

ICD Codes and Some “Post-Polio Syndrome” History

Joan L. Headley, Executive Director, Post-Polio Health International

What are ICD codes?

The International Classification of Diseases (ICD) is a clinical cataloging system of alphanumeric designations given to every diagnosis, description of symptoms and cause of death attributed to human beings.

It means that each diagnosis a human being may be given has a code or a numbered designation that goes with it. The codes are intended as a means for every medical professional in the United States and many other parts of the world to understand the diagnoses the same. They are also used by others in the healthcare industry, such as insurance companies and manufacturers of medical equipment.

The United States implemented the ICD-10 on October 1, 2015, which was late compared to some countries which immediately switched in 1998. Most countries that use the tenth edition (ICD-10) now.

What are the codes of significance to the health professionals of people who have a past history of acute poliomyelitis in the new ICD-10?

According to the official ICD documents on the World Health Organization and the Centers for Medicare and Medicaid Services sites, the following codes are the most relevant. The descriptions inserted below are from www.ICD10Data.com.

G14 – Postpolio syndrome

[Incl: postpolio myelitic syndrome;
Excl: sequelae of poliomyelitis (B91)]

“Clinical Information about post-polio syndrome: A syndrome characterized by new neuromuscular symptoms that occur at least 15 years after clinical stability has been attained in patients with a prior history of symptomatic poliomyelitis. Clinical features include new muscular weakness and atrophy of the limbs, bulbar innervated musculature, and

muscles of respiration, combined with excessive fatigue, joint pain, and reduced stamina. The process is marked by slow progression and periods of stabilization. (from *Ann NY Acad Sci* 1995 May 25;753:68-80).”

B91 – Sequelae of poliomyelitis

[Excl: Postpolio Syndrome (G-14)]

“B91-B94 is a category provided for sequelae of conditions that are no longer in an active phase. B91 is a condition resulting from (sequela) the infectious disease. The description lists the following Approximate Synonyms.

- Late effect of poliomyelitis
- Late effects of poliomyelitis
- Neurogenic bladder as late effect of poliomyelitis
- Neurogenic bladder due to late effects of acute polio
- Neurogenic bladder, late effect of acute poliomyelitis
- Osteopathy after poliomyelitis
- Osteopathy from poliomyelitis
- Paresis as late effect of poliomyelitis
- Paresis, late effects of poliomyelitis
- Poliomyelitis, late effect.”

M41.4 – neuromuscular scoliosis is the non-specific code, which is applicable to scoliosis secondary to cerebral palsy, Friedreich’s ataxia, poliomyelitis and other neuromuscular disorders. There are eight specific codes under M41.4.

What was the old code?

Why wasn’t it satisfactory?

ICD-138 was the code for the late effects of polio, i.e., any polio-related problem whether a new one or a long-existing but stable problem. In the versions of the ICD-9 manual, first established in 1979, ICD-138 was the only code available.

Many survivors in the United States were advised not to have their physicians use

continued on page 6

continued from page 5

it in their records, because the survivor would then have a “pre-existing disease,” which could make them ineligible for health coverage. Instead, physicians used codes that described the specific issue, e.g., low back pain, pain in right ankle, dysphagia, etc.

There was a need to define or describe the condition, i.e., establish criteria for research purposes. Differential diagnosis was discussed by Frederick M. Maynard, MD; David O. Wiechers, MD; Marinos Dalakas, MD; Richard Owen, MD; Mary B. Codd, MB, BCh, and others at the Research Symposium of the Late Effects of Poliomyelitis, May 25-27, 1984 in Warm Springs, Georgia.*

In 1984, Dr. Dalakas and others published “Late postpoliomyelitis muscular atrophy: clinical, virologic, and immunologic studies” in *Rev Infect Dis*. 1984 May-Jun; 6 Suppl 2:S562-7. They described “late postpoliomyelitis muscular atrophy (late PPMA) characterized by focal progressive muscle weakness, wasting, fasciculations, and muscle pains affecting previously spared muscles or muscles previously affected but recovered.”

Dr. Maynard also wrote about the importance of differential diagnosis in the July 1985 *Orthopedics*, and spoke about the problem of semantics in a presentation at the GINI (now PHI) Fifth International Polio & Independent Living Conference (1989).

He proposed definitions for the late effects of polio or post-polio sequelae as alternative synonyms, and also proposed definitions for post-polio syndrome and post-polio muscular atrophy (*Polio Network News*, Winter 1990, Volume 6, Number 1). Some presenters felt that the latter condition could be called post-polio progressive muscular atrophy or post-polio progressive muscular weakness.

