Best Practice: *Integration of Reconstructive Surgery (RCS) within the General Health Care System in Odisha (State), India*

Subthemes

- Disability prevention and treatment
- Operational capacity (health information)

Target Audience(s)

- Policy leaders
- Program managers
- Health staff
- Persons affected by leprosy
- Other partners such as NTD NGOs

Contributors

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Key Messages

Disabilities will continue to occur as a consequence of leprosy in spite of several early case detection measures. The person affected by leprosy who has disabilities is the worst sufferer because of the paralysed parts of the body which cannot be restored to normal, even after completion of multidrug therapy (MDT). In order to enable the person to be mainstreamed in the context of managing his own personal activities, earning his livelihood, reducing stigma and discrimination, and maintaining his self-esteem, reconstructive surgery is the only answer, which can be sustained and replicated if integrated into the general health care system.

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Description of the Best Practice

Introduction

Problem Statement

India achieved elimination of leprosy in 2005, and Odisha state in 2006. As a result, the vertical structures created to address issues and consequences of leprosy were no longer considered appropriate. All functions of leprosy control and its management became integrated within the general health care system (GHCS). Subsequently, the Government of India came up with the plan to focus on

residual morbidities of leprosy and rehabilitation of persons affected by leprosy under the structure titled 'Disability Prevention and Medical Rehabilitation' (DPMR). This was a great step towards management of disabilities for persons affected by leprosy as well as addressing the issues of stigma and discrimination to a significant extent. However, this development failed to successfully integrate the Reconstructive Surgery (RCS) function within the GHCS, owing to a number of factors. These include lack of RCS surgeons, lack of physiotherapists, shortage of space to accommodate long duration stay of patients, and inadequate infrastructures.

Strategic Context

Disability prevention and medical rehabilitation is one of the main objectives of the National Leprosy Eradication Programme (NLEP). RCS is very much an integral part of this function. Through the initiative and advocacy of LEPRA Society, the Government of Odisha has designated a male multi-purpose health worker as a 'Block Nodal Leprosy worker' (BNLW) for each block (sub-district level). These men are exclusively trained in leprosy and DPMR activities, and each has primary responsibility for anti-leprosy activities in his block area. Responsibilities include making line-listings of all grade-1 and grade--2 disability persons and of persons fit and willing to undergo RCS so as to make zero back-log of RCS cases by 2020.

Impact on Population

Persons affected by leprosy who have disabilities have either single or multiple disabilities in their hands, feet, and eyes. As a result, they are unable to use their hands for holding anything or eating food, unable to walk, and unable to close their eyes, making them at risk of blindness. They are subjected to not being able to manage themselves, cannot earn their livelihood, and are susceptible for begging alms. Ultimately, they are at risk of becoming the centre of stigma and discrimination and of losing self-esteem.

In RCS, active muscle / tendon is surgically rerouted to obtain the lost functions of paralysed muscle. This can enable a person to reestablish function, earn livelihood, and achieve improved appearance of the affected part and can ultimately help to reduce stigma and discrimination.

Objectives and Methodology

LEPRA Society had the rich experience of conducting 2,705 RCSs in its HOINA Surgical Centre in the State of Odisha, India, from 1994 to 2006. This was conducted under a vertical arrangement, and all expenses were covered by Lepra UK. Soon after the integration of leprosy within the GHCS, LEPRA Society shifted this responsibility to local government to ensure its sustainability. It took 5 more years (from 2007 to 2011) for LEPRA Society to streamline and institutionalize the processes of facilitating RCS to take place in government institutions. During this period, the organization worked to introduce and meet all costs for RCS in 10 government hospital locations in the state. Key efforts of LEPRA Society in this activity included providing infrastructure support to upgrade most operation theatres, supplying surgical equipment, training of 17 government surgeons, providing incentives to motivate staff including surgeons, and conducting advocacy with state level officials for RCS integration. The surgeons and

physiotherapists were sent to 'Centre of Excellences like CLTRI Chengelpettu and SIHR&LC, Karigiri, to upgrade their skills. During 2006 to 2011, a total of 1307 RCSs were performed at 10 government hospitals with complete financial support of LEPRA Society. From mid-2012 to date, RCS is being conducted without interruption at 13 government hospital locations, with support of LEPRA Society and with the government bearing most of the costs.

