EXTENDED ABSTRACT

Alternative Measures of Self-Reported Disability

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The provision of care to older adults with disabilities is widely acknowledged to be a time-consuming and expensive activity. The prevalence of the need for care with daily tasks rises sharply at older ages, and is especially high immediately prior to death. Acute- and long-term care costs through the Medicare and Medicaid programs are quite high (Spillman and Lubitz 2000) and the implicit costs of informal care provided by family members to the older population with limitations in daily activities are similarly high according to many estimates (Gibson and Houser 2007). Although a consensus has emerged that the prevalence of disability fell during the 1980s and 1990s (Freedman et al, 2004), recent increases in the proportion of the pre-retirement age population needing help with daily activities has drawn fresh attention to concerns about future rates (Martin et al. in press).

Despite the importance of disability as a phenomenon in both the public health and public policy arenas, there is no single established approach to the operational definition or measurement of it. Indeed, one survey of U.S. federal programs reveals that there are 43 different definitions of "disability" in U.S. Federal programs (Adler and Hendershot 2000). The diversity of approaches to disability measurement is particularly evident in the context of population-level household surveys eliciting self-reported responses to closed-end questions. Many such surveys include questions of this sort, yet they differ considerably with respect to the specificity of content, the extensiveness of survey items, and the language used to frame the issues. For example, the widely-used National Health Interview Survey (NHIS), in its most recent (2010) form, includes the single item "[b]ecause of a physical, mental, or emotional problem, [do you/does anyone in the family] need the help of other persons with PERSONAL CARE NEEDS, such as eating, bathing, dressing, or getting around inside this home?" The 2000 Census long form included a somewhat more detailed set of questions, including one about the

presence of "long-lasting conditions" that "... substantially limits one or more basic physical activities such as walking, climbing stairs, reaching, lifting, or carrying;" and one that asks whether because of a " … physical, mental, or emotional condition lasting 6 months or more," a household member has any difficulty dressing, bathing, getting around inside the home, going outside the home alone to shop or visit a doctor's office, and working at a job or business. The American Community Survey includes 6 items to identify individuals with disabilities: serious difficulty hearing or deaf, serious difficulty seeing or blind, serious difficulty concentrating, remembering, or making decisions, serious difficulty walking or climbing stairs, difficulty dressing or bathing, difficulty doing errands alone such as visiting a doctor's office or shopping and difficulty doing errands alone such as visiting a doctor's office or shopping.[1] Note the use, in the NHIS, of the criterion "*need for help*," in contrast to the Census's use of "*difficulty*" doing essential activities. Still another approach that has been used in some surveys is to ask whether respondents "*get help*" from others when carrying out the indicated tasks.

One widely-used source of data on prevalence and trends in disability at older ages is the National Long Term Care Survey (NLTCS), which fielded surveys in 1982, 1984, 1989, 1994, 1999, and 2004/2005. Published studies of disability trends based on NLTCS data include Manton, Gu, and Lamb (2006), Spillman (2004), and Wolf, Hunt and Knickman (2005). The NLTCS employed a two-phase design, consisting of a screener and a follow-up interview. In the first phase, large samples of the population were initially screened for disability using a series of "any problem with ____" questions (a close cousin of the "any difficulty" approach mentioned above). Only those indicating that they had "any problem" with one or more daily activities, and, among those, only those whose problem had lasted, or was expected to last, for 3 months or more, were "screened in" to the much more detailed follow-up interview, which employed

[1] The third and last items are preceeded with the phrase "Because of a physical, mental, or emotional condition,…"

questions of the "get help" variety, along with questions about the use of special equipment, in order to identify the disabled population. The mixing of different question types in the screener and follow-up interviews, in combination with several additional design features, has created analytic problems for tracking the time trend of disability prevalence (Wolf et al. 2005; Erosheva and White 2010).

