RELIVING POLIO

Forty years after the great postwar epidemic, the disease is coming back

.....to haunt its survivors

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Roberta Simon was eight years old when poliomyelitis paralyzed her from the neck down. She spent three months on her back in a Washington hospital and then began a long series of treatments and exercises that slowly, painfully restored full mobility to her limbs. Like many brave polio victims, she pushed herself hard. She was a majorette in junior high school, went to college and eventually became a surgical nurse in a Chicago-area hospital, working long hours on her feet in the operation room. "I was out there doing my thing," she says. "I though I was over polio."

She was wrong. One day 36 years after the disease disrupted her childhood, she felt some familiar symptoms. They started as muscle fatigue, weakness and pain. Then her legs collapsed under her, and she had to lean against walls to stand up straight. She went to specialists and took test after test. "They all came back negative," says Simon. "One doctor thought I was mentally ill and sent me to a psychotherapist." Finally, four years later, Simon was correctly diagnosed. She had polio. Again.

Forty years after the great polio epidemic of the 1940s and '50s swept through the U.S., infecting millions and leaving some 640,000 (mostly children) with varying degrees of paralysis, survivors are being revisited by a degenerative muscle condition that has precisely the same symptoms as a mild case of polio. The ailment is known as acute paralytic poliomyelitis sequelae, or postpolio syndrome. Doctors aren't certain what causes it or how best to treat it (for many years physicians prescribed exercises that exacerbated the condition), but they believe the problem will get worse before it gets better. Before the end of the decade, by one estimate, postpolio syndrome will strike 40% to 50% of the polio survivors, forcing many in their 50s 60s and 70s to relive the childhood pain and suffering they thought was behind them.

The symptoms of postpolio mimic those of the original disease, albeit in a less virulent form. They include fatigue and exhaustion, muscle weakness, painful joints and, sometimes, difficult breathing. The discomfort usually begins in the muscles affected by the original infection but can spread. Patients who got polio before age 10 and suffered particularly severe cases seem to be the most susceptible to the aftereffects.

What triggers postpolio syndrome? One possibility is that the polio virus becomes active again after decades of lying dormant in victims' cells. This notion gained support in 1991, when British scientists reported that 58% of the postpolio patients they tested had high concentrations of polio-type antibodies not only in their blood, which is to be expected, but also in their spinal fluid, which suggests a current infection. That does not explain, however, why the disease resurfaces so long after the original infection, and attempts to replicate the British findings have been unsuccessful. Since it's possible that the dormant virus could mutate into active new forms, scientists are searching for such culprits.

But most postpolio experts favor a competing theory that says wear and tear on the nerves is to blame. Polio initially attacks the nerves by invading the body through the mouth or nose, traveling through the bloodstream to the spinal cord and lodging in the nerve cells that control muscle activity. As the disease progresses, nerve cells in the spinal cord are damaged or killed, paralyzing muscles that lead to the arms,

legs, stomach and chest.

Fortunately, neighboring nerve cells that were not killed by the infection are often able to regenerate axons--the fingerlike connections that link nerves to muscle fiber. That's why the standard rehabilitative therapy for polio victims has been to stimulate nerve activity through heat and rigorous exercise, encouraging the healthy nerves to grow into the spaces left by their infected and damaged kin. "Use it or los it" was the refrain with which therapists urged on a generation of polio kids.

The problem is that these nerve cells have had to work a lot harder to get the muscles moving--like an eight-cylinder car running on four cylinders--and after 30 or 40 years, that can take its toll. "Everything has a finite life-span, from a car engine to the human heart," says Dr. Lauro Halstead, director of the postpolio program at the National Rehabilitation Hospital and a polio survivor. "A motor neuron is no different. Neurons that normally drive 20 muscle cells in the polio patient may now have to supply up to 2,000 muscle cells. Basically, this is a demand that the motor nerves are not designed to sustain."

Although there is no direct evidence to support the wear-and-tear theory, it does make a lot of sense. It would explain, for example, why so many people are coming down with postpolio syndrome now. The great postwar epidemic peaked in the U.S. in 1952, when more than 20,000 children were paralyzed by polio, and it tapered off in the early '60s, after the Salk vaccine and then the Sabin oral version were introduced. The first wave of postpolio symptoms appeared in the early 1980s, 30 years after the epidemic's peak, and if researchers are correct, the last wave should subside by 1997.

What can be done to help the postpolio suffers? not much, unfortunately. There are only experimental treatments. A steroid called prednisone, usually used to treat immune-system diseases like multiple sclerosis, seems to help in postpolio as well, reducing fatigue and increasing endurance. And Dr. Marinos Dalakas at the National Institute of Neurological Disorders and Stroke is experimenting with nerve growth factor, a protein that spurs the proliferation of nerve axons.

But the most effective therapy seems to be no therapy at all. Postpolio sufferers are simply advised to take it easy--to pace themselves, listen to their body and avoid activities that cause them pain. Dr. Halstead, who uses a motorized scooter instead of walking long distances, calls this "babying the motor neurons." His clinic uses sophisticated electromyography equipment that charts the activity of muscle and nerve cells in order to design exercise regimens tailored to each patient's particular weaknesses. The approach is almost the exact opposite of "use it or lose it." Says Dr. Jacquelin Perry, director of the pathokinesiology center at the Rancho Los Amigos Medical Center in California: "By decreasing the demand on these overworked neurons, we can extend their life."

For many patients, postpolio means having to take up the braces and wheelchairs they worked so hard to escape. Stanley Lipshultz, a Washington trial lawyer, is just starting to use the crutches his doctor prescribed. "I had a handicapped license plate on my car for two years before I actually used a handicapped parking space," he confesses. "The hardest part is you feel you're falling apart." says Rena Shnaider, a retired rehabilitative counselor from Oakland, California, who has spent her life in a wheelchair but who drove a car, went to college and had enough control over her body to lift herself up when needed. "I know I can't do half the things I used to, and it makes me sad to have to accept it."

If there is a bright side to postpolio syndrome, it is that the illness gives many patients an opportunity to come to terms with feelings they repressed for decades. For many, seeing those braces again stirs memories from the '50s, when they were pulled out of school, sent away for treatment and then brought home to face insensitive peers. "You remember that while everyone else was out playing football, you were watching and wishing you could be with them," says Lipshultz. Through support groups and counseling, many polio survivors are for the first time putting those unpleasant memories behind them.

"Many of us never got a chance to mourn our losses," says Shnaider. It's important for people with postpolio to face their experience and allow themselves to feel sad."

--Reported by Alice Park/New York

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