the main fieldwork, data pertaining to social and psychological consequences were gathered from leprosy patients and interaction with their caregivers and family members is carried out. Then a number of case studies with leprosy patients, two rounds of focus group discussion (FGD) with different stakeholders such as, patients, family members, and health staff were collected from all six blocks of Sonepur district which were hectic.

Limitation of this study was following the subject participants at their place of residence or was a daunting task as they were dispersed in the wide area of six blocks. To some extent, it became a limitation due to inadequate time and inconvenient traveling to communicate the patients, their respective family members and the varied socio-cultural set-ups where they are living.

### 3. Result

#### 3.1 Patients selection

All the Reconstructive surgery patients of Sonepur district were selected for the purpose of this study. It was reported that 71 patients had surgery but only 60 could be interviewed and others were migrated/died. All the patients were dispersed in six blocks of this above-said district.



**Table 2** represents the effect of RCS among the undergone surgery patients. Deformities were observed in both hand and feet of the registered RCS patients. Before surgery, 48.3% had deformities in their hands and needed full assistance but after surgery, only 18.3% required help from others. Out of 60 RCS patients, 54% had hand deformities but some extent they could manage their work. In the third parameter, after surgery, 96.6% did not need the assistance of anyone. Similarly, in feet deformities only 10% required full assistance after surgery and 93.3% need no assistance. This above table reveals that RCS enables a patient to perform all activities of hand and feet independently.



Deformities occurred body organ	Parameters	Before (%)	After (%)
Hand	Full assistance	29 (48.3)	11 (18.3)
	Some assistance	54 (90)	18 (30)
	No assistance	20 (33.3)	58 (96.6)
Feet	Full assistance	12 (20)	06 (10)
	Some assistance	19 (31.6)	04 (6.6)
	No assistance	54 (90)	56 (93.3)

**Table 2.**  
*Quality of life of pre and post RCS patients.*

**Table 3** elaborates on the satisfaction of the patients with society as a whole pre RCS. It gives data about the satisfaction level obtained from family members, friends, relatives, society and their over-all life.

In the case of the family, none of the patients are very satisfied with the acceptance of their family members. Out of 60 patients, 54, i.e., 90%, were partially satisfied with the behavior and acceptance of their family members in pre RCS. Six patients, i.e., 10%, were dissatisfied with their family members pre RCS.

In the case of friends only one, i.e., 1.6% patient found to be very satisfied with the acceptance of his friend before RCS. Forty-nine patients, i.e., 81.6% were partially satisfied by the acceptance of friends. Ten patients, i.e., 16.6% were fully dissatisfied by the behavior of their friends pre RCS.

Only one patient (1.6%) is fully satisfied with the acceptance of relatives before RCS. Eighty percent, i.e., 48 patients out of 60 were partially satisfied with the relatives before RCS, 11 patients, i.e., 18.3% were fully dissatisfied with the behavior of the relatives with them pre RCS.

If we take society as a whole, only one patient, i.e., 1.6% was fully satisfied with the society pre RCS stage. Forty-two patients, i.e., 70% were partially satisfied with the society before RCS. Seventeen patients, i.e., 28.3% were fully dissatisfied with the society before RCS.

The disease is such that no one can be satisfied with overall life. Only one patient, i.e., 1.6% was in spite of the disease fully satisfied with his overall life. Sixteen patients, i.e., 26.6% are partially satisfied with overall life. Forty-three patients, i.e., 71.6% are fully dissatisfied with their overall life.

