

## Community Eye Health of the People Affected with Leprosy (PAL) in India : an Observation

*Dr. Jyotirmoy Datta, MS\*, Dr. Swapan K. Samanta, MS, CCEH (ICEH, London) \*\*,  
Dr. Chandana Chakraborti, MD \*\*\*, Dr. Khandkar Fariduddin , MS \*\*\*\**  
Eye Department, Calcutta National Medical College & Hospital,  
\*Prof. & Head, \*\*Asst. Prof., \*\*\*RMO, \*\*\*\*Senior Resident

**Key Words:** PAL (People Affected with Leprosy), RFT (Released from Treatment), High Risk Eyes, PST (Potentially Sight Threatening) Lesions, VA (Visual Acuity), IOL (Intra Ocular Lens), Microsurgery, Integration, Community Ophthalmology, Community Dermatology. Keratoplasty

**Abstract:** Proper Multi-drug Therapy (MDT) at the early hour of detection of leprosy and anti reaction measures with newer steroids, regular supervision & monitoring of the 'RFT' population reduces the incidence of Ocular leprosy to a remarkable extent. Today most of the eye complications are due to the normal aging process or from other phenomenon like the normal healthy population. Cataract and Lagophthalmos are the main causes of blindness. In Indian Subcontinent though Surgical Coverage rate of Cataract is 50% yet the same in case of Lagophthalmos (only 19%) is lagging far behind the necessity. Integration of management of Ocular Leprosy with Community Eye Health Care Service is the talk of the day along with other health care facilities delivered to the People Affected with Leprosy (PAL). Routine eye examinations are necessary for all Paucibacillary (PB) & Multi-Bacillary (MB) patients as well as for the "RFT" population to detect and treat high risk eyes.



Address for correspondence :  
Dr. Swapan K. Samanta  
Abasbari, Tamluk, District : Purba Medinipore,  
West Bengal, Pin : 721636. India,  
E mail : swapan\_samanta1@rediffmail.com,  
swapan\_samanta@hotmail.com,  
Telefax : 03228-266101, Mobile : 09434023759

Community Eye Health Practice With "PAL"

## Introduction

Leprosy patients are doubly handicapped through visual impairment ending with blindness and deformities of the extremities along with other disabilities due to the disease, superadded with social stigma, old age and poor availability of eye care service. Today, however there is hardly any addition to the blind family of "PAL" from the newly diagnosed cases.

The leprosy situation has undergone a tremendous change over the last twenty years or so. There has been a phenomenal reduction in prevalence and incidence of leprosy over the years. The occurrence of serious and progressive forms of leprosy has greatly diminished, so also the occurrence of deformities due to the disease. These are also well reflected in the occurrence of ocular complications of leprosy. This phenomenal progress is mainly due to two important factors (a) the introduction of Multi Drug Therapy (MDT) for the treatment of the disease in the 1980's and subsequent free supply of MDT drugs to all patients in the world through WHO and (b) political commitment and intensification of anti-leprosy activities following the declaration of WHO and goal to eliminate leprosy as a public health problem (i.e.) reducing the prevalence to less than 1 case per 1000 by 2000 which was later revised to 2005" (13).

## Epidemiology

From existing surveys it is estimated that between one quarter and one-half a million leprosy or ex-leprosy patients could be blind (vision less than 6/60).(3) The incidence of ocular leprosy is influenced by many factors, specially anti-leprosy treatment, the type and duration of the disease and eye treatment received. (7, 28,29,43,47)

To review the Indian scenario, in LOSOL study at Karigiri, South India every year approximately 5.6% of patients with MB who have completed MDT can be expected to develop new ocular complications of leprosy, which often (3.9%) are potentially vision threatening. (5, 6,8,9) In coastal

Andhra Pradesh of South India, sixty percent of the patients had ocular involvement in one study. Potentially sight threatening lesions such as lagophthalmos (17.4%), iridocyclitis (14.8%), corneal anaesthesia (36.1%), keratitis / corneal opacity (14.7%) were noted. (27) In Eastern India amongst a cohort of 1137, 2.9% subjects were blind according to the WHO classification, and 20.7% had moderate visual impairment in different population group, with different patterns of leprosy-related ocular morbidity, blindness and disease type evident even in different areas of the same region. (46)

