Review Article

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

Michelle Putnam, Ph.D.[a,*], Ivan R. Molton, Ph.D.[b], Anjali R. Truitt, M.P.H.[b],
Amanda E. Smith, B.S.[b], and Mark P. Jensen, Ph.D.[b]

[a]Simmons College, School of Social Work, 300 The Fenway, Boston, MA 02115, USA
[b]Healthy Aging RRTC, Department of Rehabilitation Medicine, University of Washington, Box 356490, Seattle, WA 98195, USA

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.

Keywords: Aging; Disability; Secondary data; Measurement; Quantitative analysis

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.

Table 1
Public use data sets that include both age and disability variables with data collected between 2004 and 2015 ($N = 22$)

Name of data set and year reviewed	Survey freq.	Age variables			Disability variables					
		Date of birth	Age in years	Age of Dx, disabil. onset	Employ. status or employ. disabil.	Funct. status (ADL, IADL)	Receipt of disabil. benefits	Health insur. type	Disabil. self-report	Specific diagnostic or health condition
1. American Community Survey (2015)	A	X	X		X	X	X	X	X	X
2. American Housing Survey (2013)	B	X	X			X	X		X	X
3. American Time Use Survey (2013)	A	X	X		X					X
4. Behavioral Risk Factor Surveillance System (2014)	A		X	X	X	X		X	X	X
5. CA Health Interview Survey (2013−14)	B	X	X	X	X	X	X	X	X	X
6. Current Population Survey (2014)	C	X	X		X	X		X	X	X
7. Health and Retirement Study (2014)	B[+]	X		X	X	X	X	X	X	X
8. Medical Expenditure Panel Survey (2013)	A[+]	X	X	X	X	X		X	X	X
9. Medicare Current Beneficiary Survey (2103)	A	X			X	X	X	X		X
10. Medicare Health Outcomes Survey (2015)	A	X				X				X
11. National Beneficiary Survey (2010)	W = 4		X	X	X	X	X	X	X	X
12. National Health and Aging Trends Study (2013)	A[+]	X	X		X	X		X	X	X
13. National Health & Nutrition Exam. Survey (2013−14)	A		X	X	X	X		X	X	X
14. National Health Interview Survey (2015)	A	X	X		X	X	X	X	X	X
15. National Social Life, Health & Aging Project (2011)	W = 2[+]	X		X	X	X				X
16. National Survey of Midlife Development in the United States II: (2004−06)	W = 2[+]	X			X	X	X	X		X
17. National Survey of OAA participants (2013)	A*		X			X				X
18. National Survey of Veterans (2010)	W = 1	X			X	X	X	X	X	
19. National Survey on Drug Use and Health (2015)	A	X	X		X	X		X		X
20. Panel Study of Income Dynamics (incl. Disability & Use of Time II Supplemental Survey) (2013)	B[+]		X	X	X	X	X	X	X	X
21. Survey of Consumer Finances (2013)	T	X			X		X	X		
22. Survey of Income and Program Participation (2008)	A**, [+]	X	X	X	X	X	X	X	X	X

A = Annual, B = Biannual, C = Continuous, T = Triennial, A* = There are no data sets for 2006 and 2007, A** = Annual data collected from 4 year panels, W = Number of data waves, [+] = Longitudinal, Dx = Diagnosis, ADL = Activities of daily living, IADL = Instrumental activities of daily living.

Only 9 of the 22 data sets contained a variable that inquired about age of disability onset (i.e., age of disability, chronic condition, impairment, or age of diagnosis of a disabling condition by a medical professional).

Table 2 presents the nine data sets that we identified as having age of onset or disability duration variables. Four of these data sets were longitudinal; however, two of these follow sample panels for relatively short periods of time. The Medical Expenditure Panel Survey (MEPS) follows its sample for two years. The Survey of Income and Program Participation (SIPP) follows its panel for four years. In contrast, the Health and Retirement Study (HRS) and the Panel Study of Income Dynamics (PSID) follow participants from time of first interview until death or when the sample member is consistently unreachable. To date, the HRS has 14 waves of (since 1993) and the PSID has 39 waves of data collection (since 1968). Two of the data sets, the HRS and National Social Life, Health, & Aging Project (NSHAP) are designed to study older adults. The other seven have samples across the age continuum. Seven of the data sets use the household as the sample frame. Two survey a single individual only.

