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1

Title: The devil's in the details: variation in how estimates of late-life activity limitations across national cohort studies

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Running head: Disability across surveys

Key Points:

- We identify wide variation in the assessments of activity limitations across three large studies of older adults commonly used in research: the Health and Retirement Study, National Health and Aging Trends Study, and Medicare Current Beneficiaries Survey
- This variation in the way activity limitations are assessed has implications for the size and the level of illness of populations identified to have activity limitations
- Each approach has unique strengths; researchers as well as health systems and clinicians seeking to implement assessments of activity limitations should pay careful attention to the framing of questions based on their purpose

Why does this paper matter?

Capturing activity limitations is highly important to aging researchers. However, we found that in three large and commonly-used cohort studies of aging, assessments of activity limitation vary widely, which has implications for the populations identified.

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Abstract:

Background: Assessing activity limitations is central to aging research. However, assessments of activity limitations vary, and this may have implications for the populations identified. We aim to compare measures of activities of daily living (ADLs) and resulting prevalence and mortality across three nationally-representative cohort studies: the National Health and Aging Trends Study (NHATS), the Health and Retirement Survey (HRS), and the Medicare Current Beneficiary Survey (MCBS).

Methods: We compared the phrasing and context of questions around help and difficulty with six self-care activities: eating, bathing, toileting, dressing, walking inside, and transferring. We then compared the prevalence and 1-year mortality for difficulty and help with eating and dressing.

Results: NHATS, HRS, and MCBS varied widely in phrasing and framing of questions around activity limitations, impacting the proportion of the population found to experience difficulty or receive help. For example, in NHATS 12.4% [95% confidence interval (CI) 11.5-13.4%] of the cohort received help with dressing, while in HRS this figure was 6.4% [95% CI 5.7%-7.2%] and MCBS 5.3% [95% CI 4.7%-5.8%]. When combined with variation in sampling frame and survey approach of each survey, such differences resulted in large variation in estimates of the older population of older adults with ADL disability.

Conclusions: In order to take seriously late-life activity limitations, we must clearly define the measures we use. Further, researchers and clinicians seeking to understand the experience of older adults with activity limitations should be careful to interpret findings in light of the framing of the question asked.

Key words: functional impairment, public health, geriatrics

Background:

Clinicians, health systems, and policy makers have increasingly focused on measures of function—the ability to perform activities—rather than diseases alone to identify older adults in need of support. This focus is warranted, given that for older adults with limitations in self-care activities may lose the ability to participate in meaningful activities¹ and need to rely on unpaid family and friends or paid sources for regular assistance.² Furthermore, older adults with activity limitations are at risk for higher mortality compared to their peers without limitations,³⁻⁵ symptoms such as pain and dyspnea,^{6,7} and high health care use,^{8,9} including hospital readmissions¹⁰ and hospitalization at the end of life.¹¹

Numerous clinical and survey-based assessments have been developed to measure limitations in self-care activities in later life. The original Katz Index of Independence in Activities of Daily Living (ADLs)¹² was a clinical assessment of older adults' ability to live independently. It measured independent performance on essential self-care activities such as bathing, dressing, toileting, transferring, continence and feeding. Similarly, the Barthel index¹³ has been used in clinical settings to assess independence in essential self-care activities and mobility.¹²⁻¹⁴ A review of activity limitation indexes that was published more than three decades ago demonstrated wide variation in measurement approaches and lack of attention to patient “effort” (e.g. difficulty) or “collaboration” (e.g. use of assistive devices).¹⁵ Over the years, these additional conceptual distinctions – e.g. differences in consideration of receipt of help, use of devices and difficulty performing activities – have been incorporated into national surveys.

Prior comparisons of national surveys, both in the cross-section and over time, have demonstrated that these distinctions influence estimates of the population size and characteristics of those identified as having disability.^{16-18 19, 20} This paper compares estimates from three large and nationally-representative cohort studies, the National Health and Aging Trends Study (NHATS),²¹ the Health and Retirement Study (HRS),²² and the Medicare Current Beneficiary Survey (MCBS).²³ While other population-based surveys also capture the older adult population, NHATS, HRS and MCBS are particularly important resources for understanding the prevalence, predictors, and outcomes of disability among older adults in the United States given their size, representativeness, and link to Medicare claims data. Estimates from HRS and MCBS have been previously compared; however, comparisons with NHATS are lacking.^{19, 20}

NHATS, HRS, and MCBS use different approaches to assess activity limitations, in part due to conceptual distinctions that may influence identification of the population living with activity limitations.²⁴ These surveys differ in how measures of function relate to their larger goals: MCBS aims to assess function as an aspect of health status over time to evaluate the Medicare program,²³ HRS aims to examine function as a component of health as it changes over time at the individual and population level,²² and the NHATS aims to assess the consequences of late-life disability with an emphasis on capturing the environment (both caregiving and physical) that older adults are in.²¹ These differences in study aims are demonstrated in multiple differences in how activity limitations are assessed. For example, NHATS examines a broader range of questions around caregiver and device assistance with tasks and then asks about difficulty in independent functioning specifically, while as HRS and MCBS capture

difficulty regardless of whether a task is conducted independently, and focus questions of assistance on those who report difficulty.^{25, 26}

