# POLIO SURVIVORS IN TURKEY

Prof. Dr. Arzu Yağız On, Ege University Medical Faculty, Department of Physical Medicine and Rehabilitation, Izmir, Turkey

## **ERADICATION HISTORY OF POLIO IN TURKEY**

In 1963, oral polio vaccination started in Turkey and covered about 20% of the children, but by 1985, this rate increased to about 70%. In 1989, Turkey joined the global eradication program of the World Health Organization. In 1995, mass vaccination campaigns started and were repeated every year. With these efforts, vaccination coverage increased to 100%, meaning that polio vaccine was administered to all children in the target group.

Europe's last case of wild poliomyelitis occurred in eastern Turkey in 1998. However, Turkey is surrounded by polio active countries and is traversed by emigrants to Europe.

Turkey's most severe threat of polio comes from the 600,000 Syrian refugees because polio re-emerged there three years ago. Extensive vaccination campaigns have been conducted since 2012 not only at the Syria camps but also in the regions threatened by the disease, even in Istanbul. No new polio cases have been reported so far.

## CURRENT STATUS OF POLIO SURVIVORS IN TURKEY

With such a strong focus on eradicating polio, insufficient attention has been paid to the individuals living with polio residuals and their subsequent health and rehabilitation needs, as well as their lifetime social, financial and psychological needs.

The number of polio survivors living in Turkey, where they are living or how old they are is unknown. It is extremely challenging not only in Turkey but all over the world to estimate the number due to inaccurate diagnosing and reporting of the cases during the epidemics.

According to the national reports of case numbers for polio between 1961 and 1999, about 13,000 cases were reported. If we consider that only 10% of the polio cases were captured through the national surveillance system, we could estimate that there are 130,000 thousand survivors living in Turkey and many of them are younger than 50 years old.

These young patients challenge the healthcare, rehabilitation and education systems as they strive for employment, social integration and economic self-sufficiency.

Moreover, the possibility of post-polio syndrome in the future challenges the younger polio survivors. Such health problems not only affect employment, but also have psychosocial implications and possible limits to independence and social participation. Polio survivor needs will be a concern for at least another generation and will make additional demands on Turkey's national health systems.

#### POST-POLIO CLINIC IN EGE UNIVERSITY HOSPITAL, DEPARTMENT OF PM&R

Our team mainly includes one or two physiatrists, a physiotherapist and an orthotist. Many professional members required for an ideal team such as occupational therapist, psychologist, social worker, nurse specialist, speech and language therapist and dietitian are lacking. Available team members assume those responsibilities as well. On the other hand, we have facilities to consult the patients to the other departments such as neurology, psychiatry, respiratory medicine and endocrinology when necessary.

### Assessment protocol

Polio patients are evaluated every Thursday. First, the patients complete a detailed medical history form, regarding their original illness and subsequent sequel, including the use of orthotics and/or walking aids, social situation and lifestyle. Patients are asked about new neuromuscular and musculoskeletal symptoms including pain, perceived fatigue, weakness and changes in function.

The physiatrist reviews the patients' medical history and performs a thorough neurologic and musculoskeletal examination. Validated scales are used to measure presence, severity and impacts of fatigue and health-related quality of life. A physical therapist measures range of motion, strength and assesses mobility status. An orthotist works with the rehabilitation physician and the therapists to determine the need for orthosis and ambulatory aids.

All patients are evaluated with detailed needle EMG (electromyography) and when necessary, further evaluations and referrals are arranged. Following confirmation of poliomyelitis, the extent of subclinical involvement is determined or a diagnosis of post-polio syndrome is made using established criteria.

## Demographic data of the patients admitted to our clinic

A total of 247 patients with a history of polio have been admitted to our clinic since 1997. Confirmation of polio was made in 90% of the patients. The remaining 25 patients had been misdiagnosed as polio, when the correct diagnosis was encephalitis, stroke, cerebral palsy and other upper motor neuron syndromes.

The mean age of our 222 patients is 39 which is quite young. Most of the patients are women and most of them are married. It is not surprising because marriage is almost universal in Turkey, even for polio survivors. The educational level is high for Turkey and most of them are employed. Among the not employed patients, most of them were housewives. As an unexpected feature, the patient's sociocultural level was high compared to the general population.