Sl. no	Parameters	Very satisfied (%)	Partially satisfied (%)	Dissatisfied (%)
Pre RCS				
1	How satisfied are you with your acceptance by family	0 (0)	54 (90)	6 (10)
2	How satisfied are you with your acceptance by friends	1 (1.60)	49(81.60)	10 (16.6)
3	How satisfied are you with your acceptance by relatives	1 (1.60)	48 (80)	11 (18.3)
4	How satisfied are you with your acceptance by society	1 (1.60)	42 (70)	17 (28.3)
5	How satisfied about your overall life	1 (1.60)	16 (26.6)	43 (71.6)

**Table 3.**  
*Quality of social relation and support of pre RCS patients.*

**Table 4** presents the result of Post RCS acceptance and support. Almost 86% of patients are very satisfied with the acceptance of their family, friend, relatives, and society. But 47 (78.3%) patients showed their satisfaction on overall life. After surgery among all the criteria of acceptance, 20% replied they are partially satisfied upon their life which is greater than other cases. In other cases, only 11–13% of patients answered they feel less satisfied. A very negligible percentage of patients have been counted in the dissatisfy column. Thus, **Table 4** shows better result and improvement in the patient’s life after reconstructive surgery when compared to **Table 3**.

**Table 5** and **Figure 3** depict that after surgery among the 60 reconstructive surgery patients only 20 (33.3%) patients had changed their profession as they still had little loss of sensation in hand and feet and so they preferred a profession which needed less movement and it was flexible for them to adopt. After surgery patients were suggested to take rest for 6 months and go to work only after complete healing. So only 40 patients could prefer their same old profession presently people believe that absence of deformity is the only concern of society for an individual to lead his/her life as a normal being. Many research work on leprosy stated that deformity is creating a social stigma against this disease in society. So after surgery, it is proved that “no deformity is equal to no stigma.” RCS has given a great effort to reduce the pressure of social stigma from society.

3.2 Economic status

**Figure 4** describes the economic status of the patients after and before the RCS. Before RCS 35% of patients’ income was below Rs. 1000 but however, in post RCS it is found that only 21.6% of patients income was below Rs. 1000. Similarly, the income of 60% was between Rs. 1000 and 5000 in Pre RCS but it increased to 66.6% in post RCS. 8.3% of patients’ had earned Rs. 6000–10,000 which was only 5% in patients before surgery. In post RCS only 3.3% patient could get above Rs. 10,000 but in Pre-surgery, no one was capable to earn this much amount. So it is concluded that RCS has helped the patients to earn more than what they earned before RCS and the economic status of the patients has improved to a great level. The highest number of patients are earning a minimum amount between Rs. 1000 and 5000 because most of the patients belong to the farming profession.

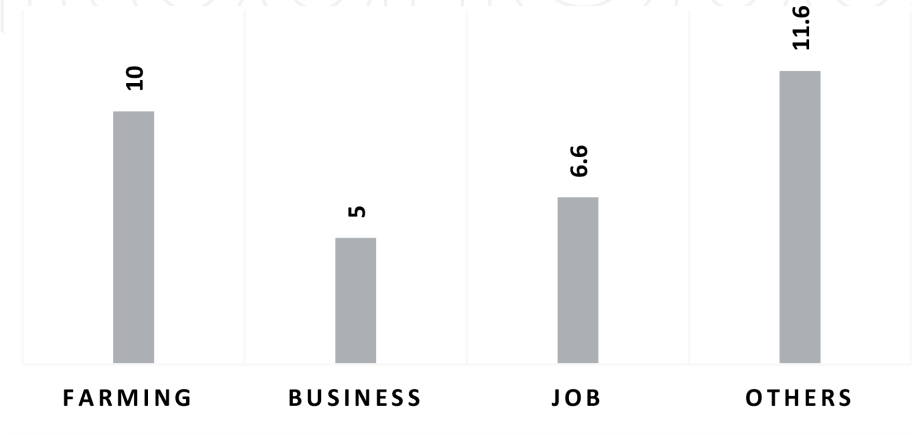
Sl. no.	Parameters	Very satisfied (%)	Partially satisfied (%)	Dissatisfied (%)
Post RCS				
1	How satisfied are you with your acceptance by family	51 (85)	8 (13.30)	1 (1.60)
2	How satisfied are you with your acceptance by friends	52 (86.60)	6 (10)	2 (3.30)
3	How satisfied are you with your acceptance by relatives	52 (86.60)	6 (10)	2 (3.30)
4	How satisfied are you with your acceptance by society	51 (85)	7 (11.60)	2 (3.30)
5	How satisfied about your overall life	47 (78.30)	12 (20)	1 (1.60)

