



## International Journal of Medical and Pharmaceutical Case Reports

12(2): 1-5, 2019; Article no.IJMPCR.50770  
ISSN: 2394-109X, NLM ID: 101648033

# Case Series: Correcting Deformities: Eliminating the Fear of Stigma

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### Authors' contributions

This work was carried out in collaboration among all authors. Authors IOA and SAA designed the study, wrote the protocol and wrote the first draft of the manuscript. Authors AOD and SUE managed the literature searches. All authors read and approved the final manuscript.

### Article Information

DOI: 10.9734/IJMPCR/2019/v12i230102

#### Editor(s):

(1) Dr. Claudio Piras, Department of Surgery, Universidade Federal do Espírito Santo, Brazil.

#### Reviewers:

(1) D. Ramachandrareddy, Vinayaka Mission Research and Deemed University, India.

(2) Vikram Mahajan, Dr. Rajendra Prasad Government Medical College Kangra, India.

Complete Peer review History: <http://www.sdiarticle3.com/review-history/50770>

Case Report

Received 29 May 2019  
Accepted 08 August 2019  
Published 13 August 2019

## ABSTRACT

**Aim:** To show how the surgery helped to eliminate the fear of the stigma associated with Hansen's disease.

**Presentation of Cases:** We present a case series of two patients with right ulnar nerve paralysis and one patient with left foot drop. They all underwent surgery for correction of their deformities with excellent outcome.

**Discussion:** From the cases presented it was clear that though all of them were treated with multi-drug therapy for one year but they were still living under the fear of stigmatization until they had their deformities corrected through surgery. There was a great transformation in the lives of these affected individuals when they had their deformities corrected through surgery. They all overcame their fear of stigmatization after the successful surgery.

**Conclusion:** Correction of deformities is one of the ways of eliminating fear of stigmatization among the patients who have residual deformities after completing their treatment for Hansen's disease.

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The government and non-governmental agencies could do more to make the service readily available and accessible to these individuals. This will help in reintegrating the treated individual back into the community and it will eventually lead to the closure of Leprosy camps.

*Keywords: Correcting deformities; stigmatization; Hansen's disease; leprosy.*

## 1. INTRODUCTION

Hansen's disease is a chronic infectious disease caused by the bacillus *Mycobacterium leprae*. The disease affects mainly the skin, nerves, eyes and the upper airway. It can spread from one person to another through respiratory droplets and it requires close contact with an infected person [1]. If this disease is not treated on time it results into development of horrifying physical deformities [1]. The global registered prevalence of Hansen's disease at the end of 2015 was 176 176 cases (0.2 cases per 10 000 people). The number of new cases reported globally in 2015 was 211 973 (2.9 new cases per 100 000 people) [2]. In Nigeria, Hansen's disease remains a disease of public health importance with over 3500 people diagnosed with the disease every year and about 25% of patients having some degree of disability [3]. Stigma and discrimination against persons and communities affected by Hansen's disease in Nigeria is very high, due to myths and superstitions associated with the disease [3].

The stigma associated with Hansen's disease is second to none and can lead to loss of employment, exclusion from society, divorce, refusal to marry from the family of the affected person e.t.c [4,5]. The stigma is not just as a result physical deformities, but many affected individuals suffered stigmatization because of belief that the disease is a divine curse or punishment for the past sins [6].

One of the ways of eliminating fear of stigmatization among the Hansen's disease patients especially those with established deformities is by correction of their deformities through surgery. Even after treatment with multi-drug therapy, an individual with obvious deformities is at risk of being stigmatized and that is why many affected individuals hide their deformities or remain at the camp for leprosy patients [7,8].

Though, reconstructive surgery was introduced into the management of Hansen's disease in 1940, [9] the service was not available in Nigeria until 2015 when the Damien foundation

sponsored the training of a doctor and a physiotherapist in India and established a Reconstructive Center in collaboration with Bowen University Teaching Hospital, Ogbomoso in February, 2015. The center is the only Reconstructive Center for Hansen's disease in Nigeria and serves as the referral center for other centers taking care of Hansen's disease patients.