In 2008, the National Institute on Aging funded what is now called the National Health and Aging Trends Study (NHATS), a new population-level household survey focused on disability trends and trajectories. As the successor study to the NLTCS, the NHATS includes among its goals the ability to produce prevalence estimates that can be compared to those produced earlier by the NLTCS. The NHATS design calls for a baseline interview with an initial sample of about 11,000 Medicare beneficiaries in mid-2011, with annual follow-up interviews thereafter. To support the goal of comparing prevalence estimates produced by NLTCS and NHATS questions, NLTCS screener questions are to be included, verbatim, in the baseline survey.

In early 2010, a draft of the disability protocol developed for NHATS was administered for purposes of evaluating validity and reliability, to a sample of 326 purposively selected respondents; 111 of those respondents were re-interviewed about a week later, for purposes of establishing the validity and reliability of the newly-developed items. Eight of the NLTCS screener questions were included in the validation study as well.

This paper presents the results of a comparative analysis of the disability measures produced by the new NHATS protocol and the earlier NLTCS screener items. We examine both overall patterns as well as item-by-item comparisons. We are particularly concerned with uncovering the circumstances of respondents that would be judged by the NLTCS screener items

to have no self-care limitations and, as a consequence, to have screened out from the detailed NLTCS follow-up interview—but that are shown, on the basis of their responses to the NHATS protocol items, to be using special equipment or devices to help them navigate daily life, or to report some degree of residual difficulty with those tasks, or to otherwise be managing, or adapting to, the physiological changes that typically accompany aging and loss of function.

THE NHATS SELF-REPORTED DISABILITY PROTOCOL

NHATS is intended to "disentangle" disability into its major components: underlying capacity, the environment, accommodations, ability to carry out basic tasks/activities independently, and the extent of engagement in household maintenance and elective activities (Freedman 2009). For purposes of this study, the salient features of the protocol are those that relate to the **use of technology or devices and environmental supports;** the **receipt of help from others**; and the **ability** to carry out tasks independently (that is, without help from another person)**.**

Existing surveys typically either embed assistive device questions in questions about difficulty with specific tasks (e.g., *Do you have difficulty ___? If yes, do you use assistive devices to ___?*), making it impossible to separate out the influence of technology use on reports of difficulty. Or, they offer a checklist of devices (e.g., walkers, wheelchairs) and durable medical equipment (e.g., respirators, hospital beds) and ask respondents whether they have used any of the following during a reference period, but do not connect these devices to use in specific tasks. NHATS adopts a sequence that first identifies device use (e.g., *In the last 30 days, have you used a cane, walker, wheelchair, or scooter?*) and then asks a series of questions about how often these devices are used for specific activities such as transferring, getting around inside one's home, and when outside one's home (e.g. *In the last 30 days, when you got out of a bed or chair,*

how often did you use your cane to help? Would you say …every time, most times, sometimes, rarely, or never?)

Environmental supports also may accommodate gaps between capacity and the demands of a task/activity. NHATS distinguishes among existing modifications, those added by the sample person or a family member and, importantly, whether the modification is used by the sample person. A range of environmental supports are assessed from grab bars in bathrooms to elevators

Finally, some individuals receive assistance or help from others. NHATS, like other surveys, documents assistance in the context of specific activities. A major difference is that as for use of assistive devices, the question of help is not embedded in a question about difficulty. Rather how people do the activity – for example always by themselves or always done by someone else for them – is the starting point. Questions about who provides the help and for what reason follow. These items are coordinated with those on assistive technology use in terms of reference period and frequency of help (every time, most times, sometimes, rarely, never).

THE NHATS VALIDATION STUDY

Although the full NHATS interview will cover a broad range of topics including household and family composition, social activities, health and economic status, the validation study focused on the self-reported disability protocol and a companion set of physical performance tests. The performance measures are for the most part well-established, but many of the self-reported disability, participation, and environment measures have innovative aspects or were newly developed. Through cognitive testing and other qualitative means, we sought to ensure content validity of these questions across community and residential care settings.