Understanding the variation in measures of activity limitation across the NHATS, HRS, and MCBS surveys is important for both researchers and for clinicians seeking to understand the experience of patients with higher functional needs. This is a complex challenge given that not only do measures of activity limitations vary across the surveys, but so do the sampling approaches and survey methods used by each survey. We therefore aimed to compare activity limitation assessments incorporated into each survey while attempting to account for these other differences across the surveys. We contrast the size and subsequent 1-year mortality of the populations identified as having limitations in each of these activities in each study. We assessed mortality in order to compare how ill individuals were when they were identified as having limitations. On balance, we expect design differences across the surveys to yield higher numbers of older adults reporting help and reporting difficulty by oneself in NHATS (due to more comprehensive identification, as described below) than in HRS or MCBS. Further, we expect that NHATS may identify more transient cases of limitations and we therefore expect mortality rates among those with limitations to be lower in NHATS than HRS or MCBS.

Methods:

We drew data from the 2016 NHATS, HRS, and MCBS surveys. While each is a nationally-representative survey, they vary in their sampling frame and approach:

NHATS: Conducted annually since 2011, NHATS was designed to assess population-level trends and individual-level dynamics in disability.²¹ The initial NHATS cohort included more than 8,000

adults age ≥ 65 , drawn from the Medicare enrollment file, with the cohort refreshed in 2015.

The NHATS sampling frame is drawn from the Medicare enrollment sample, with over-sampling at older age groups and those identified as Black individuals on the enrollment file. Initial response rates for NHATS were 70.9% in 2011 and 62.8% for the replenishment cohort in 2015, with follow-up rates ranging from 85.6% to 96.2%. NHATS is conducted in-person, with proxies (typically a family member) interviewed if a respondent is unable to participate.

HRS: Conducted every two years since 1992, the HRS was designed to assess the health and economic conditions of aging Americans.²² The HRS cohort contains adults age ≥ 51 and their spouse if they are married: approximately 20,000 people total. The HRS sample frame is a listing of households in sampled areas of the U.S., with over-sampling of Floridians, African American, and Hispanic older adults. HRS response rates range from 81.6-89.4%. Through 2016 HRS was conducted in-person or by telephone, with additional leave-behind and mail surveys, and similarly uses proxy reporters if needed.

MCBS: Conducted annually since 1992, the MCBS was designed to assess the payments for all services used by Medicare beneficiaries and to assess changes in the health and health care use experience of Medicare beneficiaries.²³ The MCBS has interviewed over 100,000 Medicare enrollees, with individuals added to the cohort each year and followed for 4 years, unlike the HRS and NHATS, which follow cohorts indefinitely. The MCBS conducts three in-person interviews per year, with one of the three collecting data on function. The MCBS sampling frame is drawn from the Medicare enrollment sample, with those age ≥ 85 oversampled. The

2016 response rate for MCBS was 47.9%, among all eligible for the survey (not specific to those already in the cohort, given that no data was reported from the 2015 MCBS).²⁷

Study sample:

For each study, we used 2016 data to identify respondents ages ≥ 70 , residing in the contiguous United States, not living in nursing home settings, and enrolled in Medicare (Medicare Advantage or Traditional Medicare). We focused on individuals age ≥ 70 as we had more confidence this population would be representative across surveys given that NHATS refreshes their cohort every 5 years. We used these criteria to define equivalent subgroups within each study.

Activity Measures:

We included all questions relating to performance of the following activities: eating, bathing, toileting, dressing, walking inside, and transferring. As illustrated in Table 1, NHATS, HRS, and MCBS vary in their approach to assessing these items. Here we highlight key differences:

Phrasing of activities: The language used to describe each activity varied. For some activities, the surveys varied in the extent of detail used to describe the specific components of a task. This may prompt older adults to more carefully consider whether they receive any help or experience difficulty with any aspect of a task. For example, while MCBS asks about eating, HRS and NHATS specify eating or cutting food. Similarly, MCBS asks about dressing, HRS specifies

dressing including putting on shoes and socks while NHATS specifies “getting dressed, for instance, by getting clothing over your head, helping with clothing behind your back like a belt [or bra], or helping put on socks or shoes?” For other activities, the surveys varied in how the task was defined. For example, in defining transferring, NHATS asks about getting out of bed, HRS asks about getting in or out of bed, and MCBS asks about getting in or out of bed or chairs.