However, our data does not represent the current status of all polio survivors in Turkey, since most of our patients are from the west part of Turkey, where most of them have access to our center via internet or email.

Sixty-seven percent of the patients met the criteria of post-polio syndrome. Forty-eight patients had concomitant neurological, rheumatologic, cardiovascular or thyroid disorders that could cause symptoms of post-polio syndrome.

## Clinical management program

Our program is established according to the specific needs of the patients and covers all aspects of life.

The first step of the treatment is to educate the patient about polio, post-polio syndrome and the problems associated with them, and to provide individual and family counseling. This may include instruction in energy conservation techniques and work simplification, as well as suggestions for adaptive techniques and equipment to maximize the individual's participation in home and work activities and to assist in learning to adjust to necessary lifestyle changes. Sometimes patients are referred to a psychiatrist or psychologist to provide such assistance.

Based on the orthotic assessment, older orthoses are repaired or modified. More frequently, new custom orthoses are fabricated.

Nutritional counseling is provided to assist patients requiring therapeutic or weight-reduction diets.

A new exercise program is established that is specifically designed for the individual. Exercise programs emphasize the prevention of overuse. The program is supervised for at least two months, and carefully monitored and modified when necessary.

As education is the key part of management, the clinic staff has developed handbooks explaining the late effects of polio, work simplification, energy conservation, home exercise programs and orthoses. We provide them both to the patient and their primary care physician. (See www. polioplace.org/sites/default/files/files/ Turkishpoliobooklet.pdf)

Although medications have been used with only partial success, we usually prescribe lamotrigine for treatment of symptoms related to post-polio syndrome, based on the results of our study indicating that this drug relieves the symptoms and improves quality of life.

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Prof. Dr. Arzu Yağız On first became interested in polio while doing a fellowship at Uppsala University in Sweden. After moving back home, she established a post-polio clinic at the Ege University hospital, one of the largest and oldest hospitals in Turkey with more than 4,000 inpatient beds.

The patient usually returns for a follow-up in one to two months to assess the success of the program and the efficacy or side effects of medical treatment; for example, the exercise program may be modified based on the exercise logbook.

#### WHAT SHOULD BE DONE FOR POLIO SURVIVORS IN TURKEY IN THE FUTURE?

To assist in national policy-making, more accurate estimates of regional prevalence of polio survivors and the degree of residual disability are needed to design effective programs and policies to meet educational, social and economic needs of young middle-aged adults.

Given the complexity of diagnosis and management of post-polio syndrome, care strategies for polio survivors should involve coordination of multiple-skilled professionals, and these strategies should be adopted for resource-poor areas.

Healthcare professionals, largely unaware of post-polio syndrome, should be educated. Publishing information or research in open access national journals is much more important for educating health professionals than publishing in international journals.

Perhaps the most important issue in Turkey is that there is no organization or support group specifically for polio survivors. Although many of the challenges faced by polio survivors are similar to those faced by people with other disabilities, post-polio syndrome is a unique situation because of its clinical picture, diagnostic difficulties and management approaches. Such an organization should be established immediately. It is also important to place information in Turkish on the internet for when patients Google polio and post-polio.

## Positive aspects of Turkey regarding treatment of polio survivors

As a result of family life and cultural structure of Turkey, families and friends give strong social support to the people with a disability. This social support, especially from family mediates most of the challenges polio survivors face in Turkey.

More importantly, general public insurance covers most of the rehabilitation services (physiotherapy at the state hospitals and private clinics) in Turkey. Even the poorest people may have access to these services. It also covers modification or fabrication of custom orthosis every two years (about \$600). However, if the patient needs more expensive orthosis such as lightweight carbon orthoses to increase comfort (about \$2500), then the patient has to pay the price difference. If the patient has polio at only one lower extremity, general public insurance covers a certain amount of manual wheelchair expense every five years (about \$300). If the patient has polio at both lower extremities, then the insurance pays a certain amount for an electric wheelchair every 5 years (about \$850).

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