The validation study sample was purposive and designed to sufficiently represent persons in three broad age ranges, persons receiving help with bathing, dressing or getting around (based

on a global question), and persons in assisted living. Individuals were recruited for the study using a short script that asked for age and the need for assistance. Recruitment in assisted living facilities was conducted separately. The sample was drawn from primary sampling units in four different states: Kansas, Texas, Florida and Maryland/Washington DC. In all, 326 individuals were interviewed. A subset were selected at random to participate in a second interview in order to assess test-retest reliability; 111 interviews were conducted. Eleven of the initial interviews were with a proxy respondent, but proxies were excluded from the re-interview subset. A distribution of the population on selected characteristics is shown below:

Sample Characteristics at Recruitment	Interview (n=326)	Re-interview (n=111)
Age		
65-74	137	49
75-84	128	41
85+	61	21
Gender		
Male	142	56
Female	184	55
Recruited from assisted living	51	16
Recruited based on report of receiving assistance (bathing, dressing, getting around)[Incl. assisted living]	90	27

ANALYSIS

As noted before, the NHATS Validation Study instrument included 8 of the NLTCS "screener" questions. These will be repeated in the full 2011 baseline survey, to permit cross-survey comparisons of the measures of disability prevalence produced through the two approaches, and to create a basis for assessing the extent to which trends in disability revealed by the 1982-2004 NLTCS have, or have not, continued to 2011. The NLTCS questions are

introduced with the following narrative: “the next few questions are about [your] abilities to do everyday activities without help. By help, I mean either the help of another person, including people who live with [you], or the help of special equipment.” This is followed by the question “do you have any problem eating without the help of another person or special equipment” and, in turn, by analogous questions concerning “getting in or out of bed;” “getting in or out of chairs;” “walking around inside without help;” “going outside without the help of another person or special equipment;” dressing; bathing; and “getting to the bathroom or using the toilet.” Each is answered by a simple “yes” or “no” response.

The NHATS protocol serves a much broader set of purposes than does the NLTCS screener – the latter is intended to be a rapidly-administered and somewhat coarse screen, such that individuals without limitations can be efficiently identified and removed from the follow-up sample, reducing overall respondent burden and field costs. However, there are many substantive points of overlap in the items covered, presenting us with an opportunity to study the comparative effectiveness of the two approaches to questionnaire design in identifying where individuals are located in the “disablement process” (Verbrugge and Jette 1994).

We present a descriptive analysis, comparing the prevalence measures produced by the two set of questions, and paying particular attention to the response patterns of those revealed by the NHATS protocol to be accommodating functional change, but classified by the NLTCS questions as free of “problems.”

RESULTS

Tables 1 through 7 present activity-by-activity comparisons of prevalence produced by the two types of questions (for the 7 NLTCS items with the closest counterparts in the NHATS); in each case, respondents are classified as “disabled” by virtue of their responses to the NHATS

protocol items in two ways: first, as "getting help" OR "having difficulty" (yes or no) or, alternatively, as "getting help" OR "having difficulty" OR "using equipment" (again, yes or no). These binary categories are cross-tabulated with the analogous NLTCS "any problem" item, also coded yes or no.

In general, across the 7 ADL activities, more people identified themselves as having "help or difficulty" using the NHATS approach than indicated "a problem with the activity" using the NLTCS approach. If the NHATS measure is expanded to include "help or difficulty or uses named equipment", the number the persons identified rises further. Furthermore, nearly every person self-identified as having a "problem" by the NLTCS question is also revealed to be getting help, or to have some difficulty with, the respective task.

The proportion of individuals in assisted living who were identified as "help or difficulty or uses named equipment" differed between the two approaches as well. The NHATS measures classified 48 of 51 individuals in assisted living in this category; whereas the NLTCS identified 31 with a "problem." There has been specific attention in the NHATS to persons in assisted living type settings since earlier cognitive testing suggests services provided by the place to residents often are not recognized as "help."

