Examining a Trend Over Three Decades in Late-life Disability Prevalence in the U.S.

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ABSTRACT

Demographers have long been interested in the implications of lengthening life for the health and functioning of the older population. Recent findings suggest that the decline in late-life disability prevalence for the 1982-2004 period may have ended and may even reverse course in the near future. Yet data to confirm this long-term trend have been lacking. This paper will present estimates of the prevalence of activity limitations among those 65 or older for 1982 and 2004 (from the National Long Term Care Survey) and from 2011 (from the National Health and Aging Trends Study). We find evidence consistent with a reversal of the decline in disability for women. For men, the oldest old are continuing to experience declines in disability but younger men's prevalence rates have stalled. We place the findings in context with recent mortality trends and discuss limitations and implications for future research on trends and related policy.

INTRODUCTION

Demographers have long been interested in understanding the implications of lengthening life for the health and functioning of the older population. Late-life disability in particular has consequences for individual wellbeing, for family's informal care giving responsibilities, and for societal costs of paid services to assist with daily activities. Indeed, the economic cost of disability and associated co-morbidities in later life are large projected to grow rapidly in the coming decades as the number of adults reaching late life continues to increase dramatically.

A series of papers based on the 1982-2004 National Long Term Care Survey (Manton 1988; Manton, Corder, and Stallard 1993, 1997; Manton and Gu 2001; Manton, Gu, and Lamb 2006) has shown a persistent downward trend in disability in the United States through 2004. Subsequent analyses of these data by other researchers (Spillman 2004; Wolf, Hunt, and Knickman 2005; Erosheva and White 2010) have pointed out several methodological issues that have implications for levels of disability, but have not altered the basic conclusion that late-life disability prevalence fell throughout the 1982-2004 period.

Crimmins has made the astute point that not all measures of health will necessarily move in the same direction in response to mortality decline (Crimmins 1996) and the same is true of disability measures. Analysis of other data sources confirmed declines were concentrated among instrumental activities of daily living (Freedman et al. 2002) during the 1980s and early 1990s. Additional cross-survey comparisons undertaken by a technical working group concluded that during the middle and late 1990s declines also occurred in limitations in activities of daily living (Freedman et al. 2004). In comparing findings across surveys, the group underscored that time period, definition of disability, treatment of the institutional population, and standardization of results by age are all important considerations.

More recent investigations across surveys for the 2000-2008 period (Freedman et al. 2013), concluded that the decline in any activity limitations had continued for those ages 85 and older from 2000 to 2008, but trends generally were flat since 2000 for those ages 65–84. Modest increases were observed for the 55- to 64-year-old group approaching late life, although prevalence remained low for this age group. The authors also noted that inclusion of the institutional population—possible with only two of the available data resources at that time—is critical to assessing trends among those ages 85 and older.

Together these findings suggest that the 20-year decline in late-life disability prevalence observed for the 1982-2004 period may have ended and may even reverse course in the near future. Yet confirmation of this long-term trend has been hampered by the absence of a single data series that covers the entire elderly population and employs a consistent approach to sampling and measurement. The NLTCS, for instance, was last fielded in 2004 and the Medicare Current Beneficiary Survey did not begin until the early 1990s. However, newly available data from the initial wave of the National Health and Aging Trends Study (NHATS), conducted in 2011, provides a new source of consistent measures. In particular, the NHATS drew its sample from the same frame as the NLTCS (i.e., Medicare enrollees age 65 and older), included individuals living in all settings, and, in a special module, repeated verbatim NLTCS disability

questions used to screen the NLTCS sample (explained in more detail below). Thus, it when used in conjunction with the NLTCS, the NHATS provides an opportunity to explore longer-term trends.

This paper will present estimates of the prevalence of activity limitations among those 65 or older for 1982 and 2004 (from the NLTCS) and from 2011 (from the NHATS). We first present estimates by age and gender and for the entire 65 and older population. We then present age- and sex-adjusted estimates that standardize all years to the same age-sex distributions. We also investigate sensitivity to one potential source of difference between the NLTCS and NHATS: coverage of the institutional population. Finally, we demonstrate how NHATS' new measures of disability compare with the NLTCS' screener items and discuss implications for our understanding of disability levels and trends going forward.

DATA

1982 and 2004 NLTCS Screener. In 1982, the National Long Term Care Survey screened nearly 20,000 older adults drawn from the Medicare Enrollment file for inclusion in a detailed interview. Much, but not all, of the screening was done by telephone. In 2004 all individuals including a new cohort of 65-69 year olds were re-screened (approximately 16,000). In intervening years, screening was limited to new entrants age 65-69 and persons not previously selected for detailed interview, so we focus in this paper on the 1982 and 2004 waves.

