Common Misconceptions Concerning the Post-Polio Syndrome

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"Someone once said that everyone has the right to their own opinion but not to those based on their own facts." John Robbins

Currently, over 99% of physicians do not possess the knowledge required to treat polio survivors for a polio-encephalic-myelitis and the Post-polio syndrome (PPS). The general level of knowledge ranges from strongly predominant ignorance to superficial perceptions and half-truths masked with misjudgement, even though the poliomyelitis disease, also known as infantile paralysis, is one of the best studied infections in the world. Due to professional ignorance, the state of recognition and the state of knowledge differ catastrophically. This is clearly at the expense of the affected patients, most of whom are misdiagnosed and subsequently wrongly treated.

For PPS patients, a misdiagnosis rate of more than 99 percent must be assumed, including asymptomatic and abortive infection courses with their sequelae. Even under the exclusive consideration of paralytic illness cases, the polio survivors still have approximately the same magnitude of misdiagnosis.

With a few exceptions, the condition PPS exceeds the imagination of those who are not affected to a point of complete incomprehension. This lack of understanding ranges from family members, friends, acquaintances, work colleagues, doctors, health insurance companies, medical services, physiotherapists, health and social services, expert ascertainment services, right up to the social courts. The patient affected has to explain countlessly everywhere, whereby encountering unbelief and ignorance and is accused of being a know-all if he is a disease related informed patient and also not infrequently discredited even to the extent of being regarded as psychosomatic, depressive or even as a simulant.

Just a few errors or opinions offered as facts repeatedly in everyday practice prevent an adequate PPS diagnosis. These are referred to below:

* Poliomyelitis is a disease of the anterior horns of the spinal cord

This statement consists of several half-truths.

1. Poliomyelitis is not just an illness, but already disease-worthy as an infection, since as such, it leaves permanent damage to the central nervous system (CNS), under which the spinal cord and brain are to be understood.
2. On infection, the spinal cord is mostly affected. The brain on the contrary is always affected. So it is strictly speaking, a polio-encephalic-myelitis disease.
3. Infection and illness lead to damage in the CNS. It usually occurs in the spinal cord, but always causes consequential damage to the brain. Strictly speaking, the brain is "preferentially" infested, which means that during the incubation phase it is reached the fastest through the blood stream by the most massive of the polio viruses.
4. Not only the anterior horns of the spinal cord, but also the side horns and hind horns, as well as the dorsal root ganglia, may be affected.

* Poliomyelitis is a disease of the alpha motor neuron

This statement is imperfect.

1. It is strictly speaking a polio-encephalic-myelitis (see above)
2. Not only alpha motor neurons, but nerve cells, which innervate the muscular fibres of voluntary movement and nearly all neuro-regulatory brain areas such as brain activation, motor skills, pain regulation, the temperature regulation, respiratory regulation, stress regulation, sensitivity, cardiac circulatory regulation, hormone regulation and emotion regulation, can be affected.

* The bulbpontine and the encephalitic form of polio infection are extreme rare

This statement is incorrect in its incompleteness.

All polio infections are encephalitic and can damage the whole brain, mostly functional depending on the functional load for a more or less long period, as a result of the ability of the brain to compensate (equalization = neurogenic plasticity), which remains hidden (subclinical) to the outside. About 5 - 10% of course forms with visible (clinical) symptoms show involvement of the central nervous system (CNS). Thus, according to general understanding, the abortive, the aparalytic and paralytic forms are meant, of which the paralytic form in about 1% of cases of infection can

be found. With regard to the Post-polio syndrome, the subclinical bulbopontine and encephalitic infectious history are virtually always given, only the clinical proportion is relatively rare.

*** The polio disease follows a stable phase after recovery**

This statement is imperfect.

It is not a real stable phase, but a clinically stable phase with a subclinical unstable background. The losses of destroyed nerve cells are compensated through previously damaged and / or healthy nerve cells. The functional and structural compensation process is subject to constant reconstruction and decomposition with a limited durational magnitude. This is only clinically visible after a loss of about 50% of the nerve cells in a functional area due to functional impairment or functional failure. Even before this limit is exceeded, a subclinical PPS degenerative process may exist, which always emanates from the brain.

*** The stable phase lasts at least 10, 15 or even 20 years**

This statement is incorrect.

PPS is a degenerative disease of the overburdened balancing nerve cells of the brain and spinal cord. Transient processes in the musculature are also affected. The period up to their overload failure depends on the magnitude of the previous damage and the duration and extent of the relative or absolute load / overload. This can last from a few years, rarely months, up to several decades, without an upper time limit.

*** A polio illness must be known for a PPS diagnosis**

This statement is incorrect.

98% of polio infections go unnoticed without disease or are uncharacteristic but also carry a PPS risk. On clinically and / or epidemiologically probable infections on diagnosis, is also at least a possible post viral late effect to be taken into consideration.

*** A PPS after an aparalytic polio is not credibly proven**

This statement is incorrect.

A PPS can be expected with the aparalytic, the abortive and the inapparent (asymptomatic) infection course. A credible verification being the same as a proof of claim does not exist for the paralytic course of infection. Clinical and para-clinical findings are generally unspecific with PPS, or otherwise even mainly inconspicuous. Decisive is a compulsory thorough medical case history. This applies for all infection courses of polio-encephalic-myelitis. Polio-related damage to the central nervous system (CNS) is proven in all infections of the asymptomatic, the abortive, aparalytic and paralytic courses. In any case, this results with the risk of a later PPS.

*** For a PPS diagnosis disease consequences must be apparent**

This statement is incorrect.

