On the operational definition of chronic disability in the National Long Term Care Survey, 1982-2004

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Abstract

Although the National Long Term Care Survey (NLTCS) is known as one of the best national surveys for assessing trends in disability, its disability measurement process has not been explained in sufficient detail in the literature. A thorough investigation of disability definition as it is operationalized by the NLTCS will thus benefit secondary users of the NLTCS data, policy-makers that rely on NLTCS-derived findings, and future designers of longitudinal disability surveys. We first describe the two ADL/IADL measures from the NLTCS, based on self-reported screen and detailed survey interviews. The NLTCS typically combined these two measures to produce prevalence estimates during 1984-1999. We then empirically assess the issue of comparability of the measures. Our findings show that the ADL disability measure from detailed interviews provides significantly higher disability assessments than the ADL disability measure from screen interviews. Finally, we examine whether discrepancies between the two disability measures are associated with certain features of survey design and respondent-level characteristics.

Background

The NLTCS represents a rich source of information on disability among Americans 65 years of age and older. The NLTCS data on basic and instrumental activities of daily living have been used to generate such major findings as the persistent decline in chronic disability among the elderly Americans (Manton, Corder and Stallard, 1997; Manton and Gu. 2001: Manton, Gu and Lamb, 2006), However, there is a concern that the survey data have been underused, especially with regard to longitudinal features (Committee on National Statistics and Committee on Population, 2006). The lack of clarity in the operational definition of chronic disability employed by the survey may be a contributing factor to low secondary usage of the NLTCS data.

The NLTCS is a two-phase survey that consists of a screen interview followed by a more detailed interview. The latter is administered only to those subjects who were initially identified as chronically disabled based on self-reported answers to screen questions. Persons who received a detailed interview in one survey wave are automatically eligible for a detailed interview in all subsequent survey waves until death. The NLTCS replenishes its sample at each wave in order to reflect the current U.S. population 65 and older. Chronic disability prevalence calculations based on the NLTCS typically use the screen interviews to assess disability prevalence for the newly screened-in sample, and the detailed interviews for the carried-over longitudinal sample (Manton et al., 2006).

Table 1: ADL and IADL tasks

assessed in the screen and

detailed NLTCS interviews

		Screen Interview	Detailed Interview
ADL	1	Eating	Eating
	2	Getting in/out of bed	Getting in/out of bed
	3	Getting around inside	Getting around inside
	4	Dressing	Dressing
	5	Bathing	Bathing
	6	Toileting	Toileting
	7	Continence	
	8	Getting in/out of chair	
	9	Getting about outside*	
IADL	1	Light housework	Light housework
	2	Laundry	Laundry
	3	Prepare meals	Prepare meals
	4	Grocery shopping	Grocery shopping
	5	Managing money	Managing money
	6	Taking medicine	Taking medicine
	7	Telephoning	Telephoning
	8		Heavy housework
	9		Getting about outside*
	10		Traveling

Determination of binary outcomes for ADL and IADL items in the NLTCS

Our summaries of the decision process provides complete and more transparent picture of ADL/IADL binary outcome determination for both, screen and detailed interviews. The standard set of NLTCS triggering questions was developed for detailed interviews only. Our version of triggering questions is available at:

- http://www.stat.washington.edu/~elena/NLTCS/ADL-Scr-Triggers.pdf
- http://www.stat.washington.edu/~elena/NLTCS/ADL-Det-Triggers.pdf
- http://www.stat.washington.edu/~elena/NLTCS/IADL-Scr-Triggers.pdf
- http://www.stat.washington.edu/~elena/NLTCS/IADL-Det-Triggers.pdf

Table 2: Triggering guestions and decision rules for ADL and IADL binary outcome determination in the NLTCS. Examples of eating (ADL) and managing money (IADL).

