# Aging with Disability among Midlife and Older Adults

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## TOPIC

"Aging with disability" means a person has persistent functional problems over years, even decades. The topic is typically studied for young adults with severe functional problems from birth or acquired during childhood/adolescence. Although germane for all age groups, aging with disability is a neglected topic for midlife and older persons. For those ages, the emphasis is change (onset of and recovery from disability) rather than long-term continuation. Yet for many middle-aged and older persons, disability persists after it begins, sometimes for the rest of life. Survivors with disability from birth/childhood are also in these ages. Regardless of when persistent disability happens in the life course, people face protracted problems for accomplishing goals, must adapt daily life and attitudes, and may feel angry or depressed.

## THEORETICAL FOCUS AND BACKGROUND

### Aging with Disability

Given the longstanding view that "aging with disability" pertains to young people, the research literature has focused on children, adolescents, and young adults. Most studies are about specific conditions, such as cerebral palsy, muscular dystrophy, Down syndrome, spinal cord injury. (See journals such as Disability and Rehabilitation, Disability and Society, Disability Studies Quarterly, American Journal of Mental Retardation.) Some studies are stretching age ranges as people with specific conditions survive into their 30's and older. Researchers who study aging with disability are often clinicians or rehabilitation specialists involved in patient care, so the studies are usually about patients. Sample sizes are modest. Population-based data on young adults with persistent disability are rare (exceptions are several surveys conducted by the National Center for Health Statistics and the National Organization on Disability/Harris). Overall, research on young adults with long-term disability shows a two-sided story of lost opportunities and blunted achievements, but high resilience and coping abilities. With regard to health over time, people with early-onset physical disability have high chances of "accelerated aging" in middle and older ages (Klingbeil et al., 2004). Due to the body's limited ability to accommodate age-related changes, they are more likely to experience secondary conditions, accelerated impairment, and more cumulative impairments (Klingbeil et al., 2004; Pentland et al., 1995; Thompson, 1999; Verbrugge, Yang, 2002). In sum, people with early-onset disability show strong psychological and social adaptation, but their physical adaptation is limited.

In recent decades, some government agencies and scientists have tried to broaden perspectives about aging with disability to include all ages (Ansello, Eustis, 1992; Kennedy, 2002; Putnam, 2007). Remarkably, resistance to this has occurred from many sides, ranging across service agencies, advocacy groups, organizations focused on specific age groups, medical and rehabilitation staff, and even persons with disabilities. To help alleviate this, three government agencies recently sponsored a conference "Aging with Disability: Demographic, Social, and Policy Considerations" (Washington, D.C., May 2012), with presentations from scientists, medical and service professionals, and advocacy representatives of 'all stripes' (Disability and Health Journal, 2014). Other strong momentum for an all-ages perspective comes from "The Toronto Declaration on Bridging Knowledge, Policy and Practice in Aging and Disability" (Bickenbach et al., 2011).

### Patterns of Disability

Scientifically, aging with disability is a "disability pattern". Defined, it is persistent disability recorded over a long time period, and it is just one of many potential patterns.

The research literature on disability patterns is longstanding. It has been largely for older adults, using large-scale population and patient-based surveys. Katz and colleagues were the first group to study disability patterns (Katz, Akpom, 1976; Katz et al., 1970). The notion had great appeal because it could summarize individuals readily. During the 1970's-1980's, analyses were mostly cross-sectional, studying combinations of disabilities people have at a given time. Research gradually shifted to mostly longitudinal analyses, as interest in disability transitions rose and longitudinal datasets became available. Currently, the research focus is trajectories of disability over time.

How are trajectories identified? Researchers can chose *a priori* patterns of keen interest (Ferrucci et al., 1996; Latham, 2012; Verbrugge, Yang et al., 2004), and review the detailed data visually or find them by simple computer programs (Bowling et al., 1994; Carlson et al., 1998; Charlton, 1989; Fortinsky et al., 1999; Verbrugge, Balaban, 1989). An alternative to this is to generate simple quantitative measures, such as individual-level means or variability over time (Beckett et al., 1996; Jette et al., 1987; Maddox, Clark, 1992; Verbrugge, Reoma et al., 1994). A big shift has occurred in recent years, with contemporary statistical techniques that allow researchers to find patterns in fully computer-based and probabilistic ways (Gill et al., 2010; Li, 2005; Nusselder et al., 2005; Taylor, Lynch, 2004; Zimmer et al., 2012). Once best-fit trajectories are obtained, descriptive review is still essential to name the patterns.

