ACTA SCIENTIFIC PAEDIATRICS

Volume 2 Issue 9 September 2019

Research Article

Joint Care Model between Rural Paediatric Setup and Tertiary Care Centre for Children with Special Needs: Indian Experience

Asish Bhakta* and Anjan Bhattacharya

AGH Kolkata, India

***Corresponding Author:** Asish Bhakta, AGH Kolkata, India

Received: June 14, 2019; **Published:** August 08, 2019

Abstract

India currently enjoys the bottom most position in World Inequality Global Index 20181. This is pronounced in the care delivery of children with special needs. According to WHO, one in every 4 to 5 children is a child with special needs. An environmental factor (e. of ICF) like urban rural divide pronounces as this health care access especially for these children. We share our successful experience of collaborating with tertiary care centre using Kolkata development model.

Keywords: Health Inequity; Disability; Joint Care; Kolkata Development Model; Parent Training; Special Needs

Introduction

In India, proper healthcare access is difficult. We report how practically, some of the challenges can be addressed to improve the ultimate outcome. The utilization of a Joint Care model between a small rural Paediatric set up and a tertiary care hospital in the city 120km away from here is reported here. Due to infrastructural reasons, it consumes more than 4 hours to tread this distance on an average. Provision of initial Basic Life Support, Triage, Stabilisation and partial Advanced Paediatric Life Saving measures are by now possible in some select centres in the rural India. But when it comes to patients with different types of developmental disorders, acquired or congenital, ranging from language delay (most common), learning disability, disorder of social interaction to movement disorders of varying severity, it poses inordinate challenges. This is often because of unavailability and inaccessibility to multidisciplinary treatment facilities in the rural sector of our country, along with a lack of comprehensive knowledge in this domain, at the current juncture, amongst healthcare professionals, including Paediatricians.

Chance association with the Kolkata Developmental Model practised successfully in Apollo Gleneagles Hospital in the city originating from academic pursuit of IPPC/DCH course run at the tertiary city hospital, led to better outcome. A communication bridge between the said rural primary care setup and the city based tertiary care Child Development Centre at the Apollo Gleneagles Hospital (CDC, AGH) in Kolkata, was established as an initial step towards abolishing the evil effects of health inequity as highlighted as a prime need in Developing Nations by the World Health Organisation (WHO).

WHO speaks

- India currently enjoys the bottom most position in World Inequality Global Index 2018 [1].
- This is pronounced in the care delivery of children with special needs.
- According to WHO, one in every 4 to 5 children is a child with special needs.
- An environmental factor (e. of ICF) like urban rural divide, pronounces as poor health care access especially for these children.

- We share our successful experience of collaborating with tertiary care centre using the Kolkata development model.

Methodology

We report five cases

- Down syndrome with acute mental depression at 16 years of age, so far untreated, comes out of depression in 18 months!!!
- Two cases of acute bacterial meningitis, prevented from worsening post meningitis disabilities.
- One case of complicated (difficult to treat) acute bacterial meningitis which developed disabilities and treated successfully through Early Intervention.
- An adolescent girl at 16 years of age suffering from Selective Mutism of several months finds her voice fully and promptly by mere 8 months, despite of irregular treatment.

Case 1

- A 16 year old girl MM was suffering from Down syndrome. Her presenting acute problem was dehydration and complete refusal to eat or drink.
- She was born to an elderly primigravida. Received partial immunisation only and was never formally diagnosed by testing. From the onset she was treated by alternative medicines (Homeopathy).
- There was also history of recent constipation.
- At the rural set up, immediate management of acute dehydration was done with intravenous fluids. Immediate referral was made to CDC, AGH Kolkata for tertiary input.
- Input from Developmental Paediatrician and Paediatric Endocrinologist unearthed acute depression and hypothyroidism, which were promptly treated along with outpatient based intensive multidisciplinary input, including intensive sessions with Child Psychologist, up on discharge following stabilisation of acute symptoms and food acceptance in 3 night's admission.
- She was also picked up with hearing loss in one ear and error of refraction both eyes. No cardiac, no orthopaedic issue.
- Within a span of next eighteen months, the monosyllabic girl started communicating regularly with 3-worded sentences. This innovative Parent Training Based multidisciplinary team approach, we coined as The Kolkata Development Model.