Temporal patterns: NHATS frames most of its questions about an individual’s activities in the last month. HRS asks respondents if they “have” difficulty and if they “ever” get help after instructing them to focus on limitations that are expected to persist for at least 3 months. MCBS asks about current limitations regardless of expected duration, and also asks separately if the impairment is expected to persist 3 months from now, thus including activity limitations that the individual perceives as temporary.

Skip patterns, attribution, and type of difficulty: While all three surveys ask about help and difficulty with activities, they vary in the order in which items are asked, skip patterns (skipping some questions based on prior responses), and the type of difficulty assessed. HRS and MCBS begin with difficulty items and then ask about help; however, HRS limits its difficulty and help questions to those with difficulty dressing or with difficulty performing at least one of the following: walking several blocks, climbing a flight of stairs, stooping, kneeling, or crouching, carrying ≥ 10 pounds, picking up a dime from a table. For its activity limitation questions HRS does not specify the circumstances under which the respondent should report difficulty (e.g. with/without help or devices); MCBS asks about underlying difficulty (without help or devices). HRS and MCBS ask about difficulty as a dichotomized yes/no, but NHATS asks about difficulty in

terms of none/a little/some/a lot. Both the HRS and MCBS then ask those who either report difficulty or who “do not do” an activity if they receive help. By contrast, NHATS first asks about how activities have been carried out in the last month (e.g. with assistive devices, with help), then questions about difficulty are tailored to responses about how activities are carried out. For those who did not receive help all the time, NHATS asks about difficulty carrying out activities independently (but with devices if used). In addition, NHATS asks about changes in behavior (doing an activity less often) and consequences of not receiving help.²⁴

Additional measures:

We include in our analysis sociodemographic characteristics measured in all three studies including age, sex, race/ethnicity, marital status, and education. Race/ethnicity was self-reported in the HRS, MCBS, and NHATS surveys. Non-nursing home residential care setting was reported using slightly different definitions across each survey.²⁸ In order to assess the relative health of beneficiaries across surveys, we included self-reported health, categorized as fair/poor vs. excellent, very good, or good.²⁹ Mortality over the 12 months following NHATS, HRS, or MCBS survey was identified from Medicare claims. Mortality data were not available for MCBS enrollees in their 4th and final year of participation in the MCBS cohort in 2016 and so only those in their first 3 years of MCBS participation were included to calculate mortality. The full MCBS cohort was used for all other analyses.

Analysis:

We first compared the demographic composition and health for the individuals meeting inclusion criteria in 2016 from NHATS, HRS, and MCBS. This was the most recent year that we

had data from all surveys, including 1-year mortality follow-up. We then chose two activities, dressing and eating, with relatively similar phrasings of the task across surveys and compared the rates of help and difficulty across the surveys. Given differences in survey skip patterns, we made several assumptions. NHATS only asks about difficulty by oneself for those who report that they at least rarely conduct the ADL by themselves, in other words, they do not always rely on others. Given that HRS and MCBS do not make that distinction, we classified every NHATS respondent who never conducted the activity by themselves as having difficulty. In NHATS, we categorized having “a little” “some” or “a lot” of difficulty as “having difficulty” to align with the dichotomized measure in HRS and MCBS. In HRS, respondents are not asked about difficulty or help unless they report at least one functional limitation or difficulty dressing. We therefore assumed that HRS respondents skipped for this reason did not have difficulty and did not receive help with any of the activities. Given that HRS and MCBS only assess help among those with difficulty, in NHATS we measured the proportion who had difficulty or help all the time among those receiving help (thus aligning with the HRS/MCBS skip patterns) and among the entire cohort regardless of difficulty.

Next, we compared the 1-year mortality rates among those with help dressing, difficulty dressing, help eating, and difficulty eating. In order to ensure that the activities we focus on (dressing and eating) were not different than other activities in patterning, we provided more detailed information on all six activities in HRS and NHATS in a Supplementary Appendix. In order to account for differences in mortality rates across the surveys, we additionally calculated the marginal increase in mortality for each activity over that survey’s mean population mortality rate as a sensitivity analysis.

We used the Stata version 16.0 *svy* commands to account for survey weighting and design, as specified in the technical guidance for each survey. This study was approved by the Mount Sinai Institutional Review Board.

Results:

We identified 5,596 respondents in NHATS, 6,698 respondents in HRS, and 8,417 respondents in MCBS who were age ≥ 70 , not living in nursing home settings, and in the contiguous United States in 2016. Details on the sample excluded due to residing in nursing home settings are in the Supplementary Appendix. As demonstrated in Table 2, mean age, proportion female, and race were similar across surveys. NHATS identified more older adults in residential care settings (6.3% [95% Confidence Interval 5.6%-7.1%] vs. 1.7% [1.3%-2.3%] in HRS and 3.0% [2.4%-3.6%] in MCBS). The proportion of married respondents was lower in NHATS compared to HRS and MCBS (50.6% [49.1%-52.2%] vs. 54.2% [52.4%-56.1%] and 54.1% [52.5%-55.8%]). More HRS respondents (29.1% [27.4%-30.8%]) reported fair/poor health compared to NHATS (23.1% [21.8%-24.4%]) and MCBS (17.2% [16.0%-18.3%]). However, MCBS had the highest rate of relying on proxies to conduct the interviews (8.0% [7.2%-8.7%]) compared to NHATS and HRS (5.3% [4.7%-6.0%] and 5.1% [4.4%-5.9%]). Across the surveys, NHATS had the highest 1-year mortality (5.1% [4.5%-5.8%]), followed by HRS (4.0% [3.5%-4.5%]), then MCBS (3.1% [2.7%-3.6%]).