## Aims & Objects

Leprosy has been declared to be eradicated (prevalence rate less than 1 per 10,000 population) from India on 30th. January, 2005. In this era of "RFT" (Released From Treatment) approximately 10 million People Affected with Leprosy around the world ("PAL") carry some ocular morbidity (Potentially Sight Threatening Lesion) as aftermath of Leprosy for the rest of their life. So Ocular Leprosy is one of the vital Community Eye Health Concerns of some of the countries of the world where Leprosy was endemic. This study will highlight the present scenario of ocular leprosy in India based on a multicentric study.

## Materials & Methods

A total number of 296 "RFT" Population from seven after care leprosy settlements / homes - at five locations (two from eastern, one from central, one from southern & the other from western) of India, were examined on spot by the same group of investigators leaded by the author between 2005-2008 on a specific protocol in search of ocular leprosy with management. Special temporary eye clinic was organized at the places (Leprosy settlement) with arrangement of Eye Examination by hand held slit lamp, binocular loupe, ophthalmoscopy, retinoscopy, refraction, schiotz tonometry, shirmer test etc. The data were compiled. Medicines and spectacles were given to those in need free of cost and patients were referred for proper eye surgery at the nearby hospital with eye dept.

## Observation

### The age and sex distribution of the study group

Places	Total patients Examined	0-25y	25-40y	>40-60y	>60y	Male	Female
India - South (Rajahmundry A.P)	49	-	3	34	12	34	15
India - West (Pune, Maharashtra)	80	1	5	23	51	45	35
India - Central (Raipur - Chhatisgarh)	27	-	-	4	23	10	17
India - East (Siliguri & Kalyanpur, West Bengal)	43	-	2	25	16	29	14
	97	-	21	61	15	44	53
<b>Total</b>	<b>296 (100%)</b>	<b>1</b>	<b>31</b>	<b>147</b>	<b>117</b>	<b>162</b>	<b>134</b>

### Pattern of distribution of eye diseases in the study group

Places	Total patients examined	Cataract (including aphakics & pseudophakics)	Lagophthalmos	Corneal Opacity	Uveitis	Refractive Error*	Other Minor Eye problems	No Eye Disease
<b>India</b>	296	198	51	44	31	132	34	85

\*except aphakic and pseudophakic

### Surgical and Refractive Coverage in the study group

Total Patients	No of eyes in need for Cataract Surgery	No of eyes with Cataract operated	<b>Cataract Surgical Rate</b>	No of eyes in need for Lagophthalmos - mos surgery	No of eyes operated for Lagophthalmos	<b>Lagophthalmos Surgical Rate</b>	No of Cases in need for Refraction	No of cases where refraction done	<b>Refraction Coverage Rate</b>
<b>India</b>	137	107	107 / (137+ 107) = <b>43.85 %</b>	51	12	12/(51+12) = <b>19.04%</b>	132	48	<b>33.3%</b>



File Picture of Post Operative (Aphakic) "PAL"

### Irreversible Blindness amongst the study group

(Best corrected Vision <6/60)

Country	Total Patients	One Eye Blind	Blind
India	296	40	18

### Discussion

In this study all the patients are Multibacillary although some were paucibacillary at presentation. There is a preponderance of male patients with mean age of the patients is 57 years. But all of them were Smear Negative and completed the scheduled dose of MDT. Proper MDT reduces the incidence of Ocular leprosy. The lesions arising out of the disease process which can lead to blindness if remain unattended, are termed Potentially Sight Threatening (PST) and these morbid conditions make the eye a high risk one. (25) Association of old age, facial patch, deformities & disabilities in limbs are the risk factors for ocular lesion, in new as well as in RFT patients. (43) The conditions are aggravated by relapse, reaction, chronic ulceration on the extremities, chronic osteomyelitis and delay in initiation of treatment. The major sight threatening lesions include Cataract (65%), Lagophthalmos (12%), Corneal Opacity (13%) & Uveitis (9%). Other condition including Dry eye syndrome was noted (9%).