We present a case series of three patients who underwent surgery with excellent outcome and how the surgery helped to eliminate the fear of the stigma associated with Hansen's disease.

## 2. CASE PRESENTATION

### 2.1 Case 1

A 48-years old politician who was diagnosed to have Hansen's disease when he was 35years old. He was a student in a University as at that time. He was treated with multi-drug therapy for one year without disclosing his status to anybody. He could not recollect whether he was placed on prednisolone. When he graduated he became a politician. He contested for the post of a Local Government Chairman and won the election. While serving as a Local Government Chairman he developed weakness in his right hand. The weakness prevented him from carrying out his official duties properly because he was not able to sign cheques or other documents because the weakness prevented him from writing properly. The fear of stigmatization prevented him from discussing his problem with his friends or seeking medical care from hospitals in his local government. He used to travel to neighboring countries where no one could recognize him to receive treatment for the weakness of his right hand. He spent a lot of money on the treatment without any significant improvement. He was coping with his official duties by dictating memos to his secretary, refusing to sign or correct documents in the presence of his aids and assigning people to write on his behalf. When he realized that his hand was not improving, he secretly visited a leprosy center in his Local Government where he was referred to our center. At our center he was

assessed to have ulnar nerve paralysis and the mode of management was explained to him. He decided to come for the surgery after completing his tenure. Throughout his treatment period he did not disclose to his friends and family members he was receiving treatment. He told them that he travelled out of the country to have some rest. Preoperative physiotherapy was done to strengthen the flexor digitorum superficialis muscle of the middle finger. He was operated using the Zancolli's Lasso procedure [6]. The POP cast and the operation site sutures were removed after three weeks and he had post-operative physiotherapy for three weeks. The post-operative period was uneventful and the correction was satisfactory. By the second month after surgery he could write properly and sign documents. He was no longer afraid that people would discover that he had Hansen's disease. He also started nursing an ambition of contesting higher political positions in the future.

## 2.2 Case 2

38-year old man who developed weakness in his left leg when he was 21 years old. The weakness got worse to the extent that he could not walk properly again. His father who was earlier treated for Hansen's disease but refused to disclose to other members of the family including his son because of fear of stigmatization took him to a Leprosy center where diagnosis of Hansen disease was made and he was treated with multi-drug therapy for one year. He was also placed on prednisolone for 6 months. Despite the treatment he did not recover from the left foot drop. Because of this deformity and the foot ulcer he could not continue his education beyond the secondary school. To avoid stigmatization, he would claim that road traffic accident was responsible for his foot drop when asked by friends and relations. He had visited many hospitals with no significant improvement in his medical condition. He also claimed that a medical doctor informed him that he would not be able to walk normally again. He was referred to our center from a leprosy center. At our center he was assessed to have left foot drop and the mode of management was explained to him. He had pre-operative physiotherapy for 10 days to strengthen the Tibialis Posterior tendon. Transfer of Tibialis Posterior with closed tenotomy was done and short leg cast was applied for four weeks. The post-operative period was uneventful and he had post-operative physiotherapy for another four weeks after which he regained the ability to dorsiflex the left foot. Two after surgery

he could walk properly and was no longer afraid of stigmatization. He had an ambition of furthering his education.

## 2.3 Case 3

26-years old tailoring apprentice who developed Hansen's disease when he was 20 years old. He received treatment at a Leprosy camp where he resides with his mother. His mother also had Hansen's disease. Though, He was treated with multi-drug therapy for one year, he did not recover from ulnar nerve paralysis of the right hand. After his secondary school education, he decided to learn tailoring and he moved to another town where people were not aware that he had Hansen's disease. Because, of the weakness of his right hand he was having challenges using scissors and his trainer usually complained bitterly about his inability to cut dress properly. The fear of stigmatization prevented him from disclosing the cause of his poor performance to his trainer. When he heard that a reconstructive center had been established, he presented himself for surgery. Preoperative physiotherapy was done to strengthen the flexor digitorum superficialis muscle of the middle finger. He was operated using the Zancolli's Lasso procedure [10]. The POP cast and the operation site sutures were removed after three weeks and he had post-operative physiotherapy for three weeks. The post-operative period was uneventful and the correction was satisfactory. He later returned to his training center and could cut cloth properly. His trainer was surprise at his change of attitude. He was no longer afraid of stigmatization because his deformity had been corrected.

