
A Study to Assess the Patients' Socio-Psychological Condition and their Acceptance in Society after Reconstructive Surgery

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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 leprosy mission Naini Prayagraj (up). with 60 RCS has undertaken leprosy patients. Out of 71 operative patients during 2021–2022, 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*

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].

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

METHODOLOGY

The study area was selected according to the highest prevalence and annual case detection rate of leprosy in Prayagraj (UP).

In the year 2019–2020, the highest ANCDR was 41.7% of Prayagraj (UP) During this study, the record of surgery patients reported that 71 had undergone for surgery of six different blocks of Prayagraj 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 Prayagraj district (UP) 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.

RESULT

All the Reconstructive surgery patients of Prayagraj district (UP) 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. 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 debilitation [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 up liftment, which gave them social status and security.

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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