## ANALYSIS DESIGN AND HYPOTHESES

We use large-scale survey data to identify disability trajectories for mid and late life adults, using contemporary statistical techniques. When the best-fit set of trajectories is found, they are graphed with age along the X axis, and predicted probability of disability (or predicted number of disabilities) along the Y axis. The graphs show slopes over time for the trajectories, and differences in levels across them. Trajectories are named by examining the characteristics of individuals in different trajectory groups using baseline and over-time characteristics that distinguish class membership.

Then, multivariate models are estimated that predict trajectory classes. Anticipating that an aging with disability class is obtained: We hypothesize that low socioeconomic status (education, income, wealth) and poor health are associated with persistent disability. Next, models consider how class membership affects outcomes. We hypothesize that aging with disability is linked with lower income, not in labor force status, depression, nursing home residence, and earlier mortality.

If the hypotheses are supported, our results tally with those for young adults.

This is the first analysis of aging with disability for midlife and older persons using large-scale survey data for the U.S. resident (community dwelling and nursing home) population.

## DATA AND METHODS

Data Source. The project involves secondary analysis of data from the Health and Retirement Study (HRS) (hrsonline.isr.umich.edu). HRS is an ongoing longitudinal panel survey of Americans over age 50 (thus, ages 51+) conducted by the Survey Research Center, University of Michigan. Primary funding is from the National Institute on Aging, with additional support from the Social Security Administration. Almost all HRS data are public-use, and data files can be downloaded for no cost. We use the RAND HRS, a user-friendly data set for all waves of HRS data prepared by the RAND Corporation (www.rand.org/labor/aging/dataprod.html). The current RAND M file has data through 2010.

Analysis Sample. The first wave of HRS was in 1992, with persons ages 51-61. In 1998, the AHEAD survey, which began with persons ages 70+ in 1993 (Soldo et al., 1997), was merged with HRS, thus adding older persons. The HRS sample is refreshed every six years (1998, 2004, 2010), adding new people ages 51-56. If a sampled person has a spouse/partner (any age), s/he is included in the HRS sample. All people are community-dwelling at first interview. Participants have followup interviews every two years. They are eligible for followups even if changes occur in marital status or residence type (e.g., nursing home). The total number of persons interviewed in recent HRS waves is ~18,000 - 20,000.

*The analysis sample for this project is HRS participants over age 50 in 1998, plus 2004 added-sample persons ages 51-56*. (1) Among the 1998 sample, some had their first interview in 1992, and others were new as of the 1998 added sample. (2) For the 2004 added sample, all had their first interview that year. (The added sample is currently a bit broader than ages 51-56; we may trim it back.) (3) We do not use the 2010 added-sample because they have just 1 wave of data in the RAND M data file. *In short, the analysis studies all U.S. residents ages >50 for the period 1998-2010 (with the caveat of 2010 ages 51-56 excluded).*

We start the analysis at 1998 rather than 1992, because the HRS disability variables changed during the 1990's. They stabilized as of 1998 and have been consistent since then. Our 1998 sample has 7 waves of data (1998-2010), and the 2004 added-sample has 4 waves (2004-2010).

Our sample N is 23,745 persons (85% from the 1998 group, 15% from the 2004 group). For the 1998 group, their initial (1998) features are 57% female, 83% white nonHispanic, mean education 11.9 years, and mean age 67. For the 2004 group, initial (2004) features are 50% female, 76% white nonHispanic, mean education 12.9 years, and mean age 55.

<u>Disability Measures</u>. Disability is defined as health-related difficulty doing personal care (ADL, activities of daily living), health-related difficulty doing household management (IADL, instrumental activities of daily living), and physical limitations (PLIM). (1) ADL items cover 6 tasks (dress, bathe/shower, eat, walk across room, get in and out of bed, using the toilet including getting up or down). Disability is scored present for a task if the person has health-related difficulty, personal help (except people with "no difficulty"), or equipment help. (2) IADL items cover 5 tasks (prepare hot meal, shop for groceries, make phone calls, take medications, manage own money). Disability is scored present for a task if the person has health-related difficulty, or personal help for health reason; equipment help for health reasons is not ascertained for IADLs. (3) PLIM items cover 9 tasks (walk one block, sit about two hours, get up from chair, climb one flight stairs, stoop/kneel/crouch, lift/carry ten pounds, pick up dime from table, reach/extend arms up, push/pull large object). Disability is scored present for a task if the person has any difficulty doing it because of a health or physical problem.