Case II: Partially treated acute bacterial meningitis

- TM, a 3year old girl child, presented with a history of Fever for two days up to 103˚F, followed by repeated vomiting and frequent loose stool for one day. Treated at home by medical quack with Injection Ceftriaxone 250mg I.M twice daily, Paracetamol syrup and ORS (oral rehydration solution). The patient was moderately dehydrated and looked drowsy. TM was immediately admitted and started intravenous fluid and antibiotics promptly.
- Over the night, she still developed slight neck stiffness and positive Kernig sign. Without delay TM was referred to Apollo Gleneagles Hospital (AGH), Kolkata. Reaching there on the very next day, she developed generalised convulsion.
- Examination of the CSF and CT-Brain suggested Partially treated Pyogenic Meningitis.
- CSF culture negative.
- Treated with antibiotics as per international protocol for 14 days and discharged after repeat CSF remained sterile. Follow up assessment for auditory and visual impairment was done after 2 weeks. The child was found OK. There was no behavioural abnormality. No neurological dysfunction developed later on follow ups over the next one year.
- Timely referral saved the child from unavoidable disabilities as a sequel of meningitis like hearing loss, visual loss, behaviour abnormality or any other neurological deficit. Early referral removed the risk of complications, although, in this case, it was as early *as possible*!

Case III: Post meningitis disabilities developed and successfully treated

- MKM, a baby boy at the age of 4 months was admitted to a different tertiary care hospital in Kolkata, with a history of fever for 5 days and Status Epilepticus.
- Convulsion continued with Inj. Lorazepam, Inj. Livetiracetum – not controlled - Midazolam was started – not controlled - Inj. Fosphenytoin added. I.V antibiotic (Meropenem and Vancomycin) continued.
- EEG showed background disorganised activity of delta and occasional theta waves. No epileptic discharge, no burst suppression. CT-Brain: Bilateral subdural hygroma, midline shift, left transverse sinus thrombosis. CXR: Normal. Blood culture: no growth. Blood urea, creatinine, LFT, Electrolytes, Ca++, Mg++ all within normal limits.

CRP: 137.8mg/L. Hb: 7gm%, WBC: 20,000/Cu mm, Platelets: 4.26lakhs/ c mm.

- At this stage the parents, unable to bear the expenses, left the hospital on their own risk and came to the rural setting mentioned in this report. Admission in this low-cost set-up allowed them to continue the same treatment regimen. The patient became afebrile but convulsion continued even after coverage with Midazolam, Phenytoin and Phenobarbitone.
- MRI examination of the brain on 10th day of his presentation revealed gross subdural effusion with midline shift, left transverse sinus thrombosis, non-haemorrhagic infarction at the left frontal periventricular white matter.
- Lifesaving manoeuvre carries utmost risk in a peripheral primary care setup in India. The convulsion was controlled only after subdural tap was done through open fontanel and 40 ml of CSF from each side was drained in a desperate attempt to save his life.
- The subdural fluid examination: 18 cell/cu mm, N-20%, L-80%, Pr-107 gm%, Sugar-121mg%, C/S-No growth, Smear-negative.
- The patient was discharged after a month with anti-convulsion coverage in a state of apparent cure from meningitis complicated with subdural effusion and status Epilepticus on presentation.
- Follow-up showed delayed developmental milestones. Reappearance of social smile was delayed to the age of 5½ months. Gross motor, fine motor, primary dentition – were all delayed. There was no language development till 1½ years of age when parents were persuaded to consult Child Development Centre (CDC) at the Apollo Gleneagles Hospital (AGH), Kolkata.

After thorough developmental assessment, the child was found to have

- Unilateral SNHL-Right
- Global developmental delay
- Autism spectrum disorder.

The child was treated with multidisciplinary approach according to the Kolkata Development Model. At present at the age of 4 years, the child is talking in meaningful full sentences, going to regular school with other normal children and doing reasonably well in classroom of age-peers.