In regards to age of onset and duration of disability variables, Table 2 lists the type of variable(s) identified and if present, the specific diagnostic or health conditions in the response set corresponding to the respective data set's onset measures. All of the nine surveys contained age of diagnosis variables with the exception of the National Beneficiary Survey (NBS), which asked about the onset of work limitation only and then followed up with a question about the condition causing of the work limitation. Three of the nine data sets, the Behavioral Risk Factor Surveillance System (BRFSS), the California Health interview survey (CHIS), and the NSHAP were quite limited in their reporting of disability in terms of the conditions, the time of onset and/or diagnosis variables. BRFSS and CHIS asked only about onset of diabetes and NSHAP asked additionally about one other diagnosis, cancer. HRS had the largest set of diagnostic and health conditions available in its codebook of any of the nine data sets, with more than 250 specific conditions listed. Within the HRS survey there was an open question asking study participants to disclose any conditions she or he (or her or his spouse) had. Interviewers code this back to the condition index. Three of the nine surveys inquired about intellectual disability — e.g. learning disability, mental retardation, cognitive disability. Four surveys inquired about mental health conditions. Onset of functional limitation was inquired about in two surveys, HRS and the SIPP. Onset of disability, including work and/or employment related, was asked about in four data sets. These were the HRS, SIPP, NBS, and PSID. Age at time of injury was asked about in the HRS and SIPP only. Specific survey item text and a more detailed alignment of age of onset and age of diagnosis variables with specific condition response sets are available to readers in Supplemental File 1 or from the authors.

Discussion

Based on the scoping review findings, there are very few options for identifying a sub-sample of persons aging with long-term disability within extant public use secondary data sets. Of the nine data sets we identified that contained age of onset or duration of disability measures, only six have potential to draw together sub-samples of individuals reporting different diagnostic conditions. Within these six, many of the diagnostic conditions (e.g. high blood pressure, bronchitis, lung disease) would likely be treated as indications of secondary health conditions, rather than as measure of a primary impairment or diagnosis (i.e., spinal cord injury).[5] Thus, the utility of using specific conditions in some of these data sets for creating an aging with disability sub-sample is very limited. Moreover, age of diagnosis of a condition by a health care professional does not necessarily equate to age at time of disability onset. Although an individual receiving a diagnosis may have physiological symptoms, these do not necessarily result in impairment or contribute to functional limitation or disability. Using an age of diagnosis variable in conjunction with a measure of age of onset of functional limitation, work limitation and/or disability, could provide information about the length of time between diagnosis and onset of limitations or disability. That said, in lieu of better measures, age of diagnosis would permit segmentation of a study sample into individuals aging with and without diagnosed chronic conditions.

Age at time first experienced function limitation and disability (including work or employment disability) may be the most useful variables for identifying a sub-sample of individuals aging with disability within existing data sets. This approach aligns more closely with social models of disability, which define disability as an experience rather than a physiological condition.[6] Most surveys we identified with onset of functional limitations or onset of disability measures also contained questions about their severity. This offers the possibility of grouping an aging with disability sub-sample by severity level of functional limitation or disability for a more refined analysis.

Longitudinal analysis of four years or more is possible within the HRS, PSID, and SIPP data sets, which holds some promise for understanding trends related to aging with disability. For example, Clarke and Latham (2014) used a variable measuring work limitation in the PSID to analyze trends in health and socioeconomic profiles over a period of thirty years. They defined persons aging with disability as individuals reporting a work disability in at least four waves of data collection between a fourteen-year period (ages 22—49) or prime working age. Using growth curve models, they found consistently lower rates of employment, income, and functional independence over time attributable to disability status.[7] This approach has merit. However given the lack of standard procedures for creating an aging with disability sub-sample, there is likely

Table 2

Types of age on onset variables found in public use data sets with data collected between 2004 and 2015 ($N = 9$)

