Review Article

Measures of aging with disability in U.S. secondary data sets: Results of a scoping review

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Abstract

Background: There remain significant knowledge gaps in our understanding of aging with long-term disability. It is possible that important advances in knowledge could be gained using existing secondary data sets. However, little is known regarding which of the data sets available to researchers contain the age-related measures needed for this purpose, specifically age of onset and/or duration of disability measures.

Objective: To better understand the capacity to investigate aging with long-term disability (e.g. mobility limitation) and aging with long-term chronic conditions (e.g. spinal cord injury, multiple sclerosis) using extant data.

Methods: Public use national and regional data sets were identified through existing reports, web-based searches, and expert nomination. The age- and disability-related variables, including age of onset and duration of disability, were tabulated for data sets meeting inclusion criteria. Analysis was descriptive.

Results: A total of $N = 44$ data sets were reviewed. Of these, 22 contained both age and disability variables. Within these 22 data sets, 9 contained an age of onset or duration of disability variable. Six of the nine data sets contained age of diagnosis for a single or set of health conditions. Onset of functional limitation is in two, and onset of self-reported and/or employment disability is in four, of the nine data sets respectively.

Conclusions: There is some, but limited opportunity to investigate aging with long-term disability in extant U.S. public use secondary data sets. © 2016 Elsevier Inc. All rights reserved.

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There is a need for more research to better understand life trajectories and later life outcomes for persons who are born with or who acquire impairments, functional limitations, and disabilities in early or mid-life. These individuals are often described as aging ''with'' disability, in counterpoint to persons who age ''into'' sustained disability for the first time in later life.[1]

Although the body of scientific literature related to aging with disability has grown over the past few decades, it remains quite small relative to the extensive body of empirical knowledge about older adults aging into disability. As a result, there is limited evidence to inform clinical practice, community-based programming, and public policies to support positive aging-related outcomes for this population. Research has established that, in general, individuals with disabilities have significant health, employment, and social inclusion disparities compared to their same-aged peers.[2] However, almost nothing is known regarding the effects of duration of disability or age of disability onset on key outcomes, including health and wellness, financial security, social networks and supports, community inclusion and participation in later life.

Existing research related to aging with disability consists mostly of cross-sectional studies with convenience samples of persons with a single diagnostic condition (like spinal cord injury) or a small, defined set of conditions as a primary diagnosis (e.g. multiple sclerosis, post-polio syndrome, cerebral palsy). Very few researchers have conducted population-level research based on large-scale, longitudinal, or trans-diagnostic data. Two primary

contributors to the lack of data to examine aging and disability issues are (1) the expense and difficulty of recruiting a national sample of persons aging with disability and (2) the lack of extant measures to identify persons aging with long-term impairment, functional limitation, and disability in publically available, nationally representative data. It is with this latter issue that this paper is concerned.

To address critical questions regarding the trajectory of disability and its impact over the lifespan, knowing (1) when impairment, functional limitation, or disability first started and (2) how long it has been experienced is crucial. Without time of onset or duration of disability markers, the identification of an aging "with" disability sub-group within a study population is extremely difficult. These measures are required in order to make a distinction between individuals who have a single episode of disability at the time of data collection from those with extended or ongoing patterns of disability.[3]

The current study was performed to determine the extent to which currently available data sets might be used to address important questions regarding aging with disability. To achieve this, we undertook a scoping review of public use data sets to address the following questions:

1. Which federally and state sponsored publically available data sets contain measures of both age and disability?
2. Which of these contain measures of time of onset or duration of disability?

Methods

Our initial sample consisted of forty surveys assessed by Mathematica in their scoping review of disability measures (which did not include age of onset or duration of disability).[4] This is the only relevant study we identified. To our knowledge, no other review of aging and disability measures has ever published in the peer-review or gray literature related to aging or disability. We then conducted a web-based search for additional state and national public use data sets. Following this, we searched the Interuniversity Consortium for Political and Social Research data repository (see www.icpsr.umich.edu). Finally we sought recommendations by national experts of potential data sets for inclusion.

To be included in the scoping review, data sets had to be publically available and in the English language, data collection had to take place in the year 2004 or later, adults had to be included in the sample, studies generating the data had to be based in the United States, and all studies had to be approved by institutional review boards. Studies of incarcerated populations were excluded, restricting the sample to data sets with community-residing adults. For surveys with more than one wave of data available since 2004, the most recent wave for which data documents could

be retrieved was selected for review. A structured review protocol captured a wide range of information about each data set. Our three step approach to identifying aging, disability, and onset and/or duration variables was: (1) we reviewed each data set for the inclusion of disability and aging measures; (2) we collected data attributes on those with disability and aging measures (e.g. population, sample size, survey type, domain): and (3) we collected specific measurement data on the disability and aging measures (e.g. type of measure, items in the measure, response choices). Additional information recorded included the data source, years and cycles of data collection, geography of the sample, survey domains measured.

Chronological age was derived from date/year of birth and/or chronological age at time of survey. Disability measures were broadly defined. We categorized the identified disability variables as follows: disability self-report, diagnosis of illness by a health care professional, inability to work due to disability or employment-related disability, functional, mobility, sensory and/or communication limitation, health insurance type, and disability benefit receipt. We defined aging with disability measures as either (1) time of onset of or (2) duration of any identified disability variables.

Two reviewers searched for data sets and jointly compiled two databases: 1) of all sources searched, and 2) of data sets that met the criteria for review. All data sets were reviewed by at least two researchers. A third and fourth researcher reviewed the final database of data sets for accuracy and consistency of data collection and recording.

Results

We screened a total of 363 sources and identified 44 distinct data sets that contained both aging and disability variables. We then eliminated data sets that were older than 2004 and those that did not include adults in the sample. Further, we chose to eliminate data sets of incarcerated populations. Our final sample consisted of 22 data sets that contained at least one age and one disability variable (see Table 1) in the most recently available year of data collection instruments. Over half of these surveys ($n = 12$) collect data annually. Seven had some type of longitudinal component to their study design. All 22 of the data sets had multiple measures of disability. Nearly all of the data sets ($n = 20$) had a measure of functional limitation, mainly instrument and activities of daily living (IADLs and ADLs). Nineteen had a measure of self-reported work limitation or employment disability. Disability self-report was found in fourteen data sets. Receipt of disability benefits and type of health insurance (both potential proxy measures of disability), were found in 12 and 17 data sets respectively. Twenty of the data sets inquired about the presence of at least one specific diagnostic condition, all self-reported.