BioScience Reports

POST-POLIO SYNDROME UPDATE

HIGHLIGHTS OF A ROUNDTABLE MEETING OF THE POST-POLIO TASK FORCE

GUEST EDITOR: Neil R. Cashman, MD

Polio Experts Grapple with the Complexities of Post-Polio Syndrome

Post-polio syndrome (PPS) is a term that encompasses a range of symptoms experienced by survivors of polio years after their original infection. Defining the exact parameters of the condition has proven to be problematic given the subjective nature of many PPS symptoms, such as pain, fatigue, and new weakness. In addition, arriving at a definitive diagnosis of the condition can be difficult even for polio specialists, because many PPS symptoms overlap with those of other common disorders, including fibromyalgia and osteoarthritis.

To help clarify these issues, Lauro Halstead, MD, Director of the Post-Polio Program at the National Rehabilitation Hospital in Washington, D.C., and Burk Jubelt, MD, Professor and Chairman of the Department of Neurology at the State University of New York Health Sciences Center in Syracuse, NY, led a roundtable discussion concerning the epidemiology, definition, and diagnosis of PPS.

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Pathophysiology Holds Clues to Post-Polio Syndrome Therapy

Recent insights into the pathophysiology of post-polio syndrome (PPS) may hold clues to effective treatment modalities, two leading investigators reported at a roundtable meeting of the Post-Polio Task Force held last April in Boston.

Of approximately 640,000 survivors of paralytic poliomyelitis who are currently living in the United States, 20% to 40% are at risk for PPS, said Neil R. Cashman, MD, Associate Professor at the Montreal Neurological Institute of McGill University and Hospital, Montreal, Quebec, Canada. The key symptoms of PPS are new weakness, fatigue, and pain.

Dr. Cashman reminded listeners that the predominant disability of polio results from invasion and destruction of motor neurons by the poliovirus, with subsequent loss of innervation in muscle fibers. The recovery phase is characterized by axonal sprouting, which serves to reinnervate some or all of these muscle fibers. It is currently thought that PPS results because these axonal sprouts cannot remain stable indefinitely, but rather degenerate over time, resulting once again

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Pathophysiology Holds Clues to PPS Therapy

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in denervation of the associated muscle fibers.

Using electrodiagnostic tests, including single-fiber electromyography (SFEMG), and muscle biopsy analyses, including immunohistochemical evaluations of neural-cell adhesion molecule (N-CAM, a molecule expressed by denervated muscle fibers), researchers have identified ongoing muscle fiber denervation in post-polio patients (Figures 1 and 2). Fibers that were denervated decades ago can be clearly differentiated from small, angulated fibers that have lost their innervation in recent weeks or months, Dr. Cashman noted. "To me, this is the best proof that there is terminal axonal degeneration going on in people who have had polio in the past," he said.

Terminal Axonal Dysfunction Observed

More recent work by Dr. Cashman's group has suggested that terminal axonal dysfunction may be even more common than terminal axonal degeneration. This research has identified normal-sized myofibers expressing N-CAM (Figure 3); these may be fibers that have lost innervation and will ultimately become small, angulated fibers, or they may be only temporarily denervated and may be destined to become reinnervated, he said.

"The interesting point is that small,

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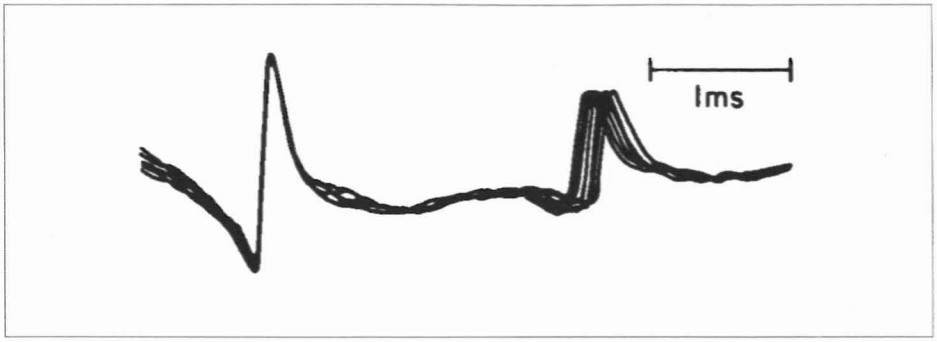

Figure 1. Single-fiber electromyography (SFEMG) data from an asymptomatic, 64-year-old patient with prior paralytic polio. Shown are 10 superimposed action potentials demonstrating "jitter" associated with motor nerve terminal degeneration.

