

Case report

CASE SERIES: CORRECTING DEFORMITIES: ELIMINATING THE FEAR OF STIGMA

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 received treatment for Hansen's disease 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. 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.

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. 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.[4]

46 One of the ways of eliminating fear of stigmatization among the Hansen's disease
47 patients especially those with established deformities is by correction of their deformities
48 through surgery. Even after treatment, an individual with obvious deformities is at risk of
49 being stigmatized and that is why many affected individuals hide their deformities or
50 remain at the camp for leprosy patients.

51 Though, reconstructive surgery was introduced into the management of Hansen's
52 disease in 1940,[5] the service was not available in Nigeria until 2015 when the Damien
53 foundation sponsored the training of a doctor and a physiotherapist in India and
54 established a Reconstructive Center in collaboration with Bowen University Teaching
55 Hospital, Ogbomoso in February, 2015. The center is the only Reconstructive Center for
56 Hansen's disease in Nigeria and serves as the referral center for other centers taking
57 care of Hansen's disease patients.

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

61 **CASE PRESENTATION**

62 Case 1

63 A 48-years old politician who was diagnosed to have Hansen's disease when he was
64 35years old. He was a student in a University as at that time. He received treatment
65 without disclosing his status to anybody. When he graduated he became a politician. He
66 contested for the post of a Local Government Chairman and won the election. While
67 serving as a Local Government Chairman he developed weakness in his right hand.
68 The weakness prevented him from carrying out his official duties properly because he
69 was not able to sign cheques or other documents because the weakness prevented him
70 from writing properly. The fear of stigmatization prevented him from discussing his
71 problem with his friends or seeking medical care from hospitals in his local government.
72 He used to travel to neighboring countries where no one could recognize him to receive
73 treatment. He spent a lot of money on the treatment without any significant
74 improvement. He was coping with his official duties by dictating memos to his secretary,
75 refusing to sign or correct documents in the presence of his aids and assigning people
76 to write on his behalf. When he realized that his hand was not improving he secretly
77 visited a leprosy center in his Local Government where he was referred to our center. At
78 our center he was assessed to have ulnar nerve paralysis and the mode of
79 management was explained to him. He decided to come for the surgery after
80 completing his tenure. Throughout his treatment period he did not disclose to his friends
81 and family members he was receiving treatment. He told them that he travelled out of
82 the country to have some rest. Preoperative physiotherapy was done to strengthen the
83 flexor digitorum superficialis muscle of the middle finger. He was operated using the
84 Zancolli's Lasso procedure.[6] The POP cast and the operation site sutures were
85 removed after three weeks and he had post-operative physiotherapy for three weeks.
86 The post-operative period was uneventful and the correction was satisfactory. By the
87 second month after surgery he could write properly and sign documents. He was no
88 longer afraid that people would discover that he had Hansen's disease. He also started
89 nursing an ambition of contesting higher political positions in the future.

90 Case 2

91 38-year old man who developed weakness in his left leg when he was 21 years old. The
92 weakness got worse to the extent that he could not walk properly again. His father who
93 was earlier treated for Hansen's disease but refused to disclose to other members of
94 the family including his son because of fear of stigmatization took him to a Leprosy
95 center where diagnosis of Hansen disease was made and he was treated. Despite the
96 treatment he did not recover from the left foot drop. Because of this deformity and the
97 foot ulcer he could not continue his education beyond the secondary school. To avoid
98 stigmatization, he would claim that road traffic accident was responsible for his foot drop
99 when asked by friends and relations. He had visited many hospitals with no significant
100 improvement in his medical condition. He also claimed that a medical doctor informed
101 him that he would not be able to walk normally again. He was referred to our center
102 from a leprosy center. At our center he was assessed to have left foot drop and the
103 mode of management was explained to him. He had pre-operative physiotherapy for 10
104 days to strengthen the Tibialis Posterior tendon. Transfer of Tibialis Posterior with
105 closed tenotomy was done and short leg cast was applied for four weeks. The post-
106 operative period was uneventful and he had post-operative physiotherapy for another
107 four weeks after which he regained the ability to dorsiflex the left foot. Two after surgery
108 he could walk properly and was no longer afraid of stigmatization. He had an ambition
109 of furthering his education.

110 Case 3

111 26-years old tailoring apprentice who developed Hansen's disease when he was
112 20years old. He received treatment at a Leprosy camp where he resides with his
113 mother. His mother also had Hansen's disease. Though, he completed his treatment he
114 did not recover from ulnar nerve paralysis of the right hand. After his secondary school
115 education, he decided to learn tailoring and he moved to another town where people
116 were not aware that he had Hansen's disease. Because, of the weakness of his right
117 hand he was having challenges using scissors and his trainer usually complained
118 bitterly about his inability to cut dress properly. The fear of stigmatization prevented him
119 from disclosing the cause of his poor performance to his trainer. When he heard that a
120 reconstructive center had been established, he presented himself for surgery.
121 Preoperative physiotherapy was done to strengthen the flexor digitorum superficialis
122 muscle of the middle finger. He was operated using the Zancolli's Lasso procedure.⁶
123 The POP cast and the operation site sutures were removed after three weeks and he
124 had post-operative physiotherapy for three weeks. The post-operative period was
125 uneventful and the correction was satisfactory. He later returned to his training center
126 and could cut cloth properly. His trainer was surprise at his change of attitude. He was
127 no longer afraid of stigmatization because his deformity had been corrected.

128 **DISCUSSION**

129 Hansen's disease is a disease which instills fear in the community because of the
130 deformities associated with it and the fact that no cure was found until the 20th century.
131 The stigma associated with Hansen's disease is second to none because it is not only
132 the affected individual that is stigmatized, the entire family and household share in the
133 stigmatization.[4] The availability of treatment for this disease condition is not enough to
134 stop the stigmatization of the affected individuals because of the irreversible deformities
135 associated with the disease. Though, those who were treated on time and have no
136 deformity after the treatment have less tendency to be stigmatized but they can still

137 suffer from stigmatization because many people still believe that the disease is
138 incurable and runs in the family.

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

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

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

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

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170 **CONCLUSION**

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

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179 **CONSENT**

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

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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.

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