Case IV: (Partially treated meningitis)

- AK, a 4 years 2m old girl was admitted at the AGH, Kolkata and discharged 2 weeks later, receiving treatment for partially treated meningitis (viral/bacterial). She went home with left sided facial palsy and behavioural abnormalities on discharge.
- AK initially presented to the rural set-up with a history of high grade fever for 6 days, with occasional vomiting and mild cough. The patient looked very sick, drowsy and irritable. She was dehydrated. There was no localising sign except slight neck stiffness. She was treated irregularly with oral antibiotics elsewhere. Upon presentation to this rural set up, the patient was sent directly to AGH, Kolkata for tertiary care treatment after giving 700 mg of Ceftriaxone intravenously and communicating the referral over telephone.
- All the relevant investigations led to the diagnosis of partially treated meningitis. On the 2nd day after admission there was generalised convulsion and on the 3rd day, the child developed left sided facial palsy. PCR for HSV-1 and 2 were negative. Treated successfully with Inj Ceftriaxone, Acyclovir, Vancomycin, and Phenytoin.
- The facial palsy subsided with therapy on follow-up. There was no recurrence of seizure. The behavioural abnormality, which manifested afterwards as hyperactivity, was successfully treated at the CDC, AGH Kolkata. Currently, AK has no residual defect using Kolkata Development Model. CBCL was used along with Vanderbilt to diagnose ADHD.
- The child is now doing well. Immediate referral to the tertiary centre seemed to have averted a potential disaster.

Case V: (Selective Mutism)

- PP, a 16 years old girl and a known case of Epilepsy with intellectual disability, visited rural OPD with a history of amenorrhoea for 3 months with her mother. USG was advised but not complied by parents.
- Few months later, they again returned to the rural clinic with the complaint that now the adolescent girl was not speaking to anybody and sitting alone with a vacant look at the most part of her day.
- Urgent referral to CDC, AGH Kolkata was made for this sudden onset of stopping to speak.

- She was diagnosed as suffering from Selective Mutism and treated accordingly with Kolkata developmental model. Within a period of 8 months she started speaking normally, which continues till date. Child Protection concerns were shared with her and her parents.

Results

The outcome was splendid and exemplary. All the five cases showed remarkable improvement in their cognitive and mental development, by virtue of which they have become functioning enough regarding self-care and communication with others.

Conclusion

According to the 'World report on disability' about 15% of the world's population lives with some form of disability, of whom 2-4% experience significant difficulties in functioning. The global disability prevalence is higher than previous WHO estimates, which date from the 1970s and suggested a figure of around10% [2].

Estimates suggest that there are at least 93 million children with disabilities in the world, but numbers could be much higher. They are often likely to be among the poorest members of the population. They are less likely to attend school, access medical services, or have their voices heard in society. Most of them reside around places like where I practice.

Their disabilities also place them at a higher risk of physical abuse, and often exclude them from receiving proper nutrition or humanitarian assistance in emergencies. Updated: 2 October 2017 [3] Unicef.

As per the Census 2011, In India out of the 121 Cr populations, 2.68 Cr persons are 'disabled' which is 2.21% of the total population. Among the disabled population 56% (1.5 Cr) are males and 44% (1.18 Cr) are females. In the total population, the male and female population are 51% and 49% respectively.

Majority (69%) of the disabled population resided in rural areas (1.86 Cr disabled persons in rural areas and 0.81 Cr in urban areas). In the case of total population also, 69% are from rural areas while the remaining 31% resided in urban areas. This is mainly due to existing Health Inequity in the rural population caused by lack of awareness, information and access to proper health care facilities.

We have successfully implemented our pioneering concept of bridging this gap through the working together of our rural paediatric setup with a city based tertiary care centre utilising, what we call "Kolkata Development Model" which has shown to be successful among the children with special needs by establishing their full potential Functionality.

For such model to work in reality, the following conditions must be met

1. Mutual respect
2. Effective collaboration
3. Efficient communication between participating centres
4. Speedy results
5. Due acknowledgements on both sides

Since Kolkata Development Model fulfils all these criteria, it was possible to develop this working model in a community, which is not best known for such collaboration to this high degree of success.

Bibliography

1. Green D. World Inequality Report. Paris (2018).
2. http://www.who.int/disabilities/world_report/2011/report.pdf
3. https://www.unicef.org/disabilities/

Volume 2 Issue 9 September 2019