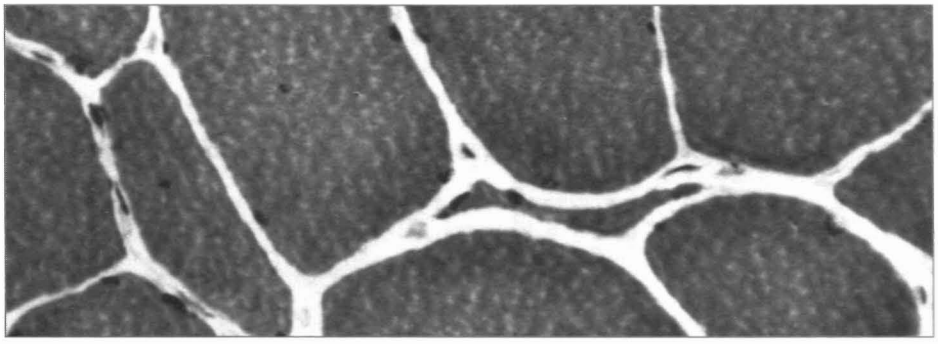

Figure 2. Angular atrophic muscle fiber in rectus femoris of a PPS patient reporting one year of new leg weakness (hematoxylin eosin stain). Isolated angular atrophic fibers indicate recent motor nerve terminal degeneration.

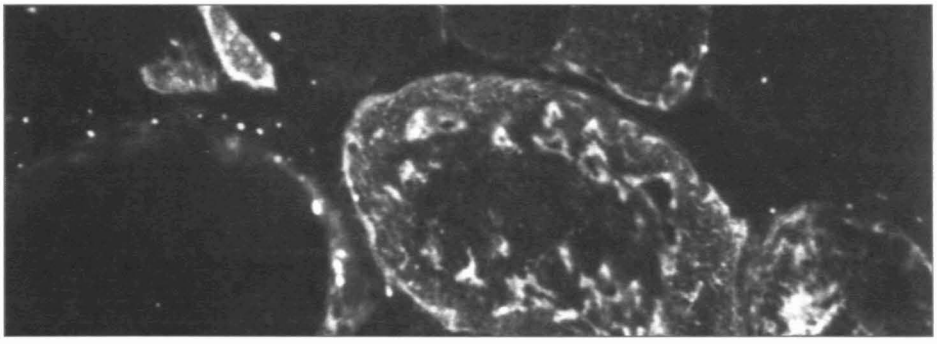

Figure 3. Neural-cell adhesion molecule (N-CAM) immunoreactivity in small- and large-diameter muscle fibers. N-CAM expression is associated with muscle denervation; normal-sized myofibers expressing N-CAM may be fibers that have lost innervation and will ultimately become small, angulated fibers, or they may be only temporarily denervated and may be destined to become reinnervated.

BioScience Reports

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Differential Diagnosis of Post-Polio Syndrome Requires Knowledge, Skill, and Persistence

Diagnosing post-polio syndrome (PPS) is a challenging process. There are no pathognomonic tests for the condition, and a definitive diagnosis can be achieved only through exclusion of other conditions that may be responsible for causing PPS-like symptoms, such as pain, new weakness, and fatigue. A successful exclusionary diagnosis of PPS depends on the knowledge, skill, and persistence of the examining physician, according to Frederick M. Maynard, MD, Professor and Chairperson of Physical Medicine and Rehabilitation at Case Western Reserve University/MetroHealth Medical Center in Cleveland, Ohio.

"Persistence is particularly important when it comes to diagnosing PPS, because it is not always possible to get to the bottom of the situation during just a few visits with the patient," Dr. Maynard said. "One diagnostic difficulty stems from the fact that a patient's symptoms may result from a synergy between post-polio residual neuromuscular dysfunction, orthopedic dysfunction, and other comorbid medical conditions."