Screen Interview	Detailed Interview			
ADL - Eating	ADL - Eating			
 Do you have any problem eating without the help of	 During the past week did anyone help you eat? Did you use special equipment to help you eat? Did someone usually stay by just in case you might			
another person or special equipment?	need help with eating?			
If question 1 was answered 'yes' or 'can't do' / 'don't do at	If any of questions 1-3 were answered 'yes' or if the			
all', the individual is ADL-disabled on eating. Otherwise,	individual did not eat at all, the individual is ADL-disabled			
no disability is recorded.	on eating. Otherwise, no disability is recorded.			
IADL – Managing Money	IADL – Managing Money			
 Are you able to manage money without the help of	 Do you usually manage money by yoursel? If you had to manage money on your own, could you			
another person or special equipment? Does a disability or a health problem keep you from	do it? Is the reason you cannot manage your own money			
managing money?	because of disability or a health problem?			
If question 1 was answered 'no' and question 2 was	If questions 1 and 2 were answered 'no', and question 3			
answered 'yes', the individual is IADL-disabled on	was answered 'yes', the individual is IADL-disabled on			
managing money. Otherwise, no disability is recorded.	managing money. Otherwise, no disability Is recorded.			

Summary: Differences between screen and detailed interview ADL and IADL items

• The screen interview has ADL triggering questions of "difficulty" type while the detailed interview has ADL triggering questions of the "gets help" type. This set-up may prompt "false negative" disability cases on the screen interview (Wolf et al., 2005).

• The detailed interview included more triggering questions per ADL or IADL task than did the screen interview. This may prompt "false positive" cases on the screen interview (Lee et al. 2007). • The screen interview had a further check for the presence of at least one chronic limitation (90+ day duration) while the detailed interview did not incorporate such checks.

Empirical Analysis: Comparison of Screen and Detailed measures Data set

We use data from 2004 wave. There were 5,201 individuals in 2004 who received the community detailed survey. 2004 is the only survey year, apart from the initial wave in1982, when all of the individuals in the detailed survey were administered the screen interview as well.

Preliminary analysis

Table 3: NLTCS 2004 screen and detailed interviews disability status classifications using ADL and IADL items common between the two interviews. N=5,201

	Non- disabled	IADL only	1-2 ADL	3-4 ADL	5-6 ADL	
Screen (6 ADL, 7 IADL)	2250	707	1205	378	361	5
Detailed (6 ADL, 7 IADL)	2242	223	1257	779	700	

Detailed interview classifies about twice as many individuals in the two most disabled groups than does the screen interview. The screen interview classifies about three times as many people in the IADI -only group

Table 4: Cross-classification of ADL disability by the screen (Y₀) and detailed (Y₁) 2004 NLTCS interviews. In parenthesis: transition probabilities from a disability category on the screen interview (Y₀) into a disability category on the detailed interview (Y₁). N=4,472 (all 2004 participants except the newly sampled healthy supplement).

Table 4 shows a lack of consistency	Counts	Y ₁ = 0 (no ADL)	Y ₁ =1 (1-2 ADL)	Y ₁ =2 (3-4 ADL)	Y ₁ =3 (5-6 ADL)	Total
in disability status assessments	Y ₀ = 0 (no ADL)	1,601 (.633)	693 (.274)	162 (.064)	75 (.030)	2,531 (1.000)
interviews, with greater amounts of ADL disability observed on the	Y ₀ = 1 (1-2 ADL)	107 (.089)	490 (.407)	449 (.373)	158 (.131)	1,204 (1.000)
detailed interview.	Y ₀ = 2 (3-4 ADL)	9 (.024)	48 (.127)	132 (.349)	189 (.500)	378 (1.000)
	Y ₀ = 3 (5-6 ADL)	19 (.053)	26 (.072)	36 (.100)	278 (.774)	359 (1.000)
	Total	1.736	1.257	779	700	4, 472

Choice of individual-level covariates

Based on existing studies on measurement error in disability assessments, the covariates are: · Demographic: Age, education, marital status, gender and race.

- Interview characteristics: Time-lag between the screen and detailed interview, proxy respondent indicator. · Note: No available records on interview mode (telephone versus in person).
- · Medical conditions: Total number of current medical conditions and medical conditions in the past year (out of a total of 27 conditions asked), a depression indicator, a cognitive impairment indicator (based on
- Short Portable Mental Status Questionnaire).