The disability variables were created from "raw" data in the RAND file; we do not use the sums that the RAND file provides. For our initial analyses, we are using any ADL disability (0-1), any IADL disability (0-1), and number of PLIMs (0-9). ADLs and IADLs are strongly skewed at 0, while PLIMs have a broader distribution. As the analysis continues, we may try counts of ADLs and IADLs.

The HRS data have several limitations for documenting aging with disability. (1) Onset and duration are problematic. Some persons enter HRS with disability present at first interview; we do not know its actual time of onset. For others without disability at first interview, they might have had disability episodes, long or short, in prior years. There is no remedy to such truncation, and we must take first interview as the starting point for identifying persistent disability. (Important note: the 1998 sample provides data for three waves before our analysis period, but those data are excluded in our analysis design; see Disability Measures.) (2) Disability between interviews is unknown. There are unobserved onsets, recoveries, and persistence. (3) HRS participants can miss one or more waves, or not answer disability questions during an interview. The statistical procedures we use are designed to find patterns using each person's available data without imputation.

<u>Predictors</u>. Sociodemographic and health characteristics influence disability experience over time. For the models that predict trajectory class membership and outcomes, we use age, gender, race/ethnicity, education (years completed), income, wealth, living arrangement (alone vs with others), marital status, and employment status. For health, we use self-rated health, count of chronic conditions, health behaviors, and access to medical care. Some of the variables are fixed (gender, race/ethnicity, education). For time-varying predictors, we use baseline values. This makes sense because we want to know how "early" features affect subsequent trajectories.

"Baseline" needs explication. The values are the first wave in our analysis window. For the 1998 group, this is respondents' third interview. For the 2004 group, it is their first interview. In both instances, "baseline" is an artifact of when someone enters HRS. Whether the measures represent the best timing for predicting disability trajectories is unknown, but --in their favor-- they are close in time to the observed disability experience.

Outcomes. Longitudinal experience of disability influences social wellbeing, psychosocial status, and length of life. For the models that predict how trajectory class membership affects such outcomes, we will study income, depression, living arrangement (alone vs with others), nursing home residence, and dead. The outcomes are measured at final wave, by timing (e.g., survival analysis), or perhaps in cumulative ways (e.g., number of waves in nursing home). These models come late in the analysis, and we have yet to choose the specific variables and model designs.

Analysis Procedures. We use generalized growth mixture modeling to identify latent classes of individuals according to their trajectories of disability adulthood. Growth mixture modeling (GMM) is an extension of conventional growth modeling that relaxes the assumption of a single population trajectory (Muthen, Muthen, 2000). By using latent trajectory classes (categorical latent variables), the growth mixture model allows different classes of individuals to vary around different mean growth curves.

The measurement part of the model captures the growth factors (intercept and slope) as measured by multiple indicators of disability over time. Age is used as the indicator of time creating a synthetic cohort from ages 51 through 100. In order to facilitate parameter interpretation, we center age at the initial point of data collection (setting age 51 to 0). The structural part of the model incorporates the growth model within a larger latent variable model by relating the growth factors to other observed and latent variables. Of particular interest is the latent trajectory class variable, which represents the unobserved subpopulation of membership for respondents. This allows a separate growth model for each of the latent classes.

Model building proceeds in a sequential process by first specifying the growth model and then incrementally increasing the number of latent classes. While substantively-based theory is used as the primary means to determine the best fitting model, good fitting models are characterized by (a) a low value for the Bayesian Information Criterion (BIC) and Akaike Information Criterion (AIC), (b) a statistically significant (low p-value) Lo-Mendell-Rubin (LMR) likelihood ratio test, and (c) distinct posterior probabilities for individual class membership. All models were estimated in Mplus Version 7.2 using full information maximum likelihood (FIML) with robust standard errors. Multiple random starts were used to minimize local optima in the likelihood. Our statistical model allows for respondents with as little as one observation to enter the model. Additionally, by including variables related to attrition (age, education, marital status, health status), maximum likelihood produces unbiased coefficients under the assumption that the attrition process is conditional on observed variables in our models (McArdle, Hamagami, 1992; Cnaan et al., 1997; Feng et al., 2006).