Implementation of Practice

LEPRA Society has been implementing a project in Odisha called "Technical Resource Unit & Strengthening Referral System" (TRU & SRS) since 2007. The goal of the project is "Improved quality of life of people affected by leprosy and its disabilities in the State of Odisha," and the main objectives are to support the government in strengthening technical capabilities, strengthening monitoring and supervision, and providing improved quality services to the affected persons through referral centres and to re-enable persons with leprosy related disabilities to achieve functional ability through corrective measures (i.e., RCS). Referral centres are situated at government institutions, particularly at district hospitals, and are staffed by a doctor, a physiotherapist, and a shoe-technician. In this project, we trained willing government surgeons and our physiotherapists on all the processes at reputed institutions (NIRTAR, CLTRI, SIHR&LC) and provided for exposure visits.

Through the referral centres and with the help of BNLWs, a line-listing of all G-1 and G-2 disability cases is made and cases are assessed very carefully to determine those who are fit and willing for RCS. We try to counsel the fit cases regarding the benefit of RCS for claw finger and thumb correction, wrist-drop correction, foot-drop correction, claw-toe correction, and lagophthalmos correction. The government has provided them an assistance of Rs. 8000 towards their loss of wages because the hospitalisation stay for pre- and post-operative management is around 2 months. We upgrade the operation theatres of the district hospitals to handle the RCS. Periodically, we monitor these beneficiaries to continue with physiotherapy in order to get the maximum benefit of functional result. Annually, we evaluate these cases to know the result of the operation and try to learn from the failures. We also annually update the line-listing of all disability cases and draw a calendar of RCS activities across the State. Persons who have received RCS are the best motivators for new referrals. (See Annex)

Due to the rich RCS experience of LEPRA Society since 1994, it was possible to expand the services through 10 referral centres across the State and to integrate the services into the GHCS. Lepra UK has funded the process towards sustainability and full integration.

See Annex below for further information on the referral system and detailed activities

Results—Outputs and Outcomes

The integrated RCS activity started at SCB Medical College, Plastic Surgery Department, Cuttack, in 2006, with a background of rich experience of LEPRA Society, and continued thereafter at Leprosy Home & Hospital Cuttack. We further developed the medical colleges at Berhampur and Burla and district hospitals at Baripada, Jharsuguda, Sonepur, and Koraput. We streamlined the activities in these

institutions and further extended the RCS services to district hospitals of Angul, Bolangir, Nuapada, Sundargarh, Sambalpur, and CHC Umarkote. The 3277 RCSs performed in these institutions from April 2006 up to March 2019 included 2235 hand surgeries (claw fingers, claw thumb, wrist-drop), 938 foot surgeries (foot-drop, claw toes), and 104 eye surgeries (lagophthalmos). Services included thorough disability assessment of all willing persons; counseling regarding the type of operation, duration of hospitalization, post-operative physiotherapy; and allowances towards loss of wages, etc. Subsequently, the assessments were done at regular intervals and the progress was recorded. All the records are well maintained at the referral centres and preserved for reference.

In order to know the quality of our RCS activity, LEPRA constituted an 'Expert Committee' (headed by an eminent RCS surgeon Dr. Palande) in April 2013 and prepared assessment criteria in terms of function, appearance, and socio-economic conditions of RCS recipients. Thereafter, we organized a series of re-orientations for the surgeons and physiotherapists, continued conducting annual reviews, and achieved very satisfactory results. The review results of last 4 years are included in the table below:

RCS Review Results

Year	No. of RCSs assessed	Results		
		Good	Fair	Poor
2014-15	131	96(73%)	25(19%)	10(8%)
2015-16	113	87(77%)	20(18%)	6(5%)
2016-17	123	100(81%)	16(13%)	7(6%)
2017-18	71	54(76%)	13(18%)	4(6%)
Total	**438**	**337(77%)**	**74(17%)**	**27(6%)**

For the results, 'good' means satisfactory both functionally and by appearance; 'fair' means functionally satisfactory but a departure by appearance; and 'poor' means unsatisfactory by function and appearance. The project is continuing with all the activities mentioned earlier in the above government institutions.