Screener weights developed by the Center for Demographic Studies for 1982 and 2004 take into account differential probabilities of selection and differential non-response. They were also post-stratified to Census totals and as such represent the entire 65 and older population in the U.S.

2011 NHATS. In 2011, NHATS was administered in person to 8,245 respondents drawn from the Medicare Enrollment file. 8,077 respondents either completed the sample person interview or were living in a nursing home and had a facility questionnaire completed by facility staff. At the end of the NHATS sample person interview, a module containing the NLTCS screener items was administered in the LS module.

NHATS analytic weights represent the Medicare eligible population, which in turn represents approximately 96% of the US population of older adults identified in the Census. The vast majority of older adults not represented by Medicare are ages 65-69. To improve comparisons with the NLTCS, which was standardized to Census control totals, we therefore standardize the NHATS estimates to the age- and sex-distributions in the 2010 Census (US Bureau of the Census, 2010).

METHODS

Screener Items. NLTCS screener items/NHATS LS module items for our purposes are shown in Table 1.

From these items we created a measure of any limitation. Respondents who reported a problem with any of the mobility or self-care activities or report being unable to carry out a domestic activity because of a disability or health problem are considered to have a limitation.

Table 1. NLTCS Screener Items/NHATS LS Module items	
Introduction: The next few questions are about your ability to do everyday activities without help. By help, I mean either the help of another person, including the people who live with you, or the help of special equipment.	
1. Do you have any problem... a. eating without the help of another person or special equipment? b. getting in or out of bed without help? c. getting in or out of chairs without help? d. walking around inside without help? e. going outside without the help of another person or special equipment? f. dressing without help? g. bathing without help? h. getting to the bathroom or using the toilet? Answer choices: **yes, no, can't do/don't do**	***2. Are you/Is SP} able to…*** a. prepare meals without help? b. do laundry without help? c. do light housework such as washing dishes? d. shop for groceries without help? e. manage money, such as keeping track of bills and handling cash? f. take medicine without help? g. make telephone calls without help? Answer choices: **yes, no** **If no:** ***3. Does a disability or a health problem keep you from [activity]?*** Answer choices: **yes, no**

NHATS' activity limitation hierarchy

To facilitate interpretation of the screener items in the broader context of NHATS, we used measures from the NHATS sample person interview to create a hierarchical measure of activity limitations that reflects adaptation to self-care, mobility, and household-related activities. Self-care activities include bathing, dressing, eating, and toileting. Mobility-related activities include getting out of bed, getting around inside one's home or building, and leaving one's home or building. Household activities include laundry, hot meals, shopping for personal items, paying bills/banking, handling medications. Four hierarchical categories were created: (1) fully able to carry out self care and mobility activities (without devices, without reducing the frequency of the activity, without difficulty and without help); (2) accommodating, with assistive devices or environmental modifications (for self-care and mobility activities) or by doing activities less frequently than a year ago (for self care, mobility and household activities), but without difficulty (3) with difficulty when carried out alone and with whatever accommodations the individual has made; and (4) with assistance from another person, which for household activities must be for health- or functioning-related reasons. We cross the NHATS-based NLTCS screener items with this hierarchical indicator to understand the breadth of disability captured and/or missed by this particular trend indicator.

Community, Residential Care, Nursing home

In 1982 NLTCS respondents were either identified as living in a nursing home or in the community. The residential care population, consisting of assisted living facilities, board and care homes, and other places where supportive services are provided, was in its infancy. By 2004, the residential care population had grown substantially and the NLTCS screener items were able to distinguish between community, residential care, and nursing homes. We classified respondents living in assisted living facilities, continuing care retirement communities, and congregate care facilities as living in residential care. Retirement communities were included with the community.

In NHATS respondents were identified as living in the community, residential care, or nursing home. Questions in the sample person interview triggered a facility questionnaire, which captured details about the place from a facility administrator (Kasper and Freedman 2012). We included individuals in all forms of residential care, including those living in "independent living" within a residential care facility, as living in residential care. Sample persons in retirement communities who were not in residential care were included in the community.

Standardization

In addition to standardizing the NHATS to 2010 Census age- and sex- distributions, we also present a set of estimates in which all years are standardized to these distributions. These estimates provide essentially control for effects of changes in the age and gender distribution on the observed NLTCS trend between 1982 and 2004 and the NHATS comparison.