To date, results produce 2-3 trajectories. As work continues, we hope the number does not exceed 4-5, since that complicates our ability to name the trajectories, and also the subsequent multivariate modeling. To name the trajectories, we use observed data and find sociodemographic and other features that distinguish the classes. We also review a sample of cases in each class to see what their observed disability data are over time.

Second, models that predict type of trajectory are designed and estimated with GMM. Time invariant sociodemographic covariates predict class membership in a logistic regression. We have some time-varying covariates, and there are potential reciprocal relationships (e.g., income affects disability, and vice versa). GMM can handle both, so subsequent models will include them.

Latent class growth analysis (LCGA) gives probabilities for all classes to an individual. However, in the end, each individual can be assigned to a single most-likely class. By doing this, we can generate some standard descriptives. We will estimate prevalence rates for the trajectories, with differentials by age and gender. This yields useful information about the "aging with disability" population (and the other longitudinal patterns) for Americans.

Third, as a general extension of the growth mixture model we include distal outcomes, asking how class membership affects them. For example, models can show how disability trajectory affects mortality risk, income (last wave), or depression (last wave), controlling for sociodemographic characteristics (age, gender, race/ethnicity, education), and health histories.

Data management is conducted with SAS (www.sas.com). The data are then imported to Mplus (www.statmodel.com), which has excellent GMM procedures. A fine example of an analysis using the steps and techniques discussed above is Clarke et al. (2010).

Analytic Matters

(1) Complex variances. The HRS sample design is a multistage area probability sample of U.S. households, suitable for household and individual-level analyses (Heeringa, Connor, 1995; also hrsonline.isr.umich.edu/meta/weightsinfo.html). For complex sampling designs like HRS, correct variances require special procedures (Lee, Forthofer, 2006). Mplus has a complex-variances routine specified as an option, and we will use it. (2) Weights. Weights are needed to obtain unbiased estimates of population parameters and model effects. Weights include nonresponse adjustments; this handles respondents who drop out of the study or miss a wave. Weights are available in the data file for community-dwelling respondents at each wave. Nursing home respondents are given weight = 0. For our substantive goals, nursing home persons are just as important as community dwellers, and they must be kept in weighted analyses. We have tested several weighting options, and opted to use the "mean community dweller weight" for this project. This is defensible, albeit not the most sophisticated option. (Based on advice 09/14, we may modify that a bit.) The LCGA procedure permits one weight for a respondent, not wave-specific weights, so we use a respondent's initial weight in the data window (1998 or 2004). (3) Missing data. We will evaluate item and wave missing data (MD) for our sample. To date, descriptive data for disability, predictors, and outcomes show very little MD; this is in part due to RAND's effort to minimize it by imputation. Besides this, LCGA and GMM are variable-based techniques, that use all available data to best advantage; separate imputation operations are not needed. (4) Proxy. HRS interview can be completed by a proxy if the panel person does not do so. We will use all existing interviews, whether self- or proxy-reported.

FINDINGS

[At abstract submission 09/14, disability variables have been prepared and checked. A file with disability, predictor, and outcome variables is prepared, and we have descriptives for the sample. A suitable weighting procedure for nursing home residents was chosen, with statistical consultation. First runs for trajectories show good fits for 2-3 classes for ADL, IADL, and PLIM. In coming months, we will finish the trajectory modeling, and do the detailed evaluations to name trajectories. To date, results suggest a class with persistent disability (aging with disability), and we hope to confirm that. Then multivariate models to predict class membership will be done, and lastly multivariate models to predict outcomes for the classes.]

DISCUSSION AND CONCLUSION

Our scientific purpose is to document prevalence of aging with disability for U.S. adults in mid and later life, and to understand its precursors and consequences. For purposes of public health planning and public attitudes, the analyses help stretch notions of "aging with disability" from just youth to all ages. We hope the project encourages more research on aging with disability for midlife and older persons, and will disseminate its results in that spirit. Eventually, as research on aging with disability for middle and older ages increases, an integrated corpus of knowledge across all ages will emerge, and programs and policies that are age-blind rather than age-targeted will be possible.

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