Diagnostic Algorithm

The process of "teasing apart" synergistic dysfunctions in a patient can be simplified through the use of a diagnostic algorithm, according to Dr. Maynard (see Table).

The first step of this algorithm was summarized during the roundtable discussion led by Drs. Lauro Halstead and Burk Jubelt (see article, page 1). The second step requires the development of a comprehensive functional history, which allows the examining physician to quantify increasing weakness. Potential tests of a patient's physical abilities include manual muscle testing; isometric strength measurement; joint range-of-motion measurements; gait evaluation; and pulmonary function tests.

The third step in the diagnostic algorithm — developing a differential diagnosis — involves not only defining the basic characteristics of each symptom, but also considering the symptoms in relation to the individual's overall health and specific lifestyle. Once this is accomplished, a diagnostic plan can be developed. In general, Dr. Maynard said, diagnostic planning can be approached by examining the primary symptoms of pain, new weakness, and fatigue, and using appropriate evaluation tests to exclude conditions other than PPS.

In Dr. Maynard's algorithm, possible causes for new weakness that should be ruled out can be categorized according to their association with one or more of the following conditions: new superimposed neurological conditions, disuse atrophy, overuse/chronic strain, and systemic comorbid medical conditions.

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Table. Diagnostic Algorithm for Post-Polio Syndrome

1) Verify an original diagnosis of acute paralytic polio (APP)
2) Evaluate the extent and severity of APP residua
3) Develop a differential diagnosis of the presenting symptom complex
4) Conduct diagnostic tests to exclude other conditions considered in the differential diagnosis
5) (If no other conditions are found): Establish the patient's baseline function and develop a rehabilitation plan
6) (If other conditions are found): Treat them and re-evaluate the patient later for rehabilitation needs

Strategies Help Manage Post-Polio Symptoms

Even though no specific treatment is currently available for post-polio syndrome (PPS), strategies are available to help improve symptoms such as weakness, pain, respiratory dysfunction, dysphagia, and fatigue. A variety of techniques were outlined by Daria A. Trojan, MD, MSc, Assistant Professor at McGill University's Montreal Neurological Institute and Hospital, Montreal, Quebec, Canada, and Robert Miller, MD, Chairman of the Department of Neurology at California Pacific Medical Center, San Francisco.

Exercise for PPS patients has long been a topic of controversy, Dr. Trojan noted. In recent years, however, numerous studies have shown that judicious exercise can have a beneficial impact on weakness. Weakness may lessen in response to non-fatiguing strengthening exercises (isometric, isotonic, or isokinetic) and aerobic exercises. Improvements in muscle strength, power, work capacity, and economy of movement have been reported. Stretching exercises to decrease or prevent contractures may also be useful in patients with weakness.

Nevertheless, patients must be careful to avoid overuse of muscles during exercise, she said. Furthermore, exercise should be avoided altogether in those who are extremely weak and fatigued. "Just the activities of daily living take all of their energy, and these patients should not be subjected to additional exercise," she explained.

Weight loss can also help in the management of weakness, Dr. Trojan noted. Excess weight increases stress on post-polio muscles and joints, necessitating greater energy expenditure to perform activities of daily living.

Orthoses, or braces, offer another method of managing weakness. These devices can be used to compensate for

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Differential Diagnosis

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The category of new superimposed neurological conditions includes entrapment neuropathies (such as those affecting the median nerve at the wrist and the ulnar nerve in the hand), generalized motor and/or sensory neuropathies, radiculopathies, spinal stenosis, and other neurological diseases (e.g., amyotrophic lateral sclerosis [ALS], multiple sclerosis [MS], myasthenia gravis). The most appropriate evaluation tests for these conditions, according to Dr. Maynard, are electrodiagnostic tests (electromyography and nerve conduction studies); x-rays and imaging studies; blood chemistries, including creatine kinase and thyroid function tests; and toxic metals screening. The algorithm follows a similar step-by-step process for the differential diagnosis of pain and fatigue in PPS.