When comparing dressing and eating we found notable differences in prevalence. Across both activities, NHATS identified the most older adults reporting help or difficulty, and MCBS identified the fewest (Figure 1). For example, in NHATS 12.4% [11.5-13.4%] of the cohort

received help with dressing, while in HRS this figure was 6.4% [5.7%-7.2%] and MCBS 5.3% [4.7%-5.8%]. NHATS identified 18.0% [16.9%-19.2%] as having difficulty dressing (or never dressing without assistance) while in HRS this was 11.6% [10.6%-12.6%] and MCBS 7.5% [6.9%-8.2%]. These differences were partially but not totally explained by skip patterns. Omitting from the NHATS estimates those who received help but had no difficulty by themselves when using devices (shown in pixelated color in Figure 1), the prevalence using NHATS was closer to that in HRS and MCBS, which do not ask those without difficulty about receipt of help. For receiving help with dressing, this restriction lowered the NHATS estimate for help with dressing to 9.9% [9.1%-10.8%].

Looking across all activities (Supplementary Appendix Tables 2 and 3), NHATS identified higher proportions than HRS of individuals who receive help and who report difficulty (columns 1 and 2). The proportions who receive help among those with difficulty (or in NHATS, with difficulty or didn't do the activity by themselves) also differed between the two studies (Supplementary Tables 1 and 2, column 3), suggesting differences are not solely attributable to skip patterns. Proportions were nearly identical for toileting and dressing, but were higher for bathing, transferring and walking using HRS and higher for eating using NHATS.

Although the surveys identified varying proportions of older adults with help and difficulty in dressing and eating, the populations identified did not differ appreciably across the three studies in terms of 1-year mortality rates (Figure 2). Mortality rates were the higher among those who received help with eating: 20.7% in NHATS, 24.8% in HRS and 17.9% in MCBS; and the lower among those who reported difficulty with dressing: 13.2% in NHATS, 11.7% in

HRS, and 8.9% in MCBS. Moreover, marginal increases in mortality from survey-specific population mortality rates did not differ by survey, with the exception of those with difficulty eating, who had a slightly lower marginal increase in mortality in MCBS (see Supplementary Appendix).

Discussion:

Across three large nationally-representative cohort studies of older adults, the NHATS, HRS, and MCBS, measures of help and difficulty with six self-care activities vary widely. While we were able to identify equivalent subgroups of older adults with similar demographic profiles, the proportions receiving help or reporting difficulty varied across studies. This appears to be at least partially driven by variations in concepts being measures and associated wording given that among those reporting difficulty in NHATS and HRS, similar proportions received help. When reducing variation from these skip patterns, such as examining the proportion receiving help among those who have difficulty, HRS and NHATS were more comparable for dressing and toileting, although still very different for the other activities.

Consistent with prior studies, the way function is assessed influences estimates of the proportion of the population of older adults identified as living with activity limitations, which has implications for researchers as well as for clinicians attempting to identify populations with activity limitations.^{18, 26} Our findings provide several new insights. We found that limiting assessment of help to those reporting difficulty results in lower estimates of the population receiving help than asking the entire population if they receive help. Why this is the case is not clear. It may be that some individuals are reluctant to admit difficulty. If this is the case, then

assessing help among those who respond that they have difficulty will bias downward estimates of assistance in HRS and MCBS. Additionally, questions that include more detail about the activity (for example, providing examples of assistance with putting on clothes or shoes vs. just stating dressing) appear to yield higher prevalence.²⁶ Previous research has demonstrated that ambiguously worded questions yield lower (presumably under-) estimates of difficulty and this same logic may apply to estimates of assistance.²⁶ Variation could also stem from differences in the perceived cause and course of limitations, as HRS and MCBS ask participants to include only limitations that are expected to persist for 3 months and only if it is due to a “physical, mental, emotional, or memory problem” (in HRS) or “physical, mental, or emotional condition” (in MCBS). In contrast, NHATS captures help in the last month without these restrictions.

For researchers interested in caregiving, work with the NHATS has the advantage of asking about help of everyone, not only those with difficulty. While not all of these individuals receiving help are experiencing difficulty when they carry out the activity on their own (with devices if used), they may be at higher risk for future difficulty or unmet care needs. In addition, this group reporting help but not difficulty when completing a task on their own is an interesting population for future study: for example, they may have cognitive impairment and thus require cueing or supervision but not experience difficulty while conducting the task, or they may simply have more individuals present to assist them if desired but not needed due to difficulty.