**Table 4.**  
*Impact of RCS on social relationship and support of post RCS patients.*

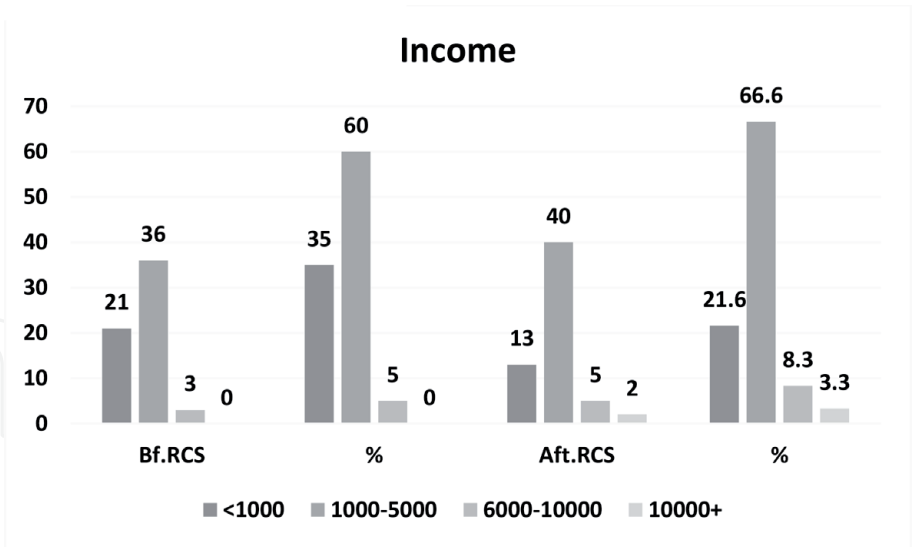


Serial number	Change in occupation	Number of patients (%)
1	Farming	6 (10)
2	Business	3 (5)
3	Job	4 (6.6)
4	Others	7 (11.7)
Total		20 (33.3)

**Table 5.**  
*Incidence of RCS patients changing profession.*



**Figure 3.**  
*Changed profession in post RCS.*



**Figure 4.**  
*Economic profile.*

#### 4. Discussion

The purpose of the study is to assess the quality of life for those who had undergone RCS with leprosy. The overall result shows that after reconstructive surgery performance of patients have improved due to better mobility of limbs. 96.6% reported that they do not need others to support to meet their expectations. This result is comparable with the similar study of John in which he explained more than 50% patients said that after correction of deformities they could meet their