## 3. DISCUSSION

Hansen's disease is a disease which instills fear in the community because of the deformities associated with it and the fact that no cure was found until the 20<sup>th</sup> century. The stigma associated with Hansen's disease is second to none because it is not only the affected individual that is stigmatized, the entire family and household share in the stigmatization [10]. The availability of treatment for this disease condition is not enough to stop the stigmatization of the affected individuals because of the irreversible deformities associated with the disease. Though, those who were treated on time and have no deformity after the treatment have less tendency to be stigmatized but they can still suffer from stigmatization because many people still believe

that the disease is incurable and runs in the family.

The fear of stigmatization makes the affected individuals to hide their deformities or status from the public. One way of reducing the fear of stigmatization among them is by correcting the deformities surgically after treatment. This will make it difficult for anybody to know whether they have suffered from Hansen's disease in the past. They also will not have any reason to hide their deformities or give a wrong reason for their deformities. One of the reasons why some affected individuals refuse to leave the leprosy camp after treatment is the presence of irreversible deformities and correction of these deformities will help in re-integrating them back into the community with less fear of being stigmatized.

For many decades many patients have benefitted from reconstructive surgery in many parts of the world but the service was not available in Nigeria until 2015. The only center where the service is available was established by Damien Foundation in collaboration with Bowen University Teaching Hospital, Ogbomoso. The center is located in South-Western Nigeria and receive referral from every part of the country.

From the cases presented it was clear that though all of them were treated with multi-drug therapy for one year but they were still living under the fear of stigmatization until they had their deformities corrected through surgery. One of them gave a wrong reason for his deformity in other to avoid stigmatization. He claimed that the cause of his limping was road traffic accident. This shows the extent that the affected individual can go to hide their deformity because of the fear of stigmatization. The other two cases were finding it difficult to cope with their jobs and could not open up to their co-workers because of the fear of stigmatization. The first case would never be able to win any election again if he disclosed his status because his opponent would use his status to campaign against him.

There was a great transformation in the lives of these affected individuals when they had their deformities corrected through surgery. They all overcame their fear of stigmatization after the successful surgery. The first case regained his confidence and he became hopeful of contesting political position in the nearest future. The second case also began to look forward to

furthering his education because he regained his ambulatory capacity.

#### **4. CONCLUSION**

Correction of deformities is one of the ways of eliminating fear of stigmatization among the patients who have residual deformities after completing their treatment for Hansen's disease. The government and non-governmental agencies could do more to make the service readily available and accessible to these individuals. This will help in reintegrating the treated individual back into the community and it will eventually lead to the closure of Leprosy camps.

#### **CONSENT**

We declare that 'written informed consent was obtained from the patients for publication of this case series. A copy of the written consent is available for review by the Editorial office/Chief Editor/Editorial Board members of this journal.

#### **ETHICAL APPROVAL**

We hereby declare that the study has been examined and approved by the appropriate ethics committee and have therefore been performed in accordance with the ethical standards laid down in the 1964 Declaration of Helsinki.

#### **ACKNOWLEDGEMENTS**

We would like to appreciate Damien Foundation Belgium for sponsoring the training of the doctor and the physiotherapist and for the establishment of the Reconstructive Center.

#### **COMPETING INTERESTS**

Authors have declared that no competing interests exist.

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*The peer review history for this paper can be accessed here:  
<http://www.sdiarticle3.com/review-history/50770>*