Limitations:

While accounting for survey weights and design allowed us to identify nationally representative cohorts that were well aligned in terms of age, sex, education, and race, it did appear that the three cohorts varied by marital status (with a slightly greater proportion unmarried in NHATS, perhaps linked to that study's more comprehensive identification of individuals living in residential care settings^{21, 30}), mortality, use of proxy respondents, and self-reported health. Notably, as Table 1 demonstrates, three indicators which one would expect to identify a high-need population - fair/poor self-reported health, mortality, and proxy respondents - appear to trend in different directions, with fair/poor health highest in HRS, mortality and residential care highest in NHATS, and proxy respondents highest in MCBS. In addition, the surveys varied in phrasing, making it challenging to pinpoint which variation is most responsible for differences in the populations identified. Finally, we are unable to assess the nursing home-dwelling population, a major limitation of this study, given that HRS, NHATS, and MCBS take different approaches to sampling older adults in institutional settings.

Nevertheless, with the groups matched so closely by age, race, sex and education, it is likely that the survey questions are more likely to drive differences in rates of activity limitations. This conclusion is consistent with prior research that has demonstrated that question wording has substantial influence on population estimates of late-life disability when administered within a single study.³¹ While the nuance in definitions that NHATS uses may be appropriate if disability is the predominant focus of research, especially given that it does appear to effectively capture a larger population of older adults with activity limitations, the simpler approach of HRS and MCBS may be more pragmatic for research that does not have disability as its central focus.

Our analysis provides lessons researchers interested in studying older adults with high care needs. Given the variation in approaches that fall under “ADL” assessment, for the sake of clarity we recommend researchers minimize use of the ADL abbreviation and instead specify the measures and activities under study. In addition, as clinicians, health systems, and insurers seek to utilize measures of function to identify those with high needs or to measure outcomes, it is important to better understand the implications of differing approaches to screening for self-care limitations. These distinctions in the framing and language around self-care activities appear to greatly influence our ability to appropriately identify and support this population of older adults with limitations in basic self-care activities. As we understand that differences in the type of laboratory test or imaging studies influence the sensitivity or specificity to detect a disease, so too must we better understand how measurement approaches affects the detection of late-life activity limitations.

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References:

1. Oh A, Gan S, Boscardin WJ, et al. Engagement in Meaningful Activities Among Older Adults With Disability, Dementia, and Depression. *JAMA Intern Med.* Apr 1 2021;181(4):560-562. doi:10.1001/jamainternmed.2020.7492
2. Wolff JL, Spillman BC, Freedman VA, Kasper JD. A National Profile of Family and Unpaid Caregivers Who Assist Older Adults With Health Care Activities. *JAMA Intern Med.* Mar 2016;176(3):372-9. doi:10.1001/jamainternmed.2015.7664
3. Gill TM, Gahbauer EA, Han L, Allore HG. Trajectories of disability in the last year of life. *N Engl J Med.* Apr 1 2010;362(13):1173-80. doi:10.1056/NEJMoa0909087
4. Landi F, Liperoti R, Russo A, et al. Disability, more than multimorbidity, was predictive of mortality among older persons aged 80 years and older. *J Clin Epidemiol.* Jul 2010;63(7):752-9. doi:10.1016/j.jclinepi.2009.09.007
5. Ankuda CK, Levine DA, Langa KM, Ornstein KA, Kelley AS. Caregiving, Recovery, and Death After Incident ADL/IADL Disability Among Older Adults in the United States. *J Appl Gerontol.* Apr 2020;39(4):393-397. doi:10.1177/0733464819826842
6. Covinsky KE, Lindquist K, Dunlop DD, Yelin E. Pain, functional limitations, and aging. *J Am Geriatr Soc.* Sep 2009;57(9):1556-61. doi:10.1111/j.1532-5415.2009.02388.x
7. Smith AK, Currow DC, Abernethy AP, et al. Prevalence and Outcomes of Breathlessness in Older Adults: A National Population Study. *J Am Geriatr Soc.* Oct 2016;64(10):2035-2041. doi:10.1111/jgs.14313
8. Reichard A, Gulley SP, Rasch EK, Chan L. Diagnosis isn't enough: Understanding the connections between high health care utilization, chronic conditions and disabilities among U.S. working age adults. *Disabil Health J.* Oct 2015;8(4):535-46. doi:10.1016/j.dhjo.2015.04.006
9. Fried TR, Bradley EH, Williams CS, Tinetti ME. Functional disability and health care expenditures for older persons. *Arch Intern Med.* Nov 26 2001;161(21):2602-7. doi:10.1001/archinte.161.21.2602
10. Greysen SR, Stijacic Cenzer I, Auerbach AD, Covinsky KE. Functional impairment and hospital readmission in Medicare seniors. *JAMA Intern Med.* Apr 2015;175(4):559-65. doi:10.1001/jamainternmed.2014.7756