Practical Concerns

Some roundtable participants expressed concern that this algorithm may require expertise beyond the range of many practicing physicians, most of whom rarely see polio survivors. Dr. Maynard agreed that such concerns were valid, but also pointed out that the emphasis of the algorithm was not turning clinicians into "instant experts" on PPS. "The real issue is — how do we help doctors recognize possible PPS in the first place, and how should it be distinguished from other conditions?" Dr. Maynard said. "Some physicians may not feel comfortable in diagnosing specific orthopedic problems associated with PPS, while others may feel less comfortable diagnosing neurological difficulties. One benefit of this algorithm is that it can assist examining physicians in knowing when to refer their patients to outside experts."

Once other conditions have been excluded through differential diagnosis, the examining physician can begin to establish a functional baseline for the patient in order to measure the progress of rehabilitation, Dr. Maynard said. A patient's baseline can be established through manual muscle testing, quantitative strength training, electromyography, and limb circumference measurements. The examining physician can also record the time it takes a patient to walk a given distance or to complete an activity of daily living, so that these times can be compared to those achieved after the patient has begun a rehabilitation program. A subjective measurement of baseline function can also be established by videotaping movements and functional activities of the patient.

"PPS is a complex syndrome that does not lend itself to easy evaluation, and it follows that rehabilitation of a patient requires considerable attention and persistence on the part of the physician," Dr. Maynard concluded. "To be effective, rehabilitation must address issues relating to general health, symptom reduction, and functional enhancement, as well as those relating to the prevention of secondary disability." ■

Management Strategies

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joint instability secondary to weak muscles; to correct gait deviations; to control joint deformities secondary to weak muscles; and to reduce pain. Studies have shown that appropriate orthoses may improve the patient's ability to walk and their perception of walking safety, and may also relieve pain. Assistive devices such as canes, crutches, wheelchairs, and scooters may be useful as well.

Techniques Reduce Pain

PPS patients can experience pain as the result of muscular, joint or biomechanical, or neurologic problems. Dr. Trojan advised that muscular pain may be reduced by using pacing strategies, including taking rest periods during activities; using moist heat, ice, and/or stretching; using assistive devices; and instituting lifestyle modifications.

Fibromyalgia, which occurs relatively frequently in post-polio patients, can be treated with amitriptyline, cyclobenzaprine, or fluoxetine, Dr. Trojan said. Also potentially helpful are aerobic exercise, relaxation techniques, heat, massage, and injection of local anesthetics. Pain resulting from joint and soft tissue abnormalities may improve with modification of extremity use, physiotherapy, orthoses, assistive devices, nonsteroidal anti-inflammatory drugs, steroid injections, or surgery.

Another potential concern in PPS is respiratory dysfunction. Preventive measures (such as pneumococcal and influenza vaccinations) should be provided, she said, and reversible causes should be treated. Ventilatory assistance may be necessary in some cases; however, noninvasive methods are preferred due to an enhanced quality of life and decreased incidence of complications.

For dysphagia, Dr. Trojan recommended dietary alterations, special breathing and swallowing techniques, eating larger meals earlier in the day, and avoiding eating when fatigued.

Managing Fatigue

Dr. Miller described several strategies for improving the common symptom of fatigue in patients with PPS. He explained that fatigue may manifest itself as a low energy state; as mental fatigue; as reduced muscular endurance; or as delayed recovery after exercise. Patients frequently experience all types.

Healthcare professionals should help patients assess the ways in which energy is currently being expended, Dr. Miller said. It may be possible in many cases to identify methods of conserving energy, he noted. Judicious use of antidepressant medications may be appropriate for some, but not all, patients. Because sleep disturbances can play a major role in fatigue, efforts should be made to normalize sleep patterns. Amitriptyline may be useful in this regard, Dr. Miller said.

As in the case of muscle weakness, fatigue symptoms can also be improved through therapeutic exercise. Studies have shown that patients who exercise enjoy better endurance, greater work

capability, and improved recovery after fatiguing activities. However, patients must be cautioned to start slowly. "The general caveat is if exercise produces fatigue, you have gone too far, and if the next day you have muscular pain, you have done too much," Dr. Miller said. "The 'no pain, no gain' aphorism that applies to normal, healthy athletes does not apply to PPS patients."