PST lesions were noted equally in Paucibacillary (PB) and Multibacillary (MB) cases, however, the nature of lesion is different. Keratitis and its sequelae were significantly more common in PB patients ( $p < 0.01$ ). Iridocyclitis and its sequelae were significantly more common in MB cases ( $p < 0.005$ ). (45). The mean duration of leprosy in the study group is 18 years. All PST lesions were found to increase with the duration of the disease. (15,17,24) Refractive error, being a vital factor, is a neglected chapter in ophthalmic service delivery for this still overlooked community.

### Management

In this study irreversible blindness was observed in one eye of 12% & both eyes of 6% of the study group which makes a very sensible figure in comparison to the general healthy population. The common causes are corneal scars like phthisis bulbi & corneal opacities of varying degree, empty socket following enucleation, absolute glaucoma & optic atrophy. Fortunately there is a considerable reduction in the incidence of risk factors due to proper & effective treatment which ultimately offer a positive visual outcome with least number of irreversible blindness as well as other deformities. (40,42)

## Cataract

Intra Ocular Lens Implantation offers good visual outcome in Leprosy following long term follow up. In Leprosy the field of cataract surgery passed through a revolution under microsurgical procedure during the past quarter of the last century. So the cataract surgical benefit by microsurgery amongst the "PAL" extended a dramatic change in their quality of life (Imagine the condition of a leprosy sufferer with deformed nose and ears wearing a pair of heavy aphakic glasses following cataract surgery by conventional Intra Capsular Cataract Extraction Method!). (38,39,41)

At the early ninth decade of twentieth century there was a great dilemma with the eye surgeons about the rationality of putting IOL amongst "PAL" where the eye is already in a burning condition with cold uveitis.(43) Nowadays the microsurgical procedure adopted for the "PAL" include simple Extra Capsular Cataract Extraction (ECCE) by Can Opener Technique with sclerocorneal stitches, ECCE through Small Incision and ECCE by Phaco emulsification followed by IOL implantation even in complicated cataract with rigid small pupil, capsulo zonular complications, iris atrophy, hard nucleus. The post operative visual outcome is very satisfactory. The complications are limited and well under control. However the immediate success of the surgery is within 90-95% (32,35,36) In one longitudinal study by the author on 200 cases (ECCE with IOL with stitches) in Eastern India the following complications were noted in the post operative period during the five year follow up:30% PCO(Posterior Capsular Opacity), 2%Endophthalmitis, 1% Retinal Detachment ,2% Optic Atrophy or Pallor of the Disc, 1% other complications. Corrected Visual Status at the end of the fifth year: 30% (> 6/18). 40% (>6/60-.6/18 ), 25% (6/60-Cf), 2% (only HM), 3% (NPL). (37) Frequent attacks of uveitis in. Postoperative period was the major complication but well controlled by local steroid. Exposure keratitis, ulcers on the palmer aspect of the hand & insensitive cornea are the common source of infection in the operated eye. PCO (Posterior Capsular Opacity) is the major complication amongst PAL. LASER Capsulotomy can help to regain better vision which are not available at the centers where the study group used to get the surgery. (45,25) The same situation is observed in Nigeria. (12) On the other hand in Western India (Pune) a study on 40 cases dealing with the post operative complication following Small Incision Cataract Surgery shows 90% VA > 6/12. 5% had PCO & Iris atrophy. (44,45) In South India (Coastal Andhra Pradesh)

a study on 500 post operative cataract cases 86% had VA 6/6-6/18). Post operative complications like vitreous haze (4%), iritis (8%) & Phthisis bulbi (8%) were noted. (18,19)

In Brazil the visual outcome and the complications following cataract surgery by phacomulsification and IOL implantation in a leprosy group were as follows: VA 20/40 - 83.9% , VA 20/60 to 20/100 - 9.7% ,VA 20/200 - 6.5%. A fare number of complications were observed eg. IOL dislocation (3.2%), Synechia (12.9%), IOL decentration (3.2%), debris on IOL surface (3.2%), Sphincter tear (19.4%), Capsular opacification (9.7%) and persistent ocular inflammation (3.2%)( 10)

