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## Prevalence and Causes of Paralysis—United States, 2013

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### Abstract

**Objectives—**To estimate the prevalence and causes of functional paralysis in the United States.

**Methods—**We used the 2013 US Paralysis Prevalence & Health Disparities Survey to estimate the prevalence of paralysis, its causes, associated sociodemographic characteristics, and health effects among this population.

**Results—**Nearly 5.4 million persons live with paralysis. Most persons with paralysis were younger than 65 years (72.1%), female (51.7%), White (71.4%), high school graduates (64.8%), married or living with a partner (47.4%), and unable to work (41.8%). Stroke is the leading cause of paralysis, affecting 33.7% of the population with paralysis, followed by spinal cord injury (27.3%), multiple sclerosis (18.6%), and cerebral palsy (8.3%).

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#### CONTRIBUTORS

All authors assisted with study design. B. S. Armour provided oversight of the statistical analysis and wrote the first draft of the article. E. A. Courtney-Long led the statistical analysis and contributed to writing the article. M. H. Fox and A. Cahill provided oversight of the statistical analysis and contributed to writing the article. H. Fredine assisted with statistical analysis and contributed to writing the article.

#### HUMAN PARTICIPANT PROTECTION

The institutional review board at the University of New Mexico determined that the project was exempt from review.

**Note.** The findings and conclusions of this article are those of the authors and do not necessarily represent the views of the Centers for Disease Control and Prevention, the Administration for Community Living, or the University of New Mexico.

**Conclusions**—According to the functional definition, persons living with paralysis represent a large segment of the US population, and two thirds of them are between ages 18 and 64 years. Targeted health promotion that uses inclusion strategies to account for functional limitations related to paralysis can be undertaken in partnership with state and local health departments.

Public health professionals are frequently challenged when estimating prevalence for people with functional limitations characterizing their disability. Paralysis is one such condition. In 2013, the Centers for Disease Control and Prevention used a standardized definition of paralysis developed by an expert panel and funded the Paralysis Prevalence & Health Disparities Survey (PPHDS). Its goal was to estimate paralysis prevalence, causes, and health effects among the US population. We present this survey's findings.

## METHODS

The PPHDS is a national random-digit-dialed telephone survey of the civilian, noninstitutionalized US population. The survey applied dual-frame sampling of landlines and cell phones in an effort to improve coverage. The final response rate for the survey was 12.1%. To ascertain paralysis, respondents were asked: "Do you or does anyone in this household have any difficulty moving their arms or legs?" Those who answered "yes" were then asked to identify the cause of this movement difficulty. Individuals who were identified by a "yes" response to the first question and then had a specified qualifying diagnosis (i.e., spinal cord injury, traumatic brain injury, stroke, complications from surgery, amyotrophic lateral sclerosis, multiple sclerosis [MS], neurofibromatosis, Chiari malformation, syringomyelia, postpolio syndrome, spinal muscular atrophy, Friedreich's ataxia, transverse myelitis, cerebral palsy, and spina bifida) identified on the second question were classified as having paralysis. The conceptual development, methodology, and validation of survey questions are described elsewhere.<sup>1</sup>

Data were weighted to account for the probability of selection and nonresponse and to adjust for age, sex, race/ethnicity, education, region, and metropolitan status population. Data also were adjusted to account for landline or cell phone use. We calculated the prevalence and weighted population estimates of paralysis and the top 4 causes along with demographic characteristics stratified by paralysis cause. (Sample sizes were insufficient to generate stable estimates for other causes that were not stroke, spinal cord injury, MS, and cerebral palsy, so they were grouped together as "other.") Although most information was gathered about the person with paralysis, a limited number of questions were asked of the actual respondent, who was the person with paralysis in 66% of cases. Therefore, information on 2 of the demographic variables (employment status and marital status) is reported for respondents with paralysis. A total of 1305 individuals with paralysis were included in the survey. (The study interviewers dialed 2 606 709 telephone numbers, and 583 678 numbers were deemed to be eligible for survey participation. From the 583 678 eligible telephone numbers, 70 458 interviews were completed and 1305 individuals identified with paralysis.)

## RESULTS

Survey findings indicated that an estimated 1.7% of the US population live with paralysis, which represents a total of 5 357 980 people in 2013 (see the Appendix, available as a supplement to the online version of this article at <http://www.ajph.org>). Approximately 72% of the persons with paralysis were younger than 65 years. Overall, persons with paralysis were mostly female (51.7%), White (71.4%), high school graduates (64.8%), married or living with a partner (47.4%), and unable to work (41.8%). Although 29.5% had a household income between \$25 000 and \$50 000, almost an equal number (28.1%) had a household income of less than \$15 000. According to body mass index (defined as weight in kilograms divided by height in meters squared), acknowledging its limitations as a measurement tool for people with paralysis,<sup>2</sup> 61.8% of the persons with paralysis were overweight or obese; 30.5% were current cigarette smokers.

