

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.

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. 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.[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

47 through surgery. Even after treatment with multi-drug therapy, an individual with obvious
48 deformities is at risk of being stigmatized and that is why many affected individuals hide
49 their deformities or remain at the camp for leprosy patients.[7,8]

50 Though, reconstructive surgery was introduced into the management of Hansen's
51 disease in 1940,[9] the service was not available in Nigeria until 2015 when the Damien
52 foundation sponsored the training of a doctor and a physiotherapist in India and
53 established a Reconstructive Center in collaboration with Bowen University Teaching
54 Hospital, Ogbomoso in February, 2015. The center is the only Reconstructive Center for
55 Hansen's disease in Nigeria and serves as the referral center for other centers taking
56 care of Hansen's disease patients.

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

60 CASE PRESENTATION

61 Case 1

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

91 Case 2

92 38-year old man who developed weakness in his left leg when he was 21 years old. The
93 weakness got worse to the extent that he could not walk properly again. His father who
94 was earlier treated for Hansen's disease but refused to disclose to other members of
95 the family including his son because of fear of stigmatization took him to a Leprosy
96 center where diagnosis of Hansen disease was made and he was treated with multi-
97 drug therapy for one year. He was also placed on prednisolone for 6 months. Despite
98 the treatment he did not recover from the left foot drop. Because of this deformity and
99 the foot ulcer he could not continue his education beyond the secondary school. To
100 avoid stigmatization, he would claim that road traffic accident was responsible for his
101 foot drop when asked by friends and relations. He had visited many hospitals with no
102 significant improvement in his medical condition. He also claimed that a medical doctor
103 informed him that he would not be able to walk normally again. He was referred to our
104 center from a leprosy center. At our center he was assessed to have left foot drop and
105 the mode of management was explained to him. He had pre-operative physiotherapy for
106 10 days to strengthen the Tibialis Posterior tendon. Transfer of Tibialis Posterior with
107 closed tenotomy was done and short leg cast was applied for four weeks. The post-
108 operative period was uneventful and he had post-operative physiotherapy for another
109 four weeks after which he regained the ability to dorsiflex the left foot. Two after surgery
110 he could walk properly and was no longer afraid of stigmatization. He had an ambition
111 of furthering his education.

112 Case 3

113 26-years old tailoring apprentice who developed Hansen's disease when he was
114 20years old. He received treatment at a Leprosy camp where he resides with his
115 mother. His mother also had Hansen's disease. Though, He was treated with multi-drug
116 therapy for one year, he did not recover from ulnar nerve paralysis of the right hand.
117 After his secondary school education, he decided to learn tailoring and he moved to
118 another town where people were not aware that he had Hansen's disease. Because, of
119 the weakness of his right hand he was having challenges using scissors and his trainer
120 usually complained bitterly about his inability to cut dress properly. The fear of
121 stigmatization prevented him from disclosing the cause of his poor performance to his
122 trainer. When he heard that a reconstructive center had been established, he presented
123 himself for surgery. Preoperative physiotherapy was done to strengthen the flexor
124 digitorum superficialis muscle of the middle finger. He was operated using the Zancolli's
125 Lasso procedure.[10] The POP cast and the operation site sutures were removed after
126 three weeks and he had post-operative physiotherapy for three weeks. The post-
127 operative period was uneventful and the correction was satisfactory. He later returned to
128 his training center and could cut cloth properly. His trainer was surprise at his change of
129 attitude. He was no longer afraid of stigmatization because his deformity had been
130 corrected.

131 DISCUSSION

132 Hansen's disease is a disease which instills fear in the community because of the
133 deformities associated with it and the fact that no cure was found until the 20th century.
134 The stigma associated with Hansen's disease is second to none because it is not only
135 the affected individual that is stigmatized, the entire family and household share in the
136 stigmatization.[10] The availability of treatment for this disease condition is not enough
137 to stop the stigmatization of the affected individuals because of the irreversible

138 deformities associated with the disease. Though, those who were treated on time and
139 have no deformity after the treatment have less tendency to be stigmatized but they can
140 still suffer from stigmatization because many people still believe that the disease is
141 incurable and runs in the family.

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

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

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

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

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173 **CONCLUSION**

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

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182 **CONSENT**

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

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187 **ETHICAL APPROVAL**

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

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