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India Needs to Focus on Its Polio Survivors

Neena Bhandari, Foreign Correspondent, *India Voice*, Sydney, Australia

The Indian Government, Non-Governmental Organisations and the larger community must invest in rehabilitating the unknown number of polio survivors facing new physical, social, cultural and economic challenges. India was certified polio-free by the World Health Organisation on March 27, 2014. Polio immunisation has been a great success story of public-private health partnership, but now we need to replicate this to improving the lives of people living with polio.

Unlike the developed world, many polio survivors in India are still very young. They will need treatment and support for many more years to come. Doctors, orthotists and physiotherapists need to be trained to recognise and manage the debilitating effects of post-polio syndrome (PPS).



ABOUT THE AUTHOR:

Neena Bhandari is a Sydney-based foreign correspondent, who contracted polio in India soon after receiving the oral polio vaccine in 1967. Since then, she has lived and worked in India, the United Kingdom and Australia as a journalist and foreign correspondent, reporting on issues ranging

from health and development, environment and education, human rights and gender to crime and law. Many bylines and many callipers on, as PPS poses new challenges each day, she is constantly evolving ways to live life to its fullest as a mother, a wife and above all a professional in the fast-paced, highly competitive media industry.

It is also time to count and document the number of polio survivors and the problems they are facing today.

Despite the odds, stories of endurance and resilience unfold as I meet polio patients in villages, towns and bustling cities.

Abhishek Kumar Kunvar

On a cold January night, I meet 26-year-old Abhishek Kumar Kunvar, a security guard on duty at a friend's house in South Delhi. Abhishek's right leg was affected by polio at the age of five. He hails from Balau village in the eastern state of Bihar, where he went to school with his older siblings. In the afternoons, he would help his parents on their small farm, growing wheat and corn. He would regularly swim in the nearby river, which provided relief to his aching limbs.

He told me how his parents took him to the state capital, Patna, to consult a doctor. He underwent corrective surgery, which made it easier for him to walk. As he grew older, he began experiencing more pain, fatigue and intolerance to cold. He was unable to do hard labour on the farm so he migrated to Delhi in search of work. Through friends and relatives, he found a job with a private security agency and now earns Rs 7,500 (slightly more than \$120 US) per month. In addition, he gets Rs 500 (about \$8 US) from the Government's Disabled Pension Scheme and travel concession on public buses and trains. The daily commute to work from his home in Mahipalpur takes two hours on the bus and one hour of walking, which he is able to manage for now. He does

continued on page 6

continued from page 1

night shift from 8 p.m. to 8 a.m., which gives him time to study for Class XII and also take computer lessons.

His family has found a girl for him to marry. With a shy smile, he says, “If you have a job, you can get married, regardless of your disability.” Marriage is a strong and sacred institution in India.

Anjula Sharma

I then meet 39-year-old Anjula Sharma in Jaipur, capital of the western state of Rajasthan. She was afflicted with polio in her left leg at the age of three. Her first memories are of the leg being put in a wooden splint every night. She was provided a KAFO (knee-ankle-foot-orthosis) with a hip band. She remembers being teased by other children and being discouraged from participating in school functions.

“I loved to dance like other girls, but was not allowed to participate. My teachers would say that I can’t do the steps properly or I will fall and hurt myself. It was depressing and disheartening,” says Anjula, who enjoyed playing hopscotch jump and skipping rope with her sisters and brother at home. Her parents ensured that she went on to complete her Master of Science in Entomology and

then a PhD in Geology.

Once she reached early 20s, her parents faced immense pressure from the community to find a polio-affected boy to marry her.

Anjula says, “My parents didn’t bow to social pressures. I am married to a loving man with a good job. We have two children – a girl, 12, and a boy, 8.” With a family to look after, Anjula has to wear the calliper for most part of the day. She finds the KAFO made of polypropylene



Anjula Sharma



Abhishek Kumar Kunvar

and leather very uncomfortable during the hot and humid summer and monsoon seasons. She is up at 6 a.m., getting the children ready for school, then sweeping and mopping the house, cooking and doing the dishes. (Most household chores are still performed manually. The middle class can employ household help and most have washing machines.)

“If you have a job, you can get married, regardless of your disability.”

She is finding it difficult to stand for long, walk long distances and climb stairs, which has greatly restricted her activities. She now goes to the market only when it is absolutely necessary. She used to teach, but quit her job when standing for long periods became exhausting.

“Geology entails fieldwork and it is physically demanding with limited job opportunities. I am planning to study fashion design and upgrade my computer skills so I can work from home. I am beginning to get lower back pain, joint and muscle pain and headaches. I am trying to space the chores and take a brief nap, which helps,” Anjula adds with a charming smile.

Laxman Garasia

From city to a remote tribal village in Rajasthan, I meet 25-year-old Laxman Garasia, who had polio in his left leg at the age of three. He lives in a thatched hut in the hills with his parents and seven siblings.

