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Brief Report

Using the international classification of functioning, disability and health to expand understanding of paralysis in the United States through improved surveillance

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Abstract

Background: Surveillance on paralysis prevalence has been conceptually and methodologically challenging. Numerous methods have been used to approximate population-level paralysis prevalence estimates leading to widely divergent prevalence estimates.

Objective/hypotheses: To describe three phases in use of the International Classification of Functioning, Disability and Health (ICF) as a framework and planning tool for defining paralysis and developing public health surveillance of this condition.

Methods: Description of the surveillance methodology covers four steps: an assessment of prior data collection efforts that included a review of existing surveys, registries and other data collection efforts designed to capture both case definitions in use and prevalence of paralysis; use of a consensus conference of experts to develop a case definition of paralysis based on the ICF rather than medical diagnostic criteria; explanation of use of the ICF framework for domains of interest to develop, cognitively test, validate and administer a brief self-report questionnaire for telephone administration on a population; and development and administration of a Paralysis Prevalence and Health Disparities Survey that used content mapping to back code items from existing national surveys to operationalize key domains.

Results: ICF coding led to a national population-based survey of paralysis that produced accurate estimates of prevalence and identification of factors related to the health of people in the U.S. living with paralysis.

Conclusions: The ICF can be a useful tool for developing valid and reliable surveillance strategies targeting subgroups of individuals with functional disabilities such as people with paralysis and others. Published by Elsevier Inc.

Keywords: Paralysis; Functional definition of disability; ICF; Surveillance

Estimates of paralysis prevalence in the U.S. vary widely, ranging from 1.4 to 5.4 million people.[1] In 2009, Congress authorized a three-part effort to address the public health challenges posed by paralysis.[2] The first two titles of the Christopher and Dana Reeve Paralysis Act provide the National Institutes of Health (NIH) with authority to investigate research to understand causes of paralysis in the hopes of identifying a cure, and explore clinical trials that lead to improved rehabilitation treatments. The third provision authorized the Centers for Disease Control and Prevention (CDC) to implement public health activities devoted to improving the quality of life for persons with paralysis and other physical disabilities.[3] The legislation recognized the importance of conducting accurate paralysis surveillance as the first step toward establishing a quality of life public health action plan for people with paralysis.

Prior research has noted numerous difficulties in conducting population-based surveillance of conditions associated with paralysis.[4] Variation in estimates can be attributed to different sampling strategies, sample size, and differing definitions of paralysis. Establishing an operational case definition of paralysis to more accurately screen for this condition is central to addressing these challenges.

One approach to developing a case definition for paralysis is to screen for diagnosed medical conditions associated with paralysis, and then query a given data source further to determine its functional expression, but this method presents challenges. The three diagnoses most

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directly linked to paralysis—stroke, SCI, and multiple sclerosis (MS)—can be screened for in surveys ("… have you ever received a diagnosis for …"), but each present unique difficulties in tracking paralysis. Stroke has an estimated prevalence of 7.3% in the adult U.S. population, with disability occurring in 65% of cases, but paralysis constitutes an unknown subset.[5] The disabling effects of stroke are potentially reversible and severity of stroke varies over time, making stroke-related paralysis time-dependent. SCI, another example, typically results from irreversible trauma. Prevalence estimates using SCI registries approach 280,000 people in the U.S.[6] but do not include non-traumatic causes of spinal cord dysfunction that can also lead to paralysis and are based on a subset of U.S. reporting sites that may not be representative of SCI experienced in all states.[7] MS prevalence estimates range from 58 to 95 per 100,000 adult population, translating to as many as 285,000 people with paralysis.[8–10] But symptoms of MS are frequently unpredictable, with exacerbations and remissions influenced by age, duration of disease and environmental exposures.[11]

An alternative approach is to base case identification on a functional definition of paralysis and then extrapolate likely etiology, but this approach is not without risks of its own. Reliability and validation procedures need to be considered to ensure credibility of the surveillance data and findings.[1] In addition, there is the need to identify and then build upon a conceptual framework that supports a functional operational case definition of the condition. Non-medical disability models from which to choose can be found among disablement frameworks, where disablement is considered the impact of chronic and acute conditions on specific body system functioning as well as people's abilities to act in necessary, usual, expected and personally desired ways in their society.[12–15]

When the World Health Organization released the International Classification of Functioning, Disability and Health (ICF) in 2001, it extended the disablement approach to health and health-related domains to describe changes in body function and structure, level of capacity, and level of performance.[16] A 2007 Institute of Medicine report cited this framework in calling for "… increased attention to the critical roles that the physical and social environments … play in determining the extent to which individuals with chronic physical and mental conditions can function independently and participate fully in community life."[17]

Since then, the ICF has been influential in providing a framework for understanding interactions of condition, environment and personal factors on influencing body function and structure, activities and participation.[18] Still, the slowness with which the ICF framework has been adapted to public health practice may reflect the lack of a standardized approach that is widely understood,[19] or more general "… challenges around the operationalization of the ICF's core concepts (that) need to be resolved."[20]

Despite these challenges, research has demonstrated the value of cross-mapping existing items in surveillance instruments on to the framework of the ICF.[21] Often termed "content comparison" or "back coding," it has been applied retrospectively to multiple disability-causing conditions including arthritis,[22] stroke[23] and dementia,[24] as well as globally.[25] The ICF continues to be proposed as a public health strategic planning tool,[26] and for use in applying classification schema to advance health promotion in the United States and Canada.[27]

Objectives

a) Develop a case definition of paralysis based on functional limitations;
b) Develop valid self-report procedures for paralysis; and
c) Develop a questionnaire that utilizes ICF domains and codes to facilitate consistent current and future data collection.

Methods

Objectives were realized through a multi-year project that involved four steps:

- An ***assessment of prior data collection efforts*** that included a review of existing surveys, registries and other data collection efforts designed to capture case definitions in use and paralysis prevalence;
- Use of a consensus conference to ***develop a case definition of paralysis*** based on the ICF rather than medical diagnostic criteria;
- Use of the ICF framework for domains of interest to ***develop, cognitively test, validate and administer a brief self-report questionnaire*** for telephone administration on a population basis;
- ***Development and administration of the 2013 Paralysis Prevalence and Health Disparities Survey*** that used content mapping to back code items from existing national surveys to operationalize key domains.

Results

Assessment of prior data collection efforts

In 2005, with guidance from a national expert panel, academic researchers conducted a national assessment of how paralysis was defined and how paralysis data were collected.[28] Tasks included a review of current surveys used to identify persons with paralysis; a survey of organizations representing persons with paralysis-related disabilities to