11. Kelley AS, Ettner SL, Morrison RS, Du Q, Sarkisian CA. Disability and decline in physical function associated with hospital use at end of life. *J Gen Intern Med*. Jul 2012;27(7):794-800. doi:10.1007/s11606-012-2013-9
12. Katz S, Ford AB, Moskowitz RW, Jackson BA, Jaffe MW. Studies of Illness in the Aged: The Index of ADL: A Standardized Measure of Biological and Psychosocial Function. *JAMA*. 1963;185(12):914-919. doi:10.1001/jama.1963.03060120024016
13. Collin C, Wade DT, Davies S, Horne V. The Barthel ADL Index: a reliability study. *International disability studies*. 1988;10(2):61-3. doi:10.3109/09638288809164103
14. Hartigan I. A comparative review of the Katz ADL and the Barthel Index in assessing the activities of daily living of older people. *International journal of older people nursing*. Sep 2007;2(3):204-12. doi:10.1111/j.1748-3743.2007.00074.x
15. Feinstein AR, Josephy BR, Wells CK. Scientific and clinical problems in indexes of functional disability. *Ann Intern Med*. Sep 1986;105(3):413-20. doi:10.7326/0003-4819-105-3-413
16. Gill TM, Gahbauer EA. Evaluating disability over discrete periods of time. *J Gerontol A Biol Sci Med Sci*. Jun 2008;63(6):588-94. doi:10.1093/gerona/63.6.588
17. Wiener JM, Hanley RJ, Clark R, Van Nostrand JF. Measuring the activities of daily living: comparisons across national surveys. *Journal of gerontology*. Nov 1990;45(6):S229-37. doi:10.1093/geronj/45.6.s229
18. Gill TM, Robison JT, Tinetti ME. Difficulty and dependence: two components of the disability continuum among community-living older persons. *Ann Intern Med*. Jan 15 1998;128(2):96-101. doi:10.7326/0003-4819-128-2-199801150-00004
19. Freedman VA, Crimmins E, Schoeni RF, et al. Resolving inconsistencies in trends in old-age disability: report from a technical working group. *Demography*. Aug 2004;41(3):417-41. doi:10.1353/dem.2004.0022
20. Freedman VA, Spillman BC, Andreski PM, et al. Trends in late-life activity limitations in the United States: an update from five national surveys. *Demography*. Apr 2013;50(2):661-71. doi:10.1007/s13524-012-0167-z
21. Freedman VA, Kasper JD. Cohort Profile: The National Health and Aging Trends Study (NHATS). *Int J Epidemiol*. Aug 1 2019;48(4):1044-1045g. doi:10.1093/ije/dyz109
22. Sonnega A, Faul JD, Ofstedal MB, Langa KM, Phillips JW, Weir DR. Cohort Profile: the Health and Retirement Study (HRS). *Int J Epidemiol*. Apr 2014;43(2):576-85. doi:10.1093/ije/dyu067

23. Adler GS. A profile of the Medicare Current Beneficiary Survey. *Health care financing review*. Summer 1994;15(4):153-63.
24. Freedman VA. Adopting the ICF language for studying late-life disability: a field of dreams? *J Gerontol A Biol Sci Med Sci*. Nov 2009;64(11):1172-4; discussion 1175-6. doi:10.1093/gerona/glp095
25. Verbrugge LM, Jette AM. The disablement process. *Social science & medicine (1982)*. Jan 1994;38(1):1-14. doi:10.1016/0277-9536(94)90294-1
26. Freedman VA. Implications of asking "ambiguous" difficulty questions: an analysis of the second wave of the asset and health dynamics of the oldest old study. *J Gerontol B Psychol Sci Soc Sci*. Sep 2000;55(5):S288-97. doi:10.1093/geronb/55.5.s288
27. (OEDA) CfMMSCOoEDaA. *MCBS 2016 Methodology Report*. 2018:118. 11/16/2018. Accessed 2/10/2022. <https://www.cms.gov/Research-Statistics-Data-and-Systems/Research/MCBS/Downloads/MCBS2016MethodReport508.pdf>
28. Toth M, Martin Palmer LA, Bercaw LE, et al. *Understanding the Characteristics of Older Adults in Different Residential Settings: Data Sources and Trends* 2020. October 2020. Accessed 2/10/2022. <https://aspe.hhs.gov/reports/understanding-characteristics-older-adults-different-residential-settings-data-sources-trends-0#exhibit1>
29. DeSalvo KB, Bloser N, Reynolds K, He J, Muntner P. Mortality prediction with a single general self-rated health question. *Journal of General Internal Medicine*. 2006/03/01 2006;21(3):267. doi:10.1111/j.1525-1497.2005.00291.x
30. Toth M, Martin Palmer LA, Bercaw LE, Voltmer H, Karon S. *Trends in the use of Residential Settings among Older Adults Issue Brief*. 2020. Accessed September 2, 2021. <https://aspe.hhs.gov/reports/trends-use-residential-settings-among-older-adults-issue-brief-0>
31. Rodgers W, Miller B. A comparative analysis of ADL questions in surveys of older people. *J Gerontol B Psychol Sci Soc Sci*. May 1997;52 Spec No:21-36. doi:10.1093/geronb/52b.special_issue.21