## Lagophthalmos

At present Lagophthalmos is the prime area for surgical intervention so as to prevent exposure keratitis and fulminating corneal ulcer amongst young adult leprosy sufferers. Lagophthalmos Surgical Coverage figures are negligible in India (19%) & Sri Lanka (8%). In Africa Lagophthalmos has a better surgical coverage of 40.4% compared to Entropion, Trichiasis, which has 24.7% coverage. Lack of awareness about the treatment available was the most common reason even for not seeking surgery. (12) But most of these leprosy sufferers remains untreated for lagophthalmos surgery due to the lack of proper eye health care delivery system and patients' apathy towards surgery. (31)



Lagophthalmos in Leprosy

## Corneal Disease

Constant supervision with measures for proper closure of the cornea by effective lid surgery for lagophthalmos, entropion and trichiasis has markedly minimized the corneal diseases in leprosy, as has regular local instillation of Artificial tear to keep the cornea moist and transparent. This is boon for PAL in the advent of 21st. century which should be followed through out the life. So also the new 3rd. & 4th. Generation antibiotics for the treatment of bacterial or fungal corneal ulcer in hyposthetic cornea offer good healing.

Keratoplasty (corneal transplantation), the treatment for Corneal Opacities after healing of the ulcer, is done very successfully amongst PAL. Although it was tried in different parts of India from 1975 the ultimate optical result was very much limited. However keratoplasty amongst PAL is of highest order in Sri Lanka.

## Iris Involvement

Today following the advent of MDT, Uveal involvement (9%) is low amongst new cases and if it happens, the severity is of minor degree and often associated with Episcleritis, ENL reaction. It is mostly a painless cold iritis. Small pupil is common and difficulty arises during surgery. However well manageable by initial treatment with local as well systemic steroid, mydriatic and may be continued with NSID in cases of bad cornea. (2,23,30)

## Community Eye Health Care Delivery

Ocular leprosy represents a considerable source of avoidable blindness which can be reduced by early detection of patients at risk and appropriate treatment. This calls for intensified effort in training of health personnel and patient education and integrating leprosy and ex leprosy patients into general eye care services (14,15,18,19). The National Leprosy Eradication Programme (NLEP) was launched in 1955 at a time when the stigma against the disease was very high. National Programme for Control of Blindness (NPCB) was initiated in India in 1976 as one of the 20 points Programme of Govt. of India when the Prevalence of Blindness was 2% - blindness from Leprosy was also included in that data. It was also started as a vertical programme. (26)

The NLEP had to become a vertical programme because of the severe prejudice against the disease. Fortunately the stigma against leprosy has reduced. As with any other

disease, co-operation, intervention and help of specialists in different disciplines would be of great help in leprosy also. Leprosy screening and surveillance programmes should include ocular examination as part of routine screening, particularly in individuals with a history of multi-bacillary disease. Individuals with known sight-threatening pathology should undergo continued active follow up. (46)

In the leprosy endemic zones of India including West Bengal Ocular Leprosy is still neglected by leprosy workers due to lack of knowledge and is often overlooked even by the Ophthalmologists. So also the PAL can not avail the existing facilities due to lack of proper transportation and guide. (4,11,33,34) Keeping this perspective in the background screening camps are being conducted by Mobile Team of eye health care personnel at the different aftercare leprosy colonies (1,8,9)

## Prevention of Blindness in Leprosy

Keeping WHO at the fore front, VISION 2020 is the ongoing Global initiative for Prevention of Blindness activities in progress all over the world. Integration in VISION 2020 initiative requires strong commitment both political and organizational (professional) for inclusion of PAL in general health and eye care.

The Prevention of ocular leprosy is achieved through the following plan :

1. Early detection and systemic treatment of leprosy
2. Eye care at primary/district/regional center under VISION 2020 plans.