Pharmacologic Therapies Assessed

Dr. Trojan noted that several pharmacologic agents have recently been evaluated or are under evaluation for the treatment of weakness and/or fatigue in PPS patients (see Table). To date, small trials have found no significant effects of amantadine, prednisone, or human growth hormone. Conversely, some improvement has been evident with bromocriptine, selegiline, insulin-like growth factor I (IGF-1), and pyridostigmine. An open-label trial in 17 PPS patients found that improvement in fatigue with pyridostigmine was significantly associated with amelioration in neuromuscular junction transmission with edrophonium (a similar, short-acting intravenous agent). This suggests that fatigue in some patients with PPS is due to anticholinesterase-responsive neuromuscular junction transmission defects. In an open-label trial of pyridostigmine in 27 PPS patients, 64% reported an improvement in fatigue. A double-blind, placebo-controlled, crossover trial in 27 PPS patients concluded that pyridostigmine produced an improvement in some measures of fatigue and strength. Because of these encouraging results, a multicenter trial of pyridostigmine in 126 PPS patients is currently underway.

"Thus far, pyridostigmine seems to be most promising," Dr. Trojan said. "However, other medications, such as IGF-1 and selegiline, should probably be investigated further."

Whenever possible, PPS patients should not receive medications that have fatiguing effects or potential inhibitory actions at the neuromuscular junction, she noted. Agents that should be avoided include beta-blockers, benzodiazepines, certain anesthetics, some antibiotics (such as tetracycline and aminoglycosides), certain anticonvulsants (such as phenytoin), some antipsychotics (such as lithium and phenothiazines), and barbiturates. ■

Table. Pharmacotherapy of Post-Polio Syndrome: Recent Trials

Drug	Category	Type of Trial	N	Results in PPS
Amantadine	Anti-viral	Randomized, placebo-controlled trial	25	No significant improvement in fatigue[1]
Prednisone (high-dose)	Steroid, anti-inflammatory	Randomized, placebo-controlled trial	17	No significant improvement in strength or fatigue[2]
Human growth hormone	Hormone	Open trial	5	Little or no improvement in muscle strength[3]
Bromocriptine	Dopamine receptor agonist	Placebo-controlled, crossover trial	5	Improvement in fatigue symptoms in 3 patients[4]
Selegiline	Neuroprotective agent	Case studies	2	Improvement in PPS symptoms[5]
Pyridostigmine	Anticholinesterase	Open trials	17, 27	Improvement in fatigue[6,7]
		Placebo-controlled, crossover trial	27	Improvement in fatigue, strength[8]
Insulin-like growth factor I (IGF-1)	Growth factor	Randomized, placebo-controlled trial	22	Improvement in recovery after exercise, no change in strength, fatigability[9]

[1]Stein DP et al. A double-blind, placebo-controlled trial of amantadine for the treatment of fatigue in patients with the post-polio syndrome. *Ann NY Acad Sci* 1995;753:296–302.
[2]Dinsmore S et al. A double-blind, placebo-controlled trial of high-dose prednisone for the treatment of post-poliomyelitis syndrome. *Ann NY Acad Sci* 1995; 753:303–313.
[3]Gupta KL et al. Human growth hormone effect on serum IGF-1 and muscle function in poliomyelitis survivors. *Arch Phys Med Rehabil* 1994;75:889-894.
[4]Bruno RL et al. Bromocriptine in the treatment of post-polio fatigue. *Am J Phys Med Rehabil* 1996;75:340–347.
[5]Bamford CR et al. Postpolio syndrome response to deprenyl (selegiline). *Int J Neurosci* 1993;71:183-188.
[6]Trojan DA et al. Anticholinesterase-responsive neuromuscular junction transmission defects in post-poliomyelitis fatigue. *J Neurol Sci* 1993;114:170-177.
[7]Trojan DA, Cashman NR. An open trial of pyridostigmine in post-poliomyelitis syndrome. *Can J Neurol Sci* 1995;22:223-227.
[8]Seizert BP et al. Pyridostigmine effect on strength, endurance, and fatigue in post-polio patients (Abstract). *Arch Phys Med Rehabil* 1994;75:1049.
[9]Miller RG et al. The effect of recombinant insulin-like growth factor 1 upon exercise-induced fatigue and recovery in patients with post polio syndrome (Abstract). *Neurology* 1997 (in press).