Calculation of Statistical Tests.

We report statistical significance based on confidence intervals that take into account the complex designs of the NLTCS and NHATS. For the final paper we intend to add statistical tests to the comparisons of standardized estimates.

PRELIMINARY RESULTS

Table 1 provides the distribution of age, sex, and residential status for NTLCS for 1982 and 2004 and for NHATS for 2011. We also provide distributions from the 2010 Census for comparison. Over time, aging of the population is evident: the groups 80-84, 85-89 and 90+ increased whereas the other groups decreased in size. The proportion of the population who were male increased (as men's life expectancy increased more than women's life expectancy). The larger share of older adults in residential care settings is also evident from 2004 (2.9%) to 2011 (5.4%) as is the decline between 1982 and 2004 in the nursing home population from nearly 6% to 3%. The slight under-representation of Medicare in the 65-69 year old age group, relative to Census, is also evident.

Figures 1 and 2 show the trends by age for men and women, respectively, for 1982, 2004 and 2011. Figure 1 suggests that for the oldest men, the trend continued to decline at the oldest ages,

but remained flat for ages 80-84 and below. For women, the trend reversed and most point estimates are significantly higher than 2004 and no longer different from 1982.

Figure 3 shows the overall trend in two ways: with only the 2011 NHATS standardized to the Census 2010 age-sex distributions (but NLTCS waves not standardized) and all three waves standardized to the Census 2010. Both lines suggest that at least half the gains in disability prevalence between 1982 and 2004 have been reversed. Overall, the age-sex adjusted rates are 26.0% in 1982, 20.0% in 2004 and 23.1 % in 2011.

Figures 4 and 5 explore whether this finding is due to different procedures for identifying (and potentially better coverage of) residential care settings by NHATS. If NHATS simply has better coverage than NLTCS of the residential care population then one might expect increases in disability rates for men and women, particularly at the older ages. However, focusing on the community alone, the figures are substantially similar to Figures 1 and 2, and show that for men ages 85 and older the trend continued to improve between 2004 and 2011, for men ages 80-84 and younger the trend flattened, and for women of all ages, gains between 1982 and 2004 were reversed. Hence, the patterns do not appear to be driven by different procedures for identifying residential care.

Table 2 shows that approximately 71% of individuals who received help with either a self-care, mobility or household activity (the latter for health-related reasons) answered one or more of the NLTCS screener items included in the NHATS. In other words, the screener items missed 29% of those who received help in the last month. Only 10% of those who had difficulty with activities (by themselves given whatever accommodations they have put into place) were captured by the screen and an even smaller percentage of those who successfully accommodated (used or more device or environmental modification or had changed their behavior but reported no difficulty). Only 1% of those fully able were picked up by the screener suggesting it effectively omits those who are functioning without any limitations.

DISCUSSION

We find evidence consistent with a reversal of the decline in disability for women. For men, the oldest old are continuing to experience declines in disability but younger men's prevalence rates have stalled. The measure used in this analysis captures only the most severely limited older adults; it appears to capture the majority of those receiving help but only a small fraction of those reporting difficulty with daily tasks.

In the paper we will discuss both reasons that have been suggested for the downward trend and reasons that have been suggested for the stopping, and possible reversal of, the downward trend. We will also place findings in the context of recent mortality findings that suggest the female advantage over men has been decaying over time.

A limitation of these comparisons is that the screener questions were placed at the end of NHATS, after a full-length interview had taken place, including performance-based activities and self-reports of detailed disability. These procedural differences may affect the reported

levels, in ways that we are unable to assess. However, we are unable to come up with a hypothesis for why placement would affect women differently than men or older men differently than their younger counterparts. We will attempt to delve further into this discussion in the paper.

Finally, we will discuss implications of findings for future research and for long-term care policy.

