

FEATURE

INFECTIOUS DISEASE

After eradication: India's post-polio problem

What of India's forgotten survivors and the debilitating post-polio syndrome that can return decades later? **Neena Bhandari** reports

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As India celebrates three years of being polio free there is an urgent need to invest in medical care for the thousands of people who made the most of life after having had poliomyelitis but are now facing the debilitating post-polio syndrome (PPS).^{1,2} PPS describes the sudden onset of muscle weakness or fatigability in people with a history of acute paralytic poliomyelitis, usually occurring 15 to 40 years later.³ Many thousands of polio survivors experience muscle weakness, fatigue, joint and muscle pain, intolerance to cold, and difficulties in sleeping, breathing, or swallowing.⁴ ↓

The March of Dimes, an international non-profit agency based in the United States and founded in 1938 by President and polio survivor Franklin D Roosevelt, warned in 2001 that as many as 20 million people worldwide are at risk of PPS, which could leave them using wheelchairs or ventilators for the rest of their lives.³

Anita Ghai, a Delhi psychology professor now aged 55, had polio in both legs aged 2. She told the *BMJ*, "My legs have become more susceptible and less tolerant to cold and fatigue and I live with severe pain in muscles and joints. These are possibly symptoms of PPS, but there are few doctors in India who recognise and understand this condition." Ghai has had a rich life and travelled the world, but about 30 years after having had polio she began to feel muscle weakness. Climbing stairs became difficult and she began using crutches with callipers. For the past eight years she has been using a wheelchair.

The first case of PPS may have been described in 1875.⁵ Many experts think that PPS occurs when the overburdened nerve cells, which sent out new connections to make up for destroyed nerve cells, begin to fail, resulting in new muscle weakness.^{6,7} Ageing may also play a part.

Polio survivors: a forgotten group?

In India, people who've had polio are largely forgotten. Many support groups exist for cancer and AIDS but none for polio. Data abound on the number of children vaccinated and on reported cases of wild polio virus since 1998, but no census of polio survivors has been taken.

In the absence of any official data for India, many experts agree that given an incidence of as many as 200 000 new cases a year before 1978 the number of people who have survived polio runs to several million.⁸ In the 1990s, between 50 000 and 150 000 new polio cases occurred annually.⁹ From 1998 to 2011, the number of cases dropped to 8511 in total.⁸

Doctors are not trained in the diagnosis and management of PPS, and many newer doctors, especially in the southern states, have not seen a polio case. Simple things like changing callipers, reducing daily activities, gentle exercises, and resting where possible, can help loss of muscle function and ease pain in PPS.⁴

The All India Institute of Medical Sciences in New Delhi ran a polio clinic until two years ago. It assessed patients and provided treatment and callipers. "We used to get 20 to 30 cases of poliomyelitis in the clinic, which was held once every week. In recent years the number of cases has been negligible. We get a few old polio cases coming for treatment of secondary problems such as altered biomechanics in the body that may need surgical intervention, wear and tear of joints, pain or a deformity," said the head of the department of orthopaedics, Prakash Kotwal.

At the capital's oldest private hospital, St Stephen's, Mathew Varghese, head of orthopaedics, sees about 50 to 60 polio cases a month and an occasional PPS case—fewer than he would expect. The proportion of patients who need surgery has also reduced substantially, he told the *BMJ*. In older patients, correction of deformity is a longer and more complicated procedure. About a decade ago, polio patients coming to St Stephen's were between the ages of 5 and 13 years, but today the youngest patient in the hospital ward is 14 and the oldest is 26 years old.

Disease as destiny

Some polio survivors don't want any medical intervention. They accept the disease as destiny and resign themselves to living with the problems associated with polio. Others want to get better, but are unable to access medical facilities because of economic and other constraints, such as distance to a hospital and whether they can see a doctor, physiotherapist, and orthotist in the same place.

Ujagar Singh, an orthopaedic surgeon, has been treating polio patients for the past three decades in Rampura Phul, Bathinda District in Punjab. He said, "I am seeing many more old polio cases in their 30s complaining of renewed muscle weakness, pain, difficulty in walking, working, and performing household chores. Most of these patients are from families trying to make ends meet and for them the expense of getting to a hospital where they can be treated is unaffordable."↓

Polio survivors with paralysed lower limbs often crawl, some use pieces of rubber to pad their knees and sandals to cover their palms, others hobble or hop on one leg, and yet others use crutches or sticks or a hand to stabilise the knee while walking. Even if they are given callipers, many survivors in rural areas discard them within weeks of being fitted.

Singh said, "The calliper makes their disability more visible and in the rural communities there is a stigma attached to disability. About 90% of the cases don't wear callipers, which has led to secondary deformities which require corrective surgery. In many cases, even surgery is difficult because of the extent of the deformity in the bone and joints with no muscle support."

Callipers for free and other measures

The government provides callipers for free to all polio survivors living below the poverty line, but there is no provision for physiotherapy and gait training. Also, there are few facilities for repairs or adjustments.