Lauro S. Halstead, MD, presented criteria for a diagnosis of post-polio syndrome (PPS) in his article “Assessment and differential diagnosis for post-polio syndrome,” published in *Orthopedics*. 1991 Nov; 14 (11):1209-17.

In 1991, once again, *Orthopedics* featured post-polio sequelae in the November and December 1991 issues. The series was introduced by Richard L. Bruno, PhD, who wrote in the November Guest Editorial that the issue would use the “more general term referring to late-onset symptoms,” that is post-polio sequelae, which he chose to abbreviate as PPS. It is important not to confuse the two similar abbreviations that are used for two distinct conditions, ie, post-polio syndrome and post-polio sequelae.

As more research was done in the ‘90s, a picture of what was happening physically to individuals with previous polio developed as a “distinct clinical entity.” The term post-polio syndrome and the development of specific criteria for it gained favor.

“As more research was done in the ‘90s, a picture of what was happening physically to individuals with previous polio developed as a ‘distinct clinical entity.’ The term post-polio syndrome and the development of specific criteria for it gained favor.”

Individuals in the US were not having problems with the codes, but advocates in other countries who were educating about post-polio syndrome were having difficulty in getting recognition from the medical community for services without an official ICD code for “post-polio syndrome.” There was a need to indicate an active neuromuscular disease with new disabling consequences, not just a past history of a disabling condition.

The criteria for post-polio syndrome were solidified at the 2000 March of Dimes Conference in Warm Springs,

Georgia, and in 2006, when the European Federation of Neurological Societies (EFNS) published nearly identical criteria.

- *Prior paralytic poliomyelitis* with evidence of motor neuron loss, as confirmed by history of acute paralytic illness, signs of residual weakness and atrophy of muscles on neurologic examination, and signs of denervation on electromyography (EMG).
- *A period of partial or complete functional recovery* after acute paralytic poliomyelitis, followed by an interval (usually 15 years or more) of stable neurologic function.
- *Gradual or sudden onset of progressive and persistent new muscle weakness or abnormal muscle fatigability* (decreased endurance), with or without generalized fatigue, muscle atrophy, or muscle and joint pain. (Sudden onset may follow a period of inactivity, or trauma or surgery.) Less commonly, symptoms attributed to post-polio syndrome include new problems with breathing or swallowing.
- *Symptoms persist* for at least a year.
- *Exclusion of other neurologic, medical, and orthopedic problems* as causes of the symptoms.

Ultimately, the work of a team from Brazil, led by polio survivor Luiz Baggio Neto and Dr. Acary S.B. Oliveira, resulted in the G14 and B91 codes added to the ICD-10 in 2010.

Do polio survivors in the US need to talk with their physicians about this?

No, it should not be a concern. Because of the Affordable Healthcare Act of 2010, people, polio survivors included, in the US can obtain health insurance even if they have a pre-existing condition.

Dr. Marny Eulberg, explains that if a provider uses any kind of electronic medical record for the visit notes then the

“The medical community has settled on the term “post-polio syndrome” with the requirement of new weakness. The definition now used for post-polio syndrome is very similar to the 1980s definition of post-polio muscular atrophy.”

computer will choose an ICD-10 code that is based on key words in the note, even if the provider did not choose a code.

Dr. Frederick Maynard comments, “The medical community has settled on the term ‘post-polio syndrome’ with the requirement of new weakness. The definition now used for post-polio syndrome is very similar to the 1980s definition of post-polio muscular atrophy.” ■

*Lauro S. Halstead, MD (polio survivor) and David O. Wiechers, MD coordinated two scientific/research meetings about the new problems of polio survivors in 1984 and 1986. The audiotapes from those meetings are on Polio Place. Special thanks to Michael Shadix, from the Roosevelt Warm Springs Institute for Rehabilitation, Warm Springs, Georgia, for donating the files and to Brian Tiburzi, PHI, for posting all of them on Polio Place. See the links below for a list of the speakers, their topics and the audio.

- Audio from First Research Symposium on the Late Effects of Poliomyelitis (1984) www.polioplace.org/resources/first-research-symposium-late-effects-poliomyelitis-audio
- Audio from Second Research Symposium on the Late Effects of Poliomyelitis (1986) www.polioplace.org/resources/second-research-symposium-late-effects-poliomyelitis-audio