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Brief Report

Identifying adults aging with disability using existing data: The case of the Health and Retirement Study

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ABSTRACT

Background: The population of persons aging with disabilities is growing. Being able to segment aging with disability sub-populations within national data sets is becoming increasingly important in order to understand the relationship of aging with disability to a range of outcomes in later life including health and wellness, economic security, and health and long-term service and support need and use.
Objective: The purpose of this study was to identify viable sub-samples of adults aging with disabilities within the Health and Retirement Study, one of the most used secondary data sets to study aging and older adults.
Method: Samples used in this research are drawn from wave 11 (2012) of the HRS. Five operationalizations of disability were used: childhood disability (n = 719), childhood chronic condition (n = 3070), adult chronic condition (n = 13,723), functional limitation in adulthood (n = 4448) and work disability (n = 5632).
Results: These subsamples are not mutually exclusive. Among respondents that reported having a childhood disability, 87% also report having at least one chronic disease in adulthood, 50% report having functional limitations in adulthood and 38% report interruption in their ability to work due to a disability. Compared to the childhood disability samples, rates of reporting fair/poor health are nearly double among adults with functional limitations or those with work disruptions because of disability.
Conclusion: Work disability and functional limitation appeared to be the most viable sub-sample options to consider when using the HRS to study experiences of adults aging with disability. Overall, age at onset is unclear.

Exploring what it means to age with a long-term disability is a new frontier in the aging and disability discourse.[1,2] Aging with disability is an umbrella term that includes persons with any type of disability that had its onset before later life. Prevalence estimates vary based on the definition of disability, but recent (2014) data from the American Community Survey suggest that 36% of older adults and 12% of the general adult population are living with disability. A recent scoping review published in *Disability & Health* determined that research in this area is limited, in part, because of a serious lack of appropriate data sources.[3] As a result, our ability to understand the aging with disability experience is limited.

The current literature related to aging with disability suggests that there are important differences in aging with disability related to medical diagnosis (e.g. intellectual disability, spinal cord injury). However it also suggests that people aging with disability share common experiences related to things like employment, social inclusion and barriers to participation. We are hindered in particular, at this time, in generating population-level knowledge about life course trajectories, engaging in comparative analysis, or identifying trends in virtually all areas of social, economic, and health outcomes because of limitations in our data sets. This limits our ability not only to understand the experience of aging with disability, but also to identify areas where interventions are needed to improve outcomes.

The diversity by which disability is defined in existing data prevents the coalescence of evidence about what it means to age with a disability. For example, disability has been defined by enrollment in benefit programs and in other cases by having a

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sensory impairment.[4,5] Although there is variation in the definition of disability across surveys, functional limitations are used to identify working-age adults with disabilities in the American Community Survey (ACS), Current Population Survey (CPS), and Medical Expenditure Panel Survey (MEPS). However, this measure of disability does not address age at onset nor does it provide detail about disability cause or type. Functional limitations could be associated with a chronic illness like multiple sclerosis or with an intellectual disability like Down's syndrome.

The Health and Retirement Study (HRS) was identified in the previous review as one of the only existing public data sources that contains measures of disability onset, which is a required variable for segmenting the aging with disability population.[3] The HRS is a nationally representative panel survey of Americans age 50 or older. Thus, the purpose of this brief report is to explore the feasibility of constructing of sub-samples within in the HRS and evaluate their viability for studying aging with disability.

Methods

Sample

We created five sub-samples for this analysis, drawn from wave 11 (2012) of the Health and Retirement Study (HRS). We used the RAND HRS Data file (Version N). The RAND HRS Data file is a user-friendly, longitudinal data set created from original HRS data by the National Institute on Aging and the Social Security Administration (RAND, 2011).The HRS is a nationally representative, cohort panel study of older adults in the U.S. Beginning with the initial wave collected in 1992, HRS has included repeated measures on an individual and spouse's health insurance status, assets, work status, family structure, and physical health and functioning. Given the highly stratified sample design of the HRS, sample weights provided by the HRS are used in the analyses of these data. The weights are adjusted, or centered, for use in all analyses. The five definitions of disability are described below based on the disability onset measures available in the HRS.