Table 1. A comparison of six self-care activity questions in NHATS, HRS, and MCBS

	NHATS	HRS	MCBS
Specific phrasing of task:			
Eating			•
Eat or cut food	•	•	
Shower, take a bath, or wash up	•		
Bathing or showering		•	•
Use the toilet	•		
Using the toilet, including getting up and down		•	•
Dressing [examples of assistance with clothes or shoes]	•		
Dressing [including assistance with shoes and socks]		•	
Dressing			•
Get around inside home	•		
Walking across a room		•	
Walking			•
Getting out of bed	•		
Getting in or out of bed		•	
Getting in or out of bed or chairs			•
Time reference			
General or ever		•	•
In the last month	•		
Expected duration			
Regardless	•		•
Only if expected to persist 3 months from now		•	•
Attribution of difficulty or help			
Regardless	•		
Because of a physical, mental, emotional, or memory problem		•	•
Type of difficulty assessed			
If activity is conducted without help or special equipment			•
If activity is conducted by oneself with devices if used	•		
Not specified		•	
Ordering and skip patterns			
Only asks those with difficulty (or doesn't do) about help		•	•
Only asks those who conduct activity by themselves about difficulty	•		
Assumes those who can perform a battery of tasks and dressing without difficulty can perform all other activities without help or difficulty		•	
Assistive devices			
For every ADL	•		•
For showering, toileting, walking, transferring		•	
Other elements of ADLs			
Asks about both direct help and help "staying nearby"			•
Asks about consequences of not having help	•		
Asks about frequency	•		
Asks about changes in frequency compared to 1 year ago	•		
Asks about duration of time receiving help	•		•

Table 2. Characteristics of a common subpopulation across surveys: community dwelling adults age 70 residing in the Continental United States, 2016

Characteristic, % (95% CI)	NHATS (N=5,596)	HRS (N=6,698)	MCBS (N=8,417)
Age (mean)	78.2 (78.0-78.4)	78.1 (77.8-78.4)	77.9 (77.7-78.0)
Female	56.5 (54.9-58.0)	55.9 (54.9-56.9)	56.7 (55.3-58.0)
Race/ethnicity:			
White, non-Hispanic	80.8 (79.6-81.8)	81.2 (78.5-83.7)	79.2 (77.2-81.3)
Black, non-Hispanic	8.3 (7.8-8.8)	8.8 (7.7-10.0)	8.2 (6.7-9.7)
Other, non-Hispanic	3.8 (3.2-4.6)	2.3 (1.8-3.1)	5.1 (4.3-5.9)
Hispanic or Latino	7.2 (6.4-8.0)	7.7 (5.7-10.4)	7.4 (6.1-8.8)
Married	50.6 (49.1-52.2)	54.2 (52.4-56.1)	54.1 (52.5-55.8)
High school or greater education	81.8 (80.6-82.9)	82.6 (80.4-84.6)	82.1 (80.7-83.6)
Fair/poor self-reported health	23.1 (21.8-24.4)	29.1 (27.4-30.8)	17.2 (16.0-18.3)
Residing in a residential setting ²	6.3 (5.6-7.1)	1.7 (1.3-2.3)	3.0 (2.4-3.7)
Proxy respondent	5.3 (4.7-6.0)	5.1 (4.4-5.9)	8.0 (7.2-8.7)
1-year mortality ¹	5.1 (4.5-5.8)	4.0 (3.5-4.5)	3.1 (2.7-3.6)