Given the 8 NLTCS binary-response items, there are 256 possible overall response patterns that might be observed in the data. However, among the 326 validation sample respondents, only 39 distinct response patterns are observed. Moreover, 237 (73%) answer "no" to all 8 "any problem" questions. The number of reported problems ranges from zero to 8 (see Figure 1), averaging 0.74. The absence of many potential response profiles is partly due to the modest sample size, but more importantly to the strongly hierarchical nature of reported problems. For example, the single most commonly reported problematic activity is "going

outside," reported to be a problem by 21% of respondents. Moreover, it is the most commonly reported problem area at every severity level (with "severity" measured by the number of reported problem activities). Either indoor mobility or bathing is the second most commonly reported problem activity at each severity level.

In work still to be completed, we will construct overall response profiles for the NHATS protocol items, and compare the response profiles across the 2 question types; we will also conduct a separate analysis of the NHATS responses among the 237 respondents classified as nondisabled by the NLTCS items.

DISCUSSION

The NHATS validation study is intended to provide information on both the validity and reliability of the newly designed disability protocol that is being fielded. At the same time, continuity with other approaches and the NLTCS in particular, is of interest. This analysis focuses on differences between the NHATS and NLTCS in who is identified as "disabled" based on receipt of help, use of devices and environmental supports in activities ,and difficulty in performing activities without assistance. Several differences emerge that suggest disaggregating these domains, as is done in the NHATS, will provide a richer and more complex picture of disability than earlier approaches. The implications for prevalence and disability trends can be assessed once national data become available in the near future.

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Table 1: Cross-tabulation of NHATS and NLTCS eating disability items

Eating

		Problem w/o help or equipment		
		NO	YES	
Help or Difficulty	NO	295	0	295
	YES	24	7	31
		319	7	326

NOTE: No one used eating utensils in the validity study so equipment = 0.

Table 2: Cross-tabulation of NHATS and NLTCS bed transfer disability items

Getting In/Out of Bed

		Problem w/o help		
		NO	YES	
Help or Difficulty	NO	260	1	261
	YES	43	20	63
		303	21	324

		Problem w/o help		
		NO	YES	
Help, difficulty, or equipment	NO	247	1	248
	YES	56	20	76
		303	21	324

Table 3: Cross-tabulation of NHATS and NLTCS indoor-mobility disability items

Walking Around Inside

		Problem w/o help		
		NO	YES	
Help or Difficulty	NO	241	17	258
	YES	44	23	67
		285	40	325

		Problem w/o help		
		NO	YES	
Help, difficulty, or equipment	NO	212	0	212
	YES	73	40	113
		285	40	325

Table 4: Cross-tabulation of NHATS and NLTCS outdoor-mobility disability items

Going Outside

		Problem w/o help or equipment		
		NO	YES	
Help or difficulty	NO	216	17	233
	YES	42	49	91
		258	66	324

		Problem w/o help		
		NO	YES	
Help, difficulty, or equipment	NO	194	3	197
	YES	64	63	127
		258	66	324

Table 5: Cross-tabulation of NHATS and NLTCS dressing disability items

Dressing

		Problem w/o help		
		NO	YES	
Help or difficulty	NO	238	4	242
	YES	61	23	84
		299	27	326

		Problem w/o help		
		NO	YES	
Help, difficulty, or equipment	NO	226	0	226
	YES	73	27	100
		299	27	326

Table 6: Cross-tabulation of NHATS and NLTCS bathing disability items

Bathing

		Problem w/o help		
		NO	YES	
Help or difficulty	NO	246	5	251
	YES	39	35	74
		285	40	325

		Problem w/o help		
		NO	YES	
Help, difficulty, or equipment	NO	148	1	149
	YES	137	39	176
		285	40	325

Table 7: Cross-tabulation of NHATS and NLTCS toileting disability items

Toileting

		Problem w/o help		
		NO	YES	
Help or difficulty	NO	284	7	291
	YES	24	8	32
		308	15	323

		Problem w/o help		
		NO	YES	
Help, difficulty, or equipment	NO	209	1	210
	YES	99	14	113
		308	15	323

NOTE: NLTCS asks getting to bathroom or using toilet.