Pathophysiology Holds Clues to PPS Therapy

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angulated fibers constitute something on the order of 1% of the fibers that one can see on a muscle biopsy [of a patient with a history of polio], whereas the total N-CAM-positive fiber population can represent 10% or more of muscle fibers, strongly suggesting that there is an ongoing process that is much more common than the terminal degeneration of axons," Dr. Cashman said.

In addition to the N-CAM data, there is substantial electrophysiologic evidence that suggests instability of nerve transmission at the neuromuscular junction (NMJ). A marked increase in SFEMG jitter (a measure of terminal axonal function and NMJ transmission) has been observed both in polio survivors who have no new symptoms and in those with PPS (see Figure 1, page 2). The increase in jitter has been shown to be correlated with the severity of the denervation.

Terminal axonal dysfunction may simply represent an intermediate stage in the process of neuronal degeneration, Dr. Cashman noted. Alternatively, it may reflect the fact that motor units in polio-affected muscles are in a constant state of remodeling. As innervation is lost from one muscle fiber, he said, an axonal sprout is sent from another motor unit to innervate that fiber; this process continues back and forth. There may also be age-related changes in the trophic support of terminal axons, Dr. Cashman noted. Growth hormone secretion diminishes with aging, resulting in decreased levels of circulating insulin-like growth factor I (IGF-1), which plays an important role in the maintenance of terminal axons.

Treatment Implications Noted

Unlike degeneration, which is irreversible, nerve terminal dysfunction may be treatable. Dr. Cashman pointed out that one of the key functions of the terminal motor axon is to release acetylcholine in order to depolarize postsynaptic muscle fibers and induce contraction. Nearly 50 years ago, studies found a defect in acetylcholine release in patients who had recovered from polio.

"Defective release of acetylcholine waxes and wanes; it can be reversible and fluctuant," he noted. "Fatigability is the sort of symptom that we should be on the lookout for, because it may be responsive to pharmaceutical therapy."

Dr. Cashman explained that the defect in acetylcholine release is reversible with injection of the anticholinesterases neostigmine or edrophonium, which increase the amount of acetylcholine in the NMJ by inhibiting its breakdown. Interestingly, Dr. Cashman noted, response to the anticholinesterase pyridostigmine can be predicted on the basis of a positive SFEMG edrophonium response (i.e., the same patients who respond to edrophonium will also experience improvement in fatigue with oral pyridostigmine therapy).

Overuse Hypothesis Described

Burk Jubelt, MD, Professor and Chairperson of the Department of Neurology at the State University of New York Health Sciences Center in Syracuse, pointed out that neither increasing fiber density nor presence of angulated muscle fibers can serve to differentiate symptomatic from asymptomatic polio survivors. However, he said, several clinical studies have demonstrated that excessive strengthening exercise of partially denervated muscles can lead to progressive weakness. Animal experiments have also shown that overwork of weak and partially denervated muscles results in more weakness.

In light of these observations, Dr. Jubelt suggested that overuse of already weakened muscles accelerates the breakdown of the remaining motor units, resulting in additional weakness. From this perspective, post-poliomyelitis progressive muscular atrophy can be classified as a secondary phenomenon resulting from overstress of motor units for many years in compensation for residual weakness. Nonfatiguing exercise can help reverse the process and may even improve strength by avoiding overstress of the already weakened muscles, he said. ■

Polio Experts Grapple with Complexities of PPS

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Definitive Data Lacking

A 1987 National Center for Health Statistics survey found that there are 640,000 survivors of paralytic polio in the United States, and that roughly half have reported new manifestations of the disorder. A 1991 survey by Windebank et al showed that 64% of survivors of paralytic polio experienced new manifestations and 44% had weakness. The results of a 1987 survey by Speier et al indicated a lower prevalence of post-polio symptoms — 42% of respondents reported new problems, including pain, decreased endurance, and increased weakness — while a 1992 study by Ramlow et al found that 28% of paralytic polio survivors suffered from new neuromuscular symptoms. Thus, based upon symptoms, about half of acute paralytic poliomyelitis (APP) survivors go on to develop PPS. However, Dr. Jubelt noted, objective criteria need to be applied to more accurately determine the incidence of PPS. Uncontrolled, retrospective studies using objective criteria have estimated that 20%-40% of APP survivors will develop PPS. "Obviously, we need better epidemiological data," he said.