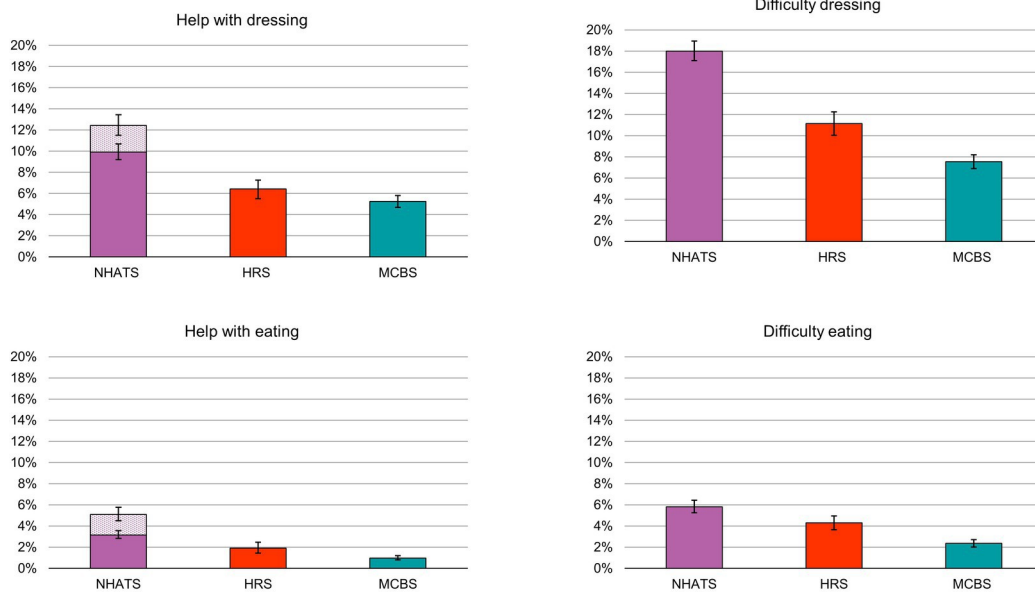
Data source: National Health and Aging Trends Study (NHATS), Health and Retirement Survey (HRS) and Medicare Current Beneficiary Survey (MCBS), 2016. ¹Given that MCBS follows individuals for 4 years and does not collect information beyond that 4 years, 12-month mortality was calculated from individuals in their 1st, 2nd or 3rd year of observation in MCBS (N=7,135). ²Generally, a location that offers services for assistance with care, although specific definitions vary across surveys

Figure 1. Proportions reporting help and difficulty with dressing and eating across nationally-representative surveys of older adults. Data from 2016 Health and Retirement Study (HRS), National Health and Aging Trends Study (NHATS), Medicare Current Beneficiaries Survey (MCBS). Respondents were age 70 years and older, residing in the Continental United States. All proportions are adjusted for survey weighting and design. The pixelated portion of the NHATS population receiving help with dressing and eating represents those who

received help but did not report difficulty with that activity. For HRS and MCBS, those who did not report difficulty were not asked about receiving help, so this population would not be captured in those surveys.

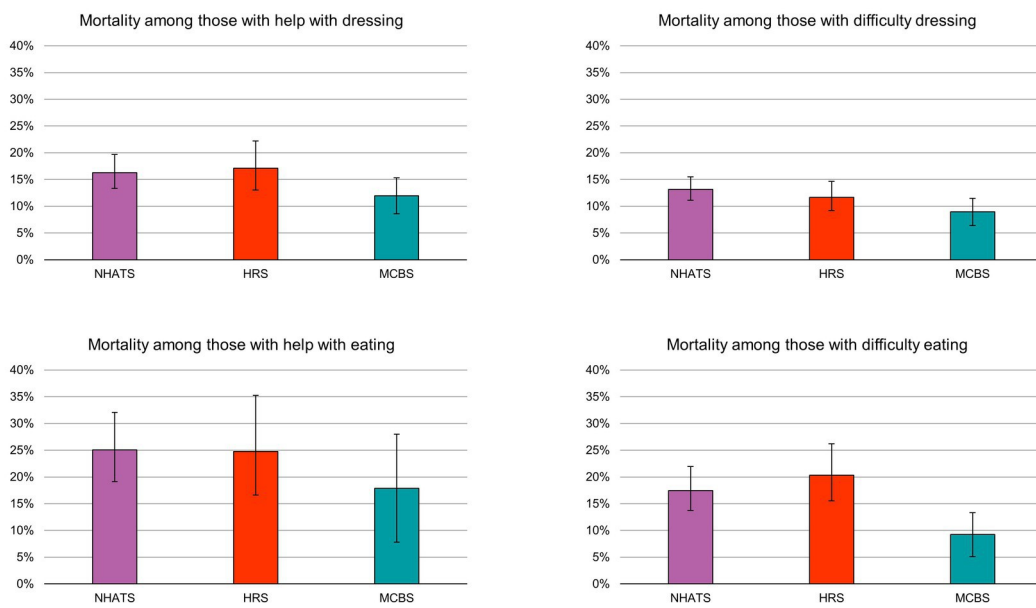
Figure 2. Differences in 1-year mortality rates across nationally-representative surveys among those with impairments in dressing and eating. Data from 2016 Health and Retirement Study (HRS), National Health and Aging Trends Study (NHATS), Medicare Current Beneficiaries Survey (MCBS). Respondents were age 70 years and older, residing in the Continental United States. All proportions are adjusted for survey weighting and design. Given that MCBS only follows respondents for 4 years (including to observe mortality), data for MCBS only included those in their first 3 years of observation in 2016.

Proportions reporting help and difficulty with dressing and eating across nationally-representative surveys of older adults



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Differences in 1-year mortality rates across nationally-representative surveys among those with impairments in dressing and eating



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