**Primary Eye Care:** Promotion and protection of eye health. by trained health workers through recognition & referral of visual disability, common simple eye diseases, lagophthalmos, painful red eye & sudden loss of vision and refraction. The field workers are simply required to assess visual acuity (either visual impairment (<6/18) or blindness VA <6/60) and lagophthalmos. This should be the primary indicators for monitoring disability (grade 2). (3)

**Secondary Eye Care:** It is being done at the Intermediate level through the Eye Departments of Sub Divisional & District hospital under Government control and Base Eye hospitals run by different NGOs".

**Eye Care at Tertiary Level** is delivered from the medical colleges & the center of excellences i.e. Regional Institutes of Ophthalmology.

## Integration

Ocular Leprosy is one of the serious Community Eye Health Concern of the Indian Subcontinent. Specially in this era of "RFT" when around 10 millions People Affected with Leprosy ("PAL") are living within the society whether independently, with the family or in a mercy home. Many of them carry some ocular morbidity as an aftermath of leprosy which requires constant monitoring, supervision and treatment. Fortunately there is beautiful integration of Management of Ocular problems of "PAL" through General Eye Health Care System. But a more rational, advanced as well as practical implementation / approach of this Community Eye Health Care Delivery System is only possible through regular interaction with those working in the Leprosy Hospitals and the other Group from the General Eye Hospitals. Globally it is the current trend to integrate leprosy control with primary health care service. The situation is very good in Indian scenario. For instance a team of Ophthalmologists & Plastic surgeons

are found to be absorbed in a team for mass lagophthalmos surgery camp being organized at a district/subdivisional / leprosy hospital. In an Eye Hospital in eastern India (Haldia Lions Eye Hospital) a separate wing (Brandt Ocular Leprosy Clinic) had been working since 2000 to cater service to PAL by the side of general healthy population in an integrated manner in both out reach and indoor services.

On the other hand the Ophthalmologists & the Para Medical Ophthalmic Assistants who are working in General Hospitals, are often lacking in proper knowledge of Ocular Leprosy due to lack of exposure to these patients during their student days or early service period. So it is a very common error for these group of doctors to miss Ocular Leprosy when they are posted in a zone which was Leprosy "Endemic" area. Time has come to integrate Community Dermatology with Community Ophthalmology to overcome the barriers of awareness, accessibility and acceptance. (16,20,21,22)



Integration Of "Pal" With General Healthy Patient In A Medical College Eye Opd In West Bengal

## Conclusion

In the Indian subcontinent, there is beautiful integration of management of ocular problems of "PAL" through General Eye Health Care System. These group of patients are now enjoying all sorts of eye health care along with the healthy population without any stigma.

There is no longer an abundant number of neglected, untreated or unattended cases of avoidable blindness from leprosy. Almost all the PAL whether "RFT" or in active stage are at least under the umbrella of primary eye care. At this historic moment of a meaningful integration, like the healthy individual of the community, the "PAL" can also dream of enjoying a good vision towards a better "quality of life". This calls for an easily accessible comprehensive cost effective eye care service delivery model for this community at the secondary and tertiary level. Reorientation of need assessment and service delivery of Ocular Leprosy (with special emphasis on

Lagophthalmos surgery and Refractive error correction) is the immediate need for Eye Health Care Personnel.

The revolutionary feature of the recent advances in Ocular Leprosy can be concluded with the following words "Today the hesitations of doctors to treat leprosy patients have gone, more so with the ophthalmologists because they do not have to handle a patient much. Handling a leprosy patient is no personal risk which the doctors should understand and tell others. Let us all unite to drive away the ignorance in medical personnel, doctors, nurses, technicians, ward attendants and others and join united to treat leprosy as a disease." (K V Desikan as a part of the key note address during the Poster Exhibition & Round Table Discussion on "Progress towards the integration of management of ocular problems of" People Affected with Leprosy" with general eye health care delivery system in Indian subcontinent "at Sarojini Devi Eye Hospital, Hyderabad, AP on 30<sup>th</sup>. January, 2007) (43)

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