Towards a Definition of PPS

PPS may be defined as a cluster of symptoms experienced by individuals who had paralytic polio years earlier, Dr. Halstead said. Typically, these symptoms occur 30 to 50 years after the initial illness, and include new weakness, fatigue, and pain in the muscles and/or joints. Less common symptoms can include muscle atrophy, breathing and swallowing difficulties, and intolerance to cold.

According to Dr. Halstead, it is useful to categorize PPS symptoms into two groups: 1) those that are caused by a progressive deterioration of motor neurons (e.g., new weakness, fatigue, and muscle atrophy); and 2) those that are sec-

Table. Diagnostic Criteria for Post-Polio Syndrome (PPS)

1. A prior episode of paralytic poliomyelitis with residual motor neuron loss (which can be confirmed through a typical patient history, a neurologic examination, and, if needed, an electrodiagnostic exam)
2. A period of neurologic recovery followed by an interval (usually 15 years or more) of neurologic and functional stability
3. A gradual or abrupt onset of new weakness and/or abnormal muscle fatigability (decreased endurance), with or without generalized fatigue, muscle atrophy, and/or pain
4. Exclusion of medical, orthopedic, and/or neurologic conditions that may be causing the symptoms mentioned in (3)

These criteria represent a consensus statement of the Post-Polio Task Force. The sensitivity, specificity, and reliability of these criteria have not yet been tested in a prospective manner.

ondary to musculoskeletal changes (e.g., muscle and joint pain from osteoarthritis, tendinitis, ligament strains, and joint deformities); the musculoskeletal changes may be a result of years of abnormal wear and tear and/or new weakness.

"I believe that new weakness is the hallmark symptom of PPS," Dr. Halstead said. "When new weakness appears in muscles previously affected by polio and/or muscles thought to be unaffected originally, it may or may not be accompanied by other symptoms. This is a crucial point to recognize — a patient can have PPS even if new weakness is the only symptom."

However, "weakness" is a notoriously difficult symptom to pin down, roundtable participants noted, and they expressed concern that some patients may be confusing "weakness" with "decreased endurance." To cloud the picture even further, there is evidence that some patients may experience subjective feelings of increased weakness in response to muscle pain, cramps, and soreness. Several investigators (Dalakas et al, 1986; Stålberg and Grimby, 1995; Agre et al, 1995) have shown a slow (1%-2% per year) decline in muscle strength in post-polio patients based on objective criteria; however, noted some roundtable participants, two 1996 studies of polio survivors by Windebank et al and Ivanyi et al failed to find a progressive decline in muscle strength, even in those patients who reported this symptom. In the study by Windebank et al, which involved 50 subjects, muscle strength tests, functional analyses, and electrophysiologic tests detected no evidence of progression over a 5-year period. Similarly, Ivanyi et al examined 56 polio survivors — 43 complaining of new progressive muscle weakness and 13 without new neuromuscular complaints — and found that there were no significant differences in reduction of muscle strength between the two groups after a mean period of 2.1 years.

Dr. Jubelt pointed out that lack of adequate control in the studies for modification of the patients' daily activities could help to explain some of the discrepancies in reported prevalence of new weakness. "When you make positive changes in a patient's daily activities, such as providing them with assistive devices, you reduce the stress on already overburdened muscles and motor neurons, which in turn reduces the progression of weakness in these patients. I think something similar could have happened in the two studies in question — even though the researchers attempted to conduct completely 'controlled' trials, they inevitably influenced the study participants' daily activities and, subsequently, effected long-term changes in the participants' health."

Roundtable participant Neil Cashman, MD concurred with Dr. Jubelt's assessment that progressive new weakness does occur in this patient population. "We have all seen this manifestation in our patients. The question is not whether increasing weakness exists as a symptom of PPS, but rather, when patients complain of weakness, is it actually due to increasing weakness or is it due to another cause, such as increased joint pain or decreased endurance? I believe that it is an endurance problem in most patients."