Visible sequelae such as muscle paralysis and muscle atrophy need not exist. 99% of polio infections occur without paralysis and their consequences such as muscular dystrophy, however not without a PPS risk. Also, paralysis may have regressed in the recovery phase after the disease.

*** A preserved sensitivity is required for a PPS diagnosis**

This statement is incorrect.

During the polio infection, areas of sensitivity such as in the dorsal root ganglia or in the brain can also be damaged and later lead to PPS symptoms.

*** At least two or more characteristic symptoms must exist for a PPS diagnosis**

This statement is incorrect.

The requirement for at least two or more existing symptoms is par excellence medical nonsense. Any indicative symptom of over 100 possibilities may or may not be required to exist. The virus infestation of nerve cells is irregular in location and extent, therefore also the late effects. In addition, weak symptoms are often not perceived or not registered as disease worthy. One mostly initially unique indicative symptom is sufficient for the suspected diagnosis.

Proofing symptoms do not exist. All possible indicative symptoms may be single or in different combinational occurrence. They may or may not be constantly present. Their occurrence can be timely, vary locally and in strength.

*** The symptoms must have persisted for at least 1 year for a PPS diagnosis**

This statement is incorrect.

The PPS usually begins insidiously creeping, but can also be suddenly noticeable. A diagnosis is obligatory on its beginning. The probability of a different causative disease with the same symptoms or additionally causative disease is always possible. However, the PPS diagnosis never excludes parallel diseases as indicative symptoms. Consequently, the diagnosis PPS is not limited in time tied to a minimum duration of its symptoms. It is also mandatory with changing symptoms.

*** Other diseases must be excluded for a PPS diagnosis**

This statement is incorrect.

The exclusion of other diseases serves to prevent their treatment not to be missed out and not just purely a PPS confirmation. Their presence does not exclude the PPS, because an exclusion diagnosis cannot be excludable as such. Parallel diseases are possible. In the presence of corresponding symptoms, the PPS diagnosis has to be kept independent from other illnesses. The suspected diagnosis thus remains.

*** A new increasing muscle weakness must be present for a PPS diagnosis**

This statement is incorrect.

Although new muscle weaknesses are common, they are not a condition for a PPS diagnosis. Predominantly the first, most frequent and main symptoms are states of fatigue, which often register very late as disease-grade with slow onset and progression. In addition to exhaustion, for example, pain, as an indicative symptom, occurs without evidence of apparent muscle weakness.

*** Clinically ill conditions with polio survivors should not automatically suggest a PPS**

This statement is misleading.

Without exception and in addition to other illnesses with polio survivors, PPS should always be considered automatically.

*** The causes of the PPS are still unknown**

This statement is incorrect.

PPS is the result of a chronic relative as well as absolute overload, caused by a polio infection with or without disease of previously damaged and diminished healthy nerve cells, which depending on the strength and duration and result of overloading, after a more or less long period of time, die-off. It is therefore as in sports medicine defined described as an overtraining syndrome. Only the molecular sequence of event processes are not yet known, which do not matter for the diagnosis and the required symptomatic treatment

*** The Post-polio syndrome is very rare**

This statement is incorrect.

When only 1% to 1‰ of polio infections have a paralysis, but all the infection courses have the risk of a later PPS, the reported cases of paralysis are multiplied by 100 to 1,000 to reach the approximate real number of polio-infected. According to the official risk profile gained from the proportion of the population, this results in the fact that there are actually always more PPS patients as defined under the definition for rare disease. A rare disease is considered to be less than 1 patient in 2,000 inhabitants.

*** Post-polio syndrome is not a disease**

This statement is incorrect.

The term syndrome is used to describe *"... the simultaneous presence of various symptoms, so called symptoms" (Wikipedia) with known cause and unknown development.* Only with known cause and known development is the term

syndrome usually avoided and generally described as clinical picture. In that sense, it is an unfortunate choice of the consensus to call the polio late effects term a *Post-polio syndrome*, as this is a disease where cause and development - with the exception of molecular biology processes - are known. On the other hand, this term refers to the characteristic variety of possible symptoms and the complexity of the disease, which is quite an advantage for primary diagnostic understanding. This is also followed by the WHO in their classification of diseases ICD 10 with the code G 14 Post-polio syndrome as a name for an independent disease.

*** Post-polio syndrome is an immunological disorder**
This statement is incorrect.

With PPS, nerve cells die-off as a result of chronic overload. The cellular decomposition process leads to the release of cell components, some of which are protein molecules that activate the immune system. This has a local inflammatory reaction resulting in the framework of cell debris removal. In some cases, it can also release poliovirus fragments from cell-inactivated and fragmented polio viruses, which lead to this nonspecific reaction. Freed virus genetic material (RNA) in the form of fragments can therefore also directly trigger an immune response. This is secondary non-causative to the PPS immune process. Immunological inflammatory processes can also be primarily triggered through chronic stress without structural degenerative processes. Chronic stress is one of the main causes of the Post-polio syndrome. The brain is also affected by this process.

Conclusion

As long as the polio-encephalic-myelitis is considered just to be polio-myelitis with almost exclusive limitation to the consequences of the body motor system in the form of pitiable paralysis and skeletal deformities, whereby other consequences of the infection to the spinal cord and especially to the brain, are not considered, then the late effects, the Post-polio syndrome cannot be understood and thus not properly diagnosed and treated. As long as clinical proof and para-clinical symptoms or finding requirements for a diagnosis are continuously being sought, where in any exclusion diagnosis, as even in this case only naturally indicative, which do not exclude such a disease and parallel diseases from the outset, misdiagnosis and mistreatment are inevitable.

The basis for the detection of a Post-polio syndrome is the medical case history. No diagnosis in the case of a suspected Post-polio syndrome is already a misdiagnosis !
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