The government also enforces quotas for jobs, tax relief, and travel concessions for disabled people, but for most people who have had polio, getting registered for these benefits is difficult in itself. Awanish Kumar Awasthi, joint secretary, Department of Disability Affairs in the Ministry of Social Justice and Empowerment, told the *BMJ*, "The government is trying to make it easier for people to get disability certification. Once the disability certificate is given to the person the entitlements follow automatically. Some states have introduced online lodgement of applications which has made it easier and faster for people to get the disability certificate. States are also organising camps at district levels to make it simpler for people to come and get the certification done."

In 1995 the government introduced the National Social Assistance Programme, a set of schemes for people living below the poverty line, including the Indira Gandhi National Disability Pension Scheme. A disability pension is provided to those aged 18 to 64 with multiple or severe disabilities. The central government provides each beneficiary with 200 rupees (£2; €2.40; \$3.30) a month, and state governments are urged to contribute another 200 rupees or more. In some states, the disability pensions can reach up to 1000 to 1200 rupees a month. The government also has other schemes for the disabled, including scholarships for students, and subsidised loans for unemployed people.

In 2011 the Post-Polio Syndrome (Education, Training and Awareness) Bill 2010 was introduced in parliament's lower house, the Lok Sabha, or House of the People. Balkrishna Shukla MP, who introduced the bill,¹⁰ said, "There are 80 lakh [8 million] people affected by PPS in the country. The purpose behind this bill is to create awareness among patients and their families as well as to seek government help in formulating strategies to fight it."

Advocates after polio

In countries such as the United States, the United Kingdom, Canada, and Australia the main source of advocacy for those with PPS has been grassroots groups of polio survivors, but India has none. Several non-governmental organisations (NGOs) have, however, been working to improve the socioeconomic lot of those who have had polio.

The Ability Unlimited Foundation (AUF), for example, each year helps about 300 people who have had polio, from villages throughout the country, by offering them training in activities that dispel various myths associated with disability in India. Its founder and artistic director, Guru Syed Sallauddin Pasha, said, "In my village disability was considered a curse of bad karma. There was a lifelong stigma with 'lame' used as a prefix to every polio survivor's name. It made me determined to restore their dignity."

He set up the foundation 25 years ago, using music and dance therapy to help polio survivors, who are trained as artists, tutors, technical assistants, or costume, sound, or stage lighting designers. Callipers, wheelchairs, and crutches are specially designed and modified for each production.↓ ↓

Vijay Kumar, aged 24, from Jharkhand, had polio at 3 years old and is now part of AUF. He told the *BMJ*: "We can do yoga and martial arts even on a wheelchair and use our hands to do leg movements. It feels good to be able to use the bad legs. I am earning 25 000 rupees a month, which has given me confidence in my abilities despite the disability."

The Rotary Naqshband Institute for the Physically Challenged has been funding NGOs such as the Family of Disabled, which provides wheelchairs and accessories to polio survivors to run their own mobile shops.

Raman Bhatia, a trustee and member of the India National Polio Plus Committee for Rotary International, told the *BMJ*, "Almost 70% of the polio survivors belong to minority communities in rural areas, who do not have access to any services. We assess their skills and help them set up stalls for photocopying, tea, grocery, stationery and other wares on a wheelchair, which they can take to weekly markets and earn about 5000 to 8000 rupees a month."↓ ↓ ↓

The trust has also been providing small modified automatic cars, three wheeled scooters, and motorised wheelchairs so that people can go to study and work. For people with polio, economic independence improves their social status.

The Delhi professor Anita Ghai said, "I have been lobbying through disability rights groups for the understanding of disability and making public places, pavements, and streets more accessible for the disabled. It has taken me years of campaigning to get a disabled toilet and car ramp put in my college."

A cure for polio and PPS remains a cherished dream. Physicians recommend that people who have had polio get a good night's sleep, maintain a balanced diet, avoid unhealthy habits such as smoking and overeating, and follow a prescribed exercise programme.⁴ Lifestyle changes, such as weight control, the use of assistive devices, and taking anti-inflammatory drugs, may help with some of the symptoms of PPS.

NB visited Delhi in January 2014 to research this story.

Competing interests: I have read and understood the BMJ Group policy on declaration of interests and declare the following interests: I had polio in 1967 in Jaipur. I am now experiencing PPS.

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Figures



Fig 1 New Delhi celebrates India's eradication of polio



Fig 2 Ujagar Singh: "I am seeing many more old polio cases in their 30s complaining of renewed muscle weakness"



Fig 3 "Sufi spinning" by the Ability Unlimited Foundation, a performing arts group for polio survivors



Fig 4 “Yoga on wheels.” The Ability Unlimited Foundation trains people who have had polio



Fig 5 Satyanand’s telephone booth on wheels in west Delhi, provided by the Family of Disabled NGO, under its Apna Rozgaar Scheme



Fig 6 Rajesh Kumar's snack shop on wheels in west Delhi, provided by the Family of Disabled NGO under its Apna Rozgaar Scheme



Fig 7 Deepak's snack shop on wheels in west Delhi, provided by the Family of Disabled NGO under its Apna Rozgaar Scheme