Stroke was the leading cause of paralysis, affecting 33.7% (1 804 850) of those with paralysis, followed by spinal cord injury (27.3%; 1 462 220), MS (18.6%; 999 080), and cerebral palsy (8.3%; 445 880). Noticeable variation among the top 4 conditions were seen in age (46.4% of those whose paralysis was caused by stroke were aged 65 years or older vs 4.0% of those with cerebral palsy), sex (65.7% female among those with MS, which is consistent with previous findings,<sup>3</sup> vs 45.9%–48.2% for other causes), marital status (65.8% married among those with MS vs 38.6%–46.6% for other causes), and smoking status (7.9% of those with cerebral palsy smoke vs 29.7%–38.1% for other causes). Other major differences were seen in employment status (7.1% of people whose paralysis was caused by stroke were employed vs 40.8% of those with cerebral palsy), obesity (37.8% of persons with stroke were obese vs 13.9% of those with cerebral palsy), and education status (32.3% of those with MS graduated from college vs 15.2%–22.5% of those with other causes).

## DISCUSSION

In 2009, Congress authorized the Centers for Disease Control and Prevention to implement public health activities targeted at improving the quality of life for people with paralysis and other physical disabilities.<sup>4,5</sup> Addressing the quality of life for people with paralysis first required identifying the population. This was difficult because paralysis is ill defined, and people living with paralysis are not sampled in sufficient numbers in existing surveys to accurately estimate prevalence, cause, and related health effects.<sup>1</sup> To assist with health promotion efforts directed at those living with paralysis, etiology of paralysis and associated health effects needed to be quantified. This report estimates that nearly 5.4 million persons live with paralysis in the United States and that the leading causes of paralysis include stroke, spinal cord injury, MS, and cerebral palsy. Sociodemographic and behavioral factors vary between people living with paralysis based on etiology.

According to the functional definition, paralysis affects a large segment of the US population, with about two thirds of the 5.4 million people between ages 18 and 64 years. Only 15.5% were employed, even though almost a quarter had a college education. About two thirds were underweight, overweight, or obese. More than 30% were current smokers, and among those with spinal cord injury, this prevalence was highest (38.1%). Opportunities

for people with paralysis to retain greater independence and full participation in society can be improved through a public health campaign that better illustrates the magnitude of paralysis in the United States and its related effect on conditions such as stroke, spinal cord injury, MS, and cerebral palsy that contribute to it.

Population estimates of spinal cord injury appear much higher in our study than in previous studies, and there appears to be a greater proportion of women with paralysis caused by spinal cord injury than previously thought.<sup>6</sup> One explanation is that the PPHDS was the first of its kind to estimate paralysis including both traumatic and nontraumatic spinal cord injury as a cause with a nationally representative population-based telephone survey.<sup>7-9</sup> Previous spinal cord injury estimates were obtained from registries or medical record review at Spinal Cord Injury Model Systems Centers, which represent an estimated 13% of new spinal cord injury cases, with the remainder receiving care in community hospitals.<sup>6</sup> Moreover, nontraumatic spinal cord injury caused by tumor or spinal stenosis accounts for an estimated 39% of all spinal cord injury hospital admissions.<sup>10</sup>

These findings were subject to at least 2 limitations. First, the PPHDS did not sample from persons living in institutions or group homes. Because persons with paralysis likely reside in greater proportions in such facilities, the results likely underestimated true prevalence. Second, estimates for paralysis were based on self or household member report and were not validated by medical record review. However, self- or family-reported data on paralysis status use telephone survey methodology similar to that used in other national health surveillance systems.

## PUBLIC HEALTH IMPLICATIONS

This article contributes to the literature by characterizing the prevalence and etiology of paralysis in the United States. These findings point to the importance of ongoing national surveillance to monitor the overall prevalence, causes, and associated health effects of paralysis. Targeted health promotion that uses inclusion strategies to account for functional limitations related to paralysis can be undertaken in partnership with state and local health departments. Walk, wheel, and run events are an example of such activities that include people with paralysis in physical activity in innovative ways. Physical adaptations to the built environment can be made to encourage inclusive activities for people with paralysis. These and other strategies that can be converted to more widespread public health practices are accessible through resources available at the National Center on Health, Physical Activity and Disability<sup>11</sup> and the Christopher and Dana Reeve Foundation Paralysis Resource Center.<sup>12</sup>

## Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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