Diagnostic Criteria for PPS

Despite the difficulties in defining and identifying PPS symptoms such as "weakness" and "decreased endurance," roundtable members agreed on some general diagnostic criteria for PPS (see Table). Ultimately, Dr. Halstead noted, the diagnosis of PPS is one of exclusion (see article, page 3). ■

Quality of Life Improves with Post-Polio Self-Care

Promotion of the concept of self-care can help to optimize wellness in patients with post-polio syndrome (PPS), according to Joan L. Headley, Executive Director of the International Polio Network, St. Louis, Missouri. "In the absence of a cure, polio survivors experiencing PPS should focus on care — medical, psychological, social, and spiritual," she said. "Good care can improve the quality of life for polio survivors and is most likely to happen when a patient and practitioner work in partnership."

To establish such a partnership, she said, it may be helpful for the physician to recognize differences between the "medical approach" and the "independent-living approach" to the management of PPS. The medical approach is oriented towards the professional; it emphasizes the illness, and focuses on the treatment of symptoms and the need to find a cure. The independent-living

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Quality of Life Improves with Self-Care

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approach is patient and family centered; it promotes a sense of health and well-being and encourages patients to take responsibility for their role in the decision-making process.

"Physicians can validate polio survivors by listening to them and acknowledging that what they are experiencing is real, treating them with empathy while drawing upon their medical and diagnostic repertoire," Ms. Headley advised. "By working together as partners, physicians and polio survivors can develop options, choose strategies, and implement changes."

Strategies Reviewed

When coping strategies are directed toward symptoms and attempts to maintain previous activity levels, patients tend to feel more helpless, depressed, and angry, Ms. Headley explained, citing a study by Westebrook et al. According to that 1996 study of polio survivors, helpful personal strategies include: 1) becoming more involved in activities that one is still able to pursue, 2) developing a philosophy of life, and 3) learning more about PPS. The ability to ask family and friends for assistance is particularly important, and interaction with other polio survivors in support groups can be beneficial.

Lifestyle changes that PPS patients have found especially beneficial include the employment of household help, the acquisition of special equipment and furniture, and making modifications in the layout of the home.

Complementary Treatment Explored

Dorothy Woods Smith, RN, PhD, Associate Professor at the University of Southern Maine College of Nursing, Portland, pointed out that debilitating pain and fatigue may persist even after PPS has been treated with surgery, pharmacologic therapy, and assistive devices. Ideally, she said, the physician should consider expanding the treatment plan to include complementary therapies aimed at lessening fatigue, relieving pain, reducing distress, and improving the quality of life.

Of particular interest are self-care techniques for eliciting a relaxation response, Dr. Woods Smith observed. Such methods include meditation, progressive muscle relaxation, and some yoga practices. In a study relevant to polio survivors conducted at the Harvard-New England Deaconess Mind/Body Medical Institute Pain Program, Margaret Caudill, MD, PhD, demonstrated that regular elicitation of the relaxation response resulted in an increase in activity, and decreases in pain severity, anxiety, depression, and anger. In the first year after completing the relaxation program, patients had 36% fewer visits to their managed care facility.

Dr. Woods Smith recommended that physicians ask patients whether they are already using alternative therapies. In a 1993 report by David Eisenberg, MD, and colleagues at Beth Israel Hospital and Harvard Medical School, 61 million Americans were estimated to be using some form of unconventional medicine. The most commonly reported therapies were acupuncture, relaxation techniques, and participation in self-help groups. The vast majority of individuals — 72% — had not told their physicians about using these modalities.

"Most of these therapies have been reported by at least some polio survivors as helpful in reducing stress, pain, fatigue, or psychological distress," she said. She acknowledged, however, that "with the rapid proliferation of new therapies, it is often difficult to distinguish the authentic from the exploitative." Reliable information can be obtained from sources such as the Office of Alternative Medicine at the National Institutes of Health; the American Holistic Medical Association; or *Alternative and Complementary Medicine*, a journal edited by physicians, Dr. Woods Smith noted.

"Ideally, physicians and polio survivors participating in partnerships with one another and with other health care providers will integrate the art and the science of medicine to offer the widest possible range of choices for healing," she concluded. ■

SUPPORTED BY AN EDUCATIONAL GRANT FROM ICN PHARMACEUTICALS, INC.

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New York, New York 10036