Name of data set and year reviewed	Sample frame and age range	Onset measure	Specific diagnostic or health conditions in the response set corresponding to the onset measures
1. Behavioral Risk Factor Surveillance System (2014)	Individual, 18 and older	X^1	Diabetes
2. CA Health Interview Survey (2013−14)	Household, 1 adult & children	X^1	Diabetes
3. Health and Retirement Study[+] (2014)	Respondent, 50 or older & spouse	X^1 X^2 X^3 X^4	Difficulty seeing, asthma, diabetes, speech impairment, respiratory disorder, heart trouble, allergic condition, epilepsy or seizures, headaches or migraines, stomach problems, high blood pressure, depression, other emotional or psychological problems, drug or alcohol problems, open responses coded to a list of 250 conditions.
4. Medical Expenditure Panel Survey[+] (2013)	Household, all members & ages	X^1	High blood pressure, heart disease, stroke, emphysema, cancer, diabetes, arthritis, asthma, attention deficit hyperactivity disorder/attention deficit disorder
5. National Beneficiary Survey (2010)	Individual, 18-full retirement age	X^4	Collapsed into mental illness, cognitive disability, muscular/skeletal and sensory disorders
6. National Health & Nutrition Exam. Survey (2013−14)	Household, all members & ages	X^1	Arthritis, gout, congestive heart failure, coronary heart disease, angina, heart attack, stroke, emphysema, thyroid, chronic bronchitis, any kind of liver condition, cancer
7. National Social Life, Health, & Aging Project (2011)	Respondent, age 62−90 & spouse	X^1	Cancer, diabetes or high blood sugar
8. Panel Study of Income Dynamics[+] (incl. Disability & Use of Time II supplemental survey) (2013)	Household, all members & ages	X^1 X^4	Learning disorder, allergic condition, angina, any emotional, nervous, or psychiatric problems, arthritis or rheumatism, asthma, cancer or a malignant tumor, chronic ear problems or infections, chronic lung disease, congestive heart failure, coronary heart disease, depression, diabetes, difficulty seeing, drug or alcohol problems, epilepsy or seizures, heart attack, heart trouble, high blood pressure or hypertension, permanent loss of memory or loss of mental ability, respiratory disorder, severe headaches or migraines, speech impairment, stomach problems, stroke, other serious, chronic condition, general work limitation
9. Survey of Income and Program Participation[+] (2008)	Household, all members & ages	X^1 X^2 X^3 X^4	Alcohol or drug problem or disorder, AIDS or AIDS related condition, arthritis or rheumatism, back or spine problems, blindness or vision problems, broken bone/fracture, cancer, carpal tunnel syndrome, cerebral palsy, deafness or serious trouble hearing, diabetes, epilepsy or seizures, head or spinal cord injury, heart trouble (heart attack/disease), hernia, high blood pressure, kidney stones/kidney trouble, learning disability, lung or respiratory trouble, mental or emotional conditions, mental retardation, missing limbs/foot/hand/finger, multiple sclerosis (MS), paralysis of any kind, stiff/deformed/foot/hand/finger, stomach trouble, stroke, thyroid trouble or goiter, tumor, cyst or growth, other

X^1 = Age at time of diagnosis of impairment or chronic condition, X^2 = Age at time of injury, X^3 = Age at time first experienced functional limitation, X^4 = Age at time first experienced disability, [+] = Longitudinal.

utility in comparing different approaches to sample construction to assess variations in sample traits and characteristics based on the type of disability measure used including chronic condition, work limitation, functional limitation, and disability self-report.

Importantly, as can be seen in Supplemental File 1, our review identified notable variation among surveys in their approach to understanding disability and its onset. For example, the HRS asks a comparatively extensive series of health and activity related questions about chronic conditions, functional limitation, disability that would permit a distinctly different analysis than could be achieved with the PSID, which inquires mainly about disability's interference with employment. That said, in our view, the HRS and PSID appear to be the best data sets for investigating aging with disability and believe that thoughtful analytical designs using data from these data sets could produce important findings from each one.

Study limitations

An important study limitation was the inclusion of only public use data sets in the scoping review conducted in English and based in the United States. Although we reviewed a large number of data sets, we do not know what the potential of privately held data is to study persons aging with disability or data from other nations or in other languages. Of course, privately held data are more difficult to access as are foreign data sets often. A second limitation is that we report on only the most recent year of a study's data collection. It is therefore possible that we may have missed age of onset or diagnosis data collection in previous survey waves.

Conclusion

Our findings indicate that the current potential to use existing secondary publically available data sets to study the aging with disability population is limited. We identified only a small number of data sets where a sub-sample of persons aging with long-term disability can be created for separate or comparative analysis. This lack of data acts as a barrier to furthering our understanding of how trajectories of disability contribute to health, social, and financial disparities over the life course. It is a significant impediment to developing evidence-based knowledge that supports positive aging outcomes for persons aging with long-term disability acquired in early or mid-life. These data limitations can be reduced by the inclusion of time of onset and duration of disability variables in more public-use data sets that contain age and disability measures.

Acknowledgment

Supplementary data

Supplementary data related to this article can be found at http://dx.doi.org/10.1016/j.dhjo.2015.07.002.

References

1. Monahan D, Wolfe D. The continuum of disability over the lifespan: the convergence of aging with disability and aging into disability. *Disabil Health J*. 2014;7:S1–S3.
2. Brucker DL, Houtenville AJ. People with disabilities in the United States. *Arch Phys Med Rehabil*; 2015. http://dx.doi.org/10.1016/j.apmr.2015.02.024.
3. Verbrugge L, Yang L. Aging with disability and disability with aging. *J Disabil Policy Stud*. 2002;12(4):253–267.
4. Livermore G, Whalen D, Prenovitz S, Aggerwal R, Bardos M. *Disability Data in National Surveys*. Retrieved from: http://mathetmatica-mpr.com; 2011. on April 15, 2015.
5. Molton IR, Terrill AL, Smith AE, et al. Modeling secondary health conditions in adults aging with physical disability. *J Aging Health*. 2014;26(3):335–359.
6. Brandt E, Pope A. *Enabling America: Assessing the Role of Rehabilitation Science and Engineering*. Institute of Medicine. Washington, D.C: National Academy Press; 1997.
7. Clarke P, Latham K. Life course health and socioeconomic profiles of Americans aging with disability. *Disabil Health J*. 2014;7:S15–S23.