Sample 1: Childhood disability

Experiencing disability during childhood may result in accumulated impairment over the life course.[6] Retrospective reports of childhood disability were asked of all respondents starting with HRS Wave 9 (2008): “Before you were 16 years old, were you ever disabled for six months or more because of a health problem? That is, were you unable to do the usual activities of classmates or other children your age?” A dichotomous variable was created, where yes = 1. Childhood disability was used as a measure of early-life physical functioning. Respondents were asked to provide specific childhood disability diagnoses if they answered yes to this question. Respondents are only allowed to report only one main cause of childhood disability. The top three most commonly reported causes of childhood disability include: other musculoskeletal or connective tissue problems; “other” health condition; and other circulatory problems. The frequency with which each diagnosis was recorded varies greatly and unsuitable for creating sub-categories of childhood disability type.

Sample 2: Childhood health condition

Experiences of chronic disease in childhood have been linked to lifetimes of disease and disability.[7] Also in Wave 9 (2008), a similar retrospective question was asked of all respondents for the first time in HRS's history related to their physical functioning before age 16, “Were there any other important or serious health problems that you had before age 16 that you could tell me about?” A dichotomous variable was created where yes = 1. Childhood health condition was used as a measure of early-life physical health. Specific health condition diagnoses were attainable but much like Childhood Disability, the frequency with which each diagnosis was recorded varies greatly thus limiting its usability. The top three most commonly reported causes of childhood health condition include: other health condition; allergies; and other musculoskeletal or connective tissue problems.

Sample 3: Adult functional limitations

Adult functional limitation was defined as having difficulty with any one of six activities of daily living (ADLs), including dressing, bathing, eating, getting in or out of bed, walking across a room, and using the toilet or any one of 5 instrumental activities of daily living (IADLs), including cooking, shopping, using the telephone, taking medication or managing money. These are self-reported responses to questions about difficulty. For example, “Because of a health or memory problem do you have any difficulty with dressing, including putting on shoes and socks?”. A dichotomous variable was constructed where Yes = 1. ADLs are basic activities necessary for personal care and generally are an indicator of a greater level of disability or frailty than IADLs, which are activities more closely related to the ability to live independently.[8]

Sample 4: Adult chronic condition

The presence of or absence of chronic conditions for each respondent was based on self-reported physician diagnosis with a question stem: “Has a doctor ever told you …”. The 2012 HRS asks about only seven chronic conditions. These were: high blood pressure, diabetes, cancer, lung disease, heart condition, arthritis, and stroke. A dichotomous variable was created to where 1 = respondent self-reported physician diagnosis of at least one ailment, 0 = otherwise. Diagnosis of at least one chronic illness in adulthood used as a measure of physical health in adulthood.

Sample 5: Adult work limitation

Work limitation is a lesser studied disability construct[9]; but an important one to understand as it relates to life course experiences of living with disability. To assess the impact of disability in adulthood on work, HRS asks, “Do you have any impairment or health problem that limits the kind or amount of paid work you can do?” A dichotomous variable was created where Yes = 1.

These five dichotomous variables were independently used as sample selection criteria to create five conceptually unique populations of adults aging with disability in order to compare their sociodemographic and health characteristics.

Measures & analysis

Age at disability onset

In order to identify samples of adults aging with disability versus those aging into disability, some measure of onset is required. Table 2 outlines the disability onset variables available in the HRS. As noted above, onset age of childhood disability and/or chronic condition is embedded in the question about presence of disability. No specific onset age is obtained in supplemental questions and there is no information about the duration of those childhood conditions. Respondents who report work limitations are explicitly ask about the year and month in which the health problem first began to bother the respondent. Using these dates and the respondent's current age, a rough description of age at onset was calculated. In addition to giving the date of onset, respondents are also offered three additional onset-related responses: *all of Respondent's life*, *does not remember, onset was gradual*, and *does not bother the respondent*. Onset date of functional limitations is asked, but only at the time of exit interview. Exit