Table 1. Sample sizes and weighted distributions by age, gender, and residence: NLTCS, NHATS, and Census

	1982 NLTCS		2004 NLTCS		2011 NHATS		2010 Census
Characteristics	n	%	n	%	n	%	%
AGE							
6569	5481	31.1%	4809	27.4%	1417	27.2%	30.9%
7074	4978	27.1%	2538	23.5%	1610	24.6%	23.0%
7579	3918	19.8%	2552	20.5%	1569	18.9%	18.2%
8084	2733	12.3%	2514	15.2%	1590	14.8%	14.3%
8589	1685	6.8%	2133	3.0%	1067	9.6%	9.0%
90+	855	2.9%	1447	4.4%	824	4.9%	4.7%
GENDER							
Male	7471	39.3%	6425	41.9%	3285	42.9%	43.1%
Female	12179	60.7%	9568	58.1%	4792	57.1%	56.9%
RESIDENCE							
Community	17658	94.3%	14660	94.1%	7197	91.7%	96.9%
Residential care	0	0.0%	649	2.9%	412	5.4%	N/A
Nursing home	1992	5.7%	684	3.0%	468	3.0%	3.1%

[1]Includes both community and residential care

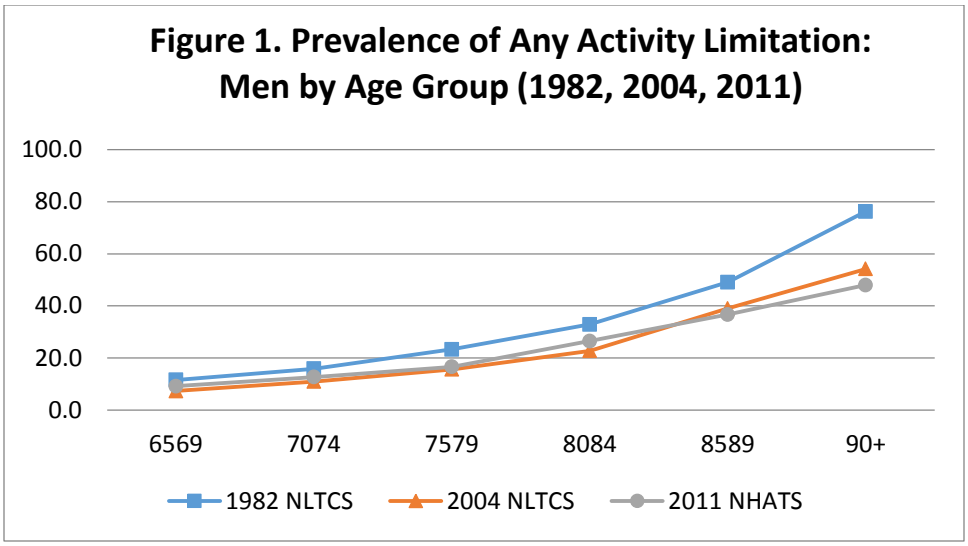


Figure 1. Prevalence of Any Activity Limitation: Men by Age Group (1982, 2004, 2011)
100.0
80.0
60.0
40.0
20.0
0.0
6569
7074
7579
8084
8589
90+
1982 NLTCS
2004 NLTCS
2011 NHATS

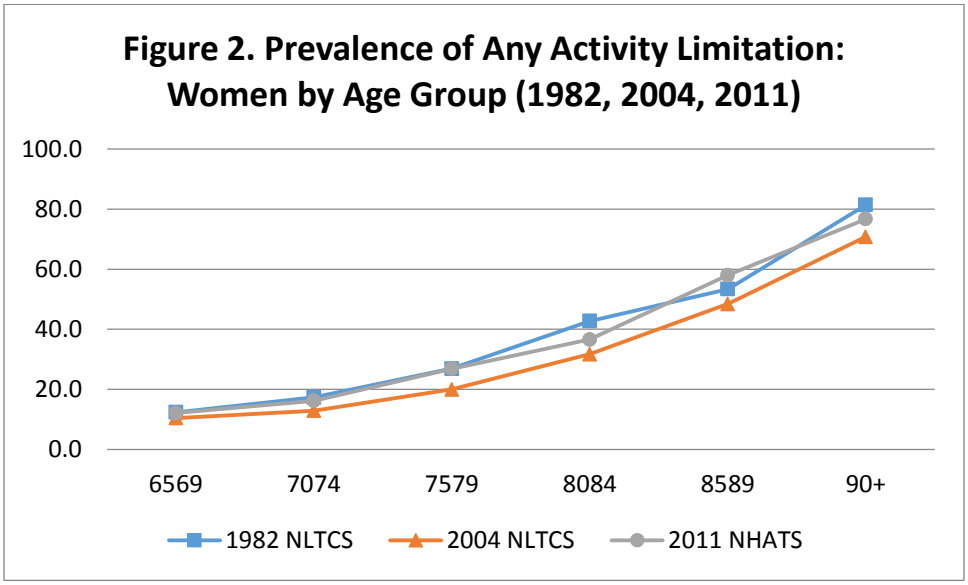