expectations [10], subjectively assessed, 85% and above were satisfied with their social acceptance with respect to family, relatives, and peers, 13% were partially satisfied and 2% were dissatisfied. These results were corroborating with that of Ebenezer et al.'s study [11]. Similarly, Virmond and Palande stated that RCS has undergone patients' income and acceptance which was reduced to a great extent before disease, again regained. Therefore, they opined that early correction of disabilities prevents dehabilitation [12]. When it was discussed in regard to depression and anxiety of leprosy patients, a psychological study of Ramanathan et al. explained that 25 randomly selected patients undergoing corrective surgical procedure for their disabilities and deformities, high anxiety and depression levels were found preoperatively and in contrast to the result of the present study only 40% could meet their expectations [13]. After interaction with all the RCS patients, it was observed that they followed the doctor's advice for 6 months complete rest and avoided to lift heavy materials. This had helped them for complete recovery and no complications for which the satisfaction level is high 85%. If we discuss about the gender difference in the impact of leprosy; women with leprosy are more vulnerable than men in respect to all aspects like relationship, acceptance and workability. This study observed that 6.6% women were separated, rejected and avoided by their family and community members. These similar findings were observed in Mull et al. study which was conducted in Karachi. They reported that the proportion of diagnosed male with leprosy were high than female. They observed that women were not forewarned about MDT regimens and it might have been due to practice of purdah and lack of female health worker [14]. In addition, Naik et al. explained that women faced more domestic violence and deprived from personal contacts with others [15]. Similarly, Carol et al. and Janna et al. reported that women are more vulnerable because they were derived from personal contact with their family as well as community. Even they observed that women were more sufferers from rejection and isolation [16, 17]. Besides, according to psychological domain, Oliveira and Romanelli reported that female leprosy patients tend to neglected themselves, that the fear of abandonment, stigma and they are concerned about their appearance [18]. In addition Mankar et al. measured the QOL for the sexes and found it relatively higher impact of leprosy on women than the control leprosy patients [19]. Thus deformity and disabilities among patients made them to deprive from work activities. Another study of Natasja et al. explained that comparison of SLASA scale assessment on limitation of activities of the patients after 1 year it revealed that those had reconstructive surgery showed a significant improvement in their activities but there was no significant change found among them who declined RCS. Thus, concluded that reconstructive surgery has a beneficial effect on the functioning of limbs [20]. This present study result showed that due to the avoidance of further difficulties in their life only 33% changed their profession. It was earlier stated by Dharmendra that, "the beggar problem is a difficult one in India as the money and institutions needed for them are not available" [21]. Thus, it has been reported that in many studies: begging is the ideal profession of leprosy patients. One of these papers of Harvinder and Brakel, they specified that isolation and prohibition of the patients make them incapable to do any profession for their livelihood. Therefore, they choose to beg as their profession and stick to it till the end of their life [22]. If we consider the income of surgery patients before RCS they faced problem due to their deformities and lost strength to continue their work. Thus their socioeconomic status is categorized as per SES scale of Kuppuswamy into five groups. Sixty percent were earning Rs. 1000–5000 and no one was getting 10,000. After surgery 3.3% are earning more than 10,000 and <5 people were in <1000 and rest was in the bracket of Rs. 6000–10,000 with SES scale. This suggests that RCS brought an economic upliftment, which gave them social status and security. (\$ = 70.30/– and £ = 90.39).

5. Conclusion

Reconstructive surgery (RCS) had revealed the visible impact among the leprosy patients. This study concludes that patients who had undergone RCS have improved quality of life when compare to their past experience before RCS and with those who are still concealing the deformities and disabilities without availing the RCS facilities due to social stigma. It may be noted that in case of leprosy the self-stigma dominates among all leprosy patients. This needs a proper counseling at family level to understand the disease, its curability nature and that is not a hereditary by nature. This study reports that post RCS acceptance by society and the level of quality of overall life has improved to 78.3% from 1.6% in pre-surgery. Similarly, the performance of limbs in post RCS is very satisfactory, i.e., 96.6% in hand and 93.3% in foot mobility.

The findings of this present work will hopefully could motivate the hidden and concealed cases to come forward and avail the free surgery RCS in designated centers. In turn, the surgeons would also be encouraged for their great effort which could reduce social stigma among these leprosy patients. It will also help to dispel the misconception about disease and create awareness about diagnosis and treatment. Thus, RCS reduces the social stigma in a significant way.

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Conflict of interest

The authors declare that there is no conflict of interest regarding the publication of this chapter.

Abbreviations

RCS	reconstructive surgery
QOL	quality of life
ANCDR	annual case detection rate
PPP	public private partnership
NGO	non-government organization
<i>M. leprae</i>	<i>Mycobacterium leprae</i>
NLEP	National Leprosy Elimination Programme
DLO	District Leprosy Officer
MO	Medical Officer

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