

More people live with paralysis than doctors knew

April 21 2009, By LAURAN NEERGAARD , AP Medical Writer



This undated handout photo provided by Alan T. Brown, shows spinal cord patient Brown in his wheelchair in Hollywood, Fla. Five times more people are living with a spinal-cord injury than doctors have thought _ nearly 1.3 million Americans _ says stunning new research that finds many of them unable to afford key health care. (AP Photo/Photo Provided by Alan T. Brown)

(AP) -- Surprising new research says nearly 1.3 million Americans are living with a spinal-cord injury, five times more than previous estimates.

Overall, 5.5 million people in the U.S. have some degree of paralysis due

to a variety of neurologic problems, from multiple sclerosis to strokes, says the report released Tuesday.

The findings will help health authorities finally understand the scope of need in this largely hidden population.

"They're not all Christopher Reeves," said study author Anthony Cahill, a disability specialist at the University of New Mexico, referencing the late actor's extensive spinal-cord injury and his highly publicized quest for groundbreaking treatments to overcome it.

Not only have less extensive injuries often gone uncounted, but the report suggests that people are living longer with paralysis - and they're now starting to face the added complications of aging on top of a disability.

"There's no road map for somebody like me," said Alan T. Brown of Hollywood, Fla., who broke his neck 21 years ago, just before his 21st birthday.

From a youth spent in wheelchair marathons, he's entering middle age suddenly needing more care, like an electric wheelchair instead of a manual. Infections are becoming more common. That's on top of the extra hurdles to arrange routine care, like a colonoscopy.

"Before World War II, you were lucky to live" after a spinal-cord injury, said Joseph Canose of the Christopher & Dana Reeve Foundation, which funded the study. "Now that they're living much longer, many of our supports are wholly inadequate."

Until now, people with the worst injuries were most likely to be counted, Cahill said, those like Reeve who wind up at specialty treatment centers. Even less firm were estimates of how many people have arms or legs

paralyzed or partly paralyzed by some other condition.

So, with advice from the Centers for Disease Control and Prevention and leading disability specialists, Cahill designed a survey of 33,000 U.S. households to measure how many people are living with some form of paralysis.

Beyond the overall toll, the findings paint a sobering picture of the cycle of [paralysis](#) and poverty. About a quarter of the paralyzed have an annual household income below \$10,000, compared with 7 percent of the U.S. population, the report said.

That doesn't surprise disability experts: Patients often lose their jobs, and caregiving needs can cost a spouse a job, too, ending employer insurance. Treatment, including the physical therapy that can improve independence and sometimes movement, is costly. There are income limits to qualify for Medicaid, and cash-strapped states are limiting coverage.

The Reeve foundation plans to use the findings to push for health policy changes, including ending a federal requirement that disabled workers wait 24 months before getting health care through Medicare. Also on its target list: insurance policies that forbid \$400 air cushions for wheelchairs until someone's already suffered a skin ulcer that can require a \$75,000 hospital stay.

Florida's Brown knows he's lucky, able to pursue a lucrative public relations career and be a mentor to other [spinal-cord](#) patients despite being mostly paralyzed from the chest down. Before his injury, he had a private insurance policy that lasted until recently. Now, he said, "I'm paying out of pocket like you wouldn't believe," and worries about how his wife and two young sons will cope if he worsens enough that he has to quit working.

"I thought I was bigger than the chair. I finally realized the chair is bigger than me," Brown said.

On the Net:

Christopher & Dana Reeve Foundation:

<http://www.christopherreeve.org/>

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