Multivariate models: Impact of covariates on changes in disability status

Missing data and statistical model:

- Out of 4.472 individuals. 1087 (24.3%) had missing data on some covariates.
- · Depression and cognitive impairment had the largest amounts of missing data due to proxy use (i.e., only sampled person was eligible to answer those questions).
- · We use the approach of list-wise deletion of cases with missing data on covariates.
- We use cumulative logit model for matched pairs of observations where Yo is disability assessment by the screen, and Y1 is disability assessment by the detailed interview:

 $\operatorname{logit}\left[P\left(Y_{j} \leq i\right) \mid X\right] = \alpha_{i} + \gamma_{j} + \sum_{k=1}^{K} X_{k}, \quad i = 0, 1, 2, 3, \ j = 0, 1.$

Table 5: Parameter estimates for matched pairs marginal models

Variable	Model (a)	Model (b)	Conclusions from statistical
intercept (Y=1)	0.626***	2.021***	modeling:
intercept (Y=2)	2.051***	3.724***	
ntercept (Y=3)	3.317***	5.139***	 The odds of (Y₁ ≤ <i>i</i>)
Detailed Interview (yes=1, no=0)	835***	-1.001***	equal $exp(-0.835) = 0.43$
Interview time-lag (months)			times the odds of $(\mathbf{Y}_0 \leq i)$,
Lag=0			in Model (a).
0 < Lag < 1 month	044	0.016	I his implies: the detailed
Lag > 1 month	056	101	Interview tends to assign
Age category (over 65)			higher disability categories
65-69			This ordering becomes
70-74		.499***	stronger when we control for
75-79		.275**	other covariates in Model (b)
80-84		.025	Time-lag variable has no
85+		614***	significant effect, after
Proxy (yes=1, no=0)		953***	controlling for interview type.
Education (some college=1, HS or less=0)		009	Older people (85+), those
Marital status (married=1, non-married=0)		.327***	with proxy respondents,
Gender (female=1, male=0)		129*	women, cognitively impaired
Race (white=1, other=0)		031	and non-married persons
Depression (yes=1, no=0)		044	tend to be classified into
Cognitive impairment (yes=1, no=0)		779***	higher disability categories by
Medical conditions (current)		316***	the detailed than by the
Medical conditions (past)		184***	screen survey, controlling for
*** - p-value <0.001, ** - p-value < 0.01,*	- p-value < (0.05	other covariates.

Conclusions from statistical modeling:

• The influence of past and current medical conditions is the most striking: differences between the two disability assessments become more severe for persons reporting larger numbers of medical conditions. This finding can be explained by differences in placement of disability questions in the detailed and screen interviews:

. In the detailed interview disability questions came after a section on medical conditions; in the screen interview - after a section on demographics.

 The discrepancy between the two measures of disability status persisted after we redefined detailed-based ADL outcomes by using additional disability duration questions to adjust for inaccuracies in determining disabilities as chronic in the detailed interviews.

Implications:

· The discrepancy in disability measures between two phases of the NLTCS is problematic because it makes different categories of NLTCS participants (newly sampled, returning, healthy supplement, etc.) to be subjected to different combinations of disability measures. Difference in NLTCS disability measures in the unexpected direction illustrates a possibility of a significant measurement error that is due to survey implementation. • Our findings again raise the issue of replicability in survey research, especially when researchers deal with latent constructs such as disability.

References:

[1] Manton, K. G., Corder, L. S. and Stallard, E. (1997). Chronic disability trends in elderly United States populations: 1982-1994. Proceedings of the National Academy of Sciences, 94, 2593-8. [2] Manton, K. G. and Gu, X. (2001). Changes in the prevalence of chronic disability in the United States black and

nonblack population above age 65 from 1982 to 1999. PNAS, 98, 6354-9. [3] Manton, K. G., Gu, X. and Lamb, V. L. (2006). Change in chronic disability from 1982 to 2004/2005 as measured by long-term changes in function and health in the U.S. elderly population. PNAS, 103 (48),18374-9.

[4] Committee on National Statistics and Committee on Population. (2006). Summary from the expert meeting on the future of the National Long-Term Care Survey. The National Academies, National Institute on Aging. [5] Wolf, D. A., Hunt, K. and Knickman, J. (2005). Perspectives on the recent decline in disability at older ages. The

Milbank Quarterly, 83 (3), 365-395.

[6] Lee, S., Mathiowetz, N. A. and Tourangeau, R. (2007). Measuring disability in surveys: Consistency over time and across respondents. Journal of Official Statistics, 23 (2), 163-184.