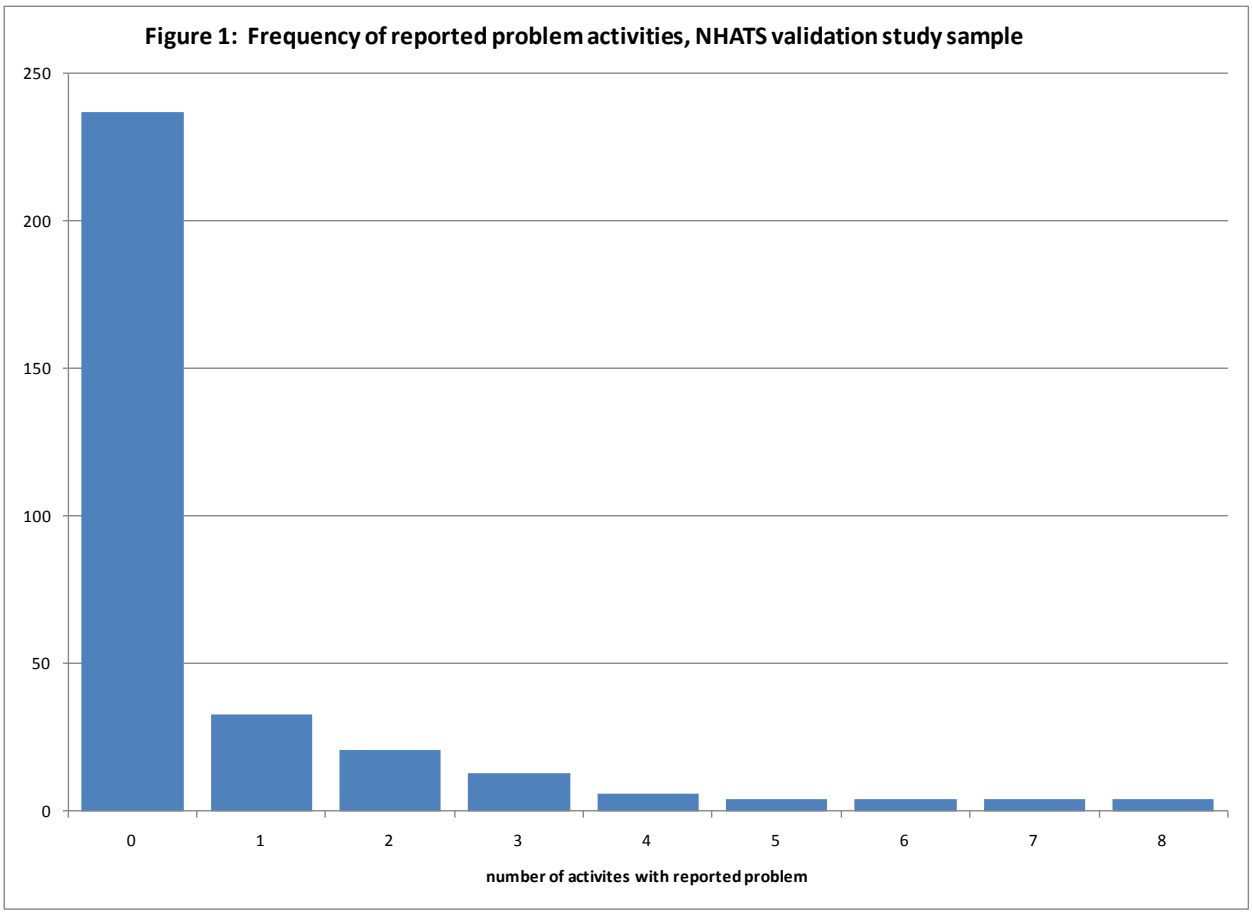
Figure 1: Frequency of reported problem activities, NHATS validation study sample
250
200
150
100
50
0
0
1
2
3
4
5
6
7
8
number of activites with reported problem