Lessons Learned

LEPRA Society contributed to the concept of DPMR enormously due to its rich experience. It supported the Odisha Government NLEP programme in the form of the District Technical Support Team (DTST) project from 2004 to 2007, when the maximum capacity-building programme for GHCS staff was conducted. The DTST project was followed by the TRU & SRS project in which the expert physiotherapists and non-medical supervisorys (NMSs) were retained to provide quality services. During the phase-out period, the government retained these committed physiotherapists and NMSs who continued to provide excellent services and also motivated the BNLWs, health workers, and Accredited Social Health Activists (ASHAs) to refer regular cases to the nearest referral centres. (See Annex). These

activities gathered momentum, and most of the GHCS staff contributed to this. One experience, however, needs mentioning. In one institution, we were embarrassed when none of the department staff, including doctors, cooperated due to stigma. This was mitigated with several explanatory/awareness meetings.

Replicability and Scalability

From a vertical NGO set up, the model started at a government institution in an integrated mode and partnership with LEPRA Society. This structure delivered quite a good achievement and acknowledgement and prompted its replication in another government institution. Gradually, one after another, we have replicated the same model in other government institutions successfully. Integration of leprosy-related morbidity management services are crucial to guarantee sustainability and to appropriately address the needs of people affected by leprosy in the long run. Integration takes time (in this example integration took about 5 years) and requires government's will. Mobilization of surgeons and placing of physiotherapists at each center, which are essential components of ensuring quality, were ensured by the government. Only a few states in the country are able to integrate this function within the GHCS, and Odisha was the first state to integrate this. This important activity is now fully integrated and is sustainable in nature.

Conclusions

Persons affected by leprosy-related disability have the right to live with dignity. They have landed with disability either due to their ignorance or lack of appropriate service by the system, but it does not mean that they have to suffer throughout their entire lifetime. The success rate of RCS is around 94%, and they can avail this opportunity. There is no other method that will allow these persons to regain the enablement of their paralysed part. That is why RCS is considered a 'Best Practice' model for leprosy. This model is replicable, as it has been successfully replicated from one institution to another, and it is sustainable, as the regular services have been continued for last 14 years without hindrance.

Further Readings

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3. Srinivasan H, Palande DD. WHO Action Programme for the Elimination of Leprosy. Essential surgery in leprosy: techniques for district hospitals. World Health Organization, 1996. http://www.who.int/iris/handle/10665/63357
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Annex: Flow-Chart of Referral System (for DPMR Services)

Village (ASHA) → Any person suspected of having disability due to leprosy referred to SC/PHC/CHC and on the advice of the MO/HW promote regular self-care & disability care practices

Sub Centre (HW) →

Implementation
- Self care demo & follow up & promotion of MCR footwear
- Advice to RCS cases
  - for surgery
  - for follow up

Referral
- Reaction / drug reaction
- Disability persons

CHC (MO/PMW/ BNLW) →

Implementation
- Organise regular weekly DPMR clinics
- Manage leprosy reactions / neuritis
- Assess all cases of leprosy disabilities
- Provide self-care, ulcer dressing, ulcer-kit/dressing material, MCR footwear
- Identify & refer patient needing RCS
- Identify patient needing G-2 footwear
- Monitor all DPMR services
- Repeated counselling of all cases

Referral
- Reactions/neuritis cases difficult to manage
- Complicated ulcers
- Reconstructive surgery cases
- Patients needing G-2 footwear
- Follow up of RCS cases

District Nucleus (DLO/PT/LT/ST) Apex Team (All specialists) →

Implementation
- Management of reactions/neuritis
- Management of complicated ulcers
- Provide aids & appliances
- Selection & refer of RCS cases
- Follow up of RCS cases
- Manage footwear/shoe unit (G-2 manufacture & supply)
- Laboratory investigations

Referral
- Refer RCS cases/nerve abscess for operation
- Refer RCS review cases
- Refer difficult ulcer cases

Referral Centres / RCS Centres (Surgeon/SN/PT) →

Implementation
- Final screening, physio assessments, and admission for RCS
- Reconstruction/ decompression/ amputation surgery
- follow up after RCS
- RCS Review

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