He quit studying after Year VI because he couldn't walk 5km to school daily. He wore a KAFO, but discarded it after five months because the rigid steel calliper made it impossible to use Indian-style toilets and he found the leather very uncomfortable during the long summer season. His mother would carry him to most places till he was 10 years old. He then learned to use his hand to support the thigh and walk. Sometimes he uses a crutch for support, but the hilly terrain makes it difficult. Recently, he has got a job in a café in the nearby Muchala Mahavir Jain Temple complex, where he makes chappatis (unleavened flatbread) during lunchtime and earns Rs 100 (slightly more than \$1.60 US) and gets free food and accommodation.

With a sheepish smile he tells me that he has two wives. He had met his first wife at a village fair and the second one nearby. His wives work in the fields and contribute their income to the family. Laxman says, "I have worked in a sweet shop and steel factory in big cities. The income was good, but I couldn't cope with the physical demands of the job. I have begun to experience more pain, fatigue and intolerance to cold."

Polio Still Stigmatized in India

Polio is one of the leading causes of physical disability in India. Disability still has a stigma attached to it. It is seen by many as a curse or bad karma or destiny. But I found the stares and glares from the people around were less than it used to be during my growing up years with polio.

It was heartening to see survivors so well adapted to the challenges of everyday living. But as they grow older and the debilitating effects are compounded by



Laxman Garasia

the weakness, pain and fatigue of the post-polio syndrome, they will need all the help they can get to continue to have a productive life. Accessibility at home and in public spaces is a big issue. Some NGOs are providing motorised wheelchairs, three-wheeled scooters and modified automatic cars to survivors to enable them to pursue their education and employment.

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More investment is required in the research and design of low-cost prostheses, orthoses and developmental aids appropriate for Indian seasons and cultural setting. "Callipers are now made of polypropylene and aluminium rods and joints. Patients prefer open sandals to shoes because of extreme heat and humidity. There are government subsidies in public hospitals for patients from lower income families," says J.K. Bhinda, orthotist, who retired as the Head of Orthotics at the Rehabilitation and Research Centre, Sawai Man Singh hospital, Jaipur.

Resources for Parents

Parents of young polio survivors must ensure that their child has a comfortable calliper at all times. Children outgrow their callipers very quickly and if it is uncomfortable, they will discard them. So it is essential to consult the orthotist on a regular basis. Deformities can be prevented in most children with polio

continued on page 8

continued from page 7

with simple things such as wearing the calliper and daily exercises. A good resource is the World Health Organization's 60-page document entitled "Guidelines for the Prevention of Deformities in Polio" (<http://apps.who.int/bookorders/anglais/detart1.jsp?sesslan=1&codlan=1&codcol=93&codcch=79>).

Parents must treat their child normally. Encourage him/her to participate in play and other social and cultural activities. Over-sympathising or doing all the errands for your child will prevent him/her from growing into a confident and independent young person. Modify your home to increase mobility. For example, do away with stairs where possible, provide proper rails in bathrooms, get a mobility chair.

If parents can form support groups and meet regularly to exchange news on latest research, orthotists, physiotherapists, hydrotherapists in their local area, it will go a long way in benefitting the young polio survivors. I would be keen to help facilitate such support groups and organise a conference on Living with PPS with the help of PHI.

India Should Consider Salk Vaccine

The other problem in India has been the number of Vaccine Developed Polio Virus (VDPV) cases. It makes no difference

whether the child contracted polio through a wild poliovirus or through VDPV. The oral polio vaccine can cause paralysis in very rare cases (about one in 2.7 million children). Maybe it is time for India to move to the injectable Salk vaccine like some of the developed countries.

"India needs to evolve a holistic model for the large number of polio survivors living in India."

Deepak Gupta, a doctoral fellow and a senior United Nations advisor on strategic health communication in Asia, says, "India needs to evolve a holistic model for the large number of polio survivors living in India. It is a dire human need for the government and the programme sector in India to actually have specialised units dedicated to rehabilitation and treatment of polio survivors, providing socio-psycho counselling, education (including skills-development) and livelihood."

Neena and PPS

On a personal note, my good leg is losing power. I can no longer walk or stand for long, get on and off escalators on my own, and climbing stairs is painful. Osteopenia, fractures, bursitis, headaches, fatigue, muscle atrophy and constant pain are posing new challenges. Regular hydrotherapy and massage helps, and I am learning to conserve energy by spacing activities and household chores, and using technology for work and entertainment. Above all, I am learning to be kind to myself. ■

Suggested Readings:

After Eradication, India's Post-Polio Problem
(<http://www.bmj.com/content/348/bmj.g2275>)

A Life Battle With Polio
(http://www.india-voice.com/joomla/index.php?option=com_content&task=view&id=451&Itemid=52)



J.K. Bhinda, a retired orthotist, working at the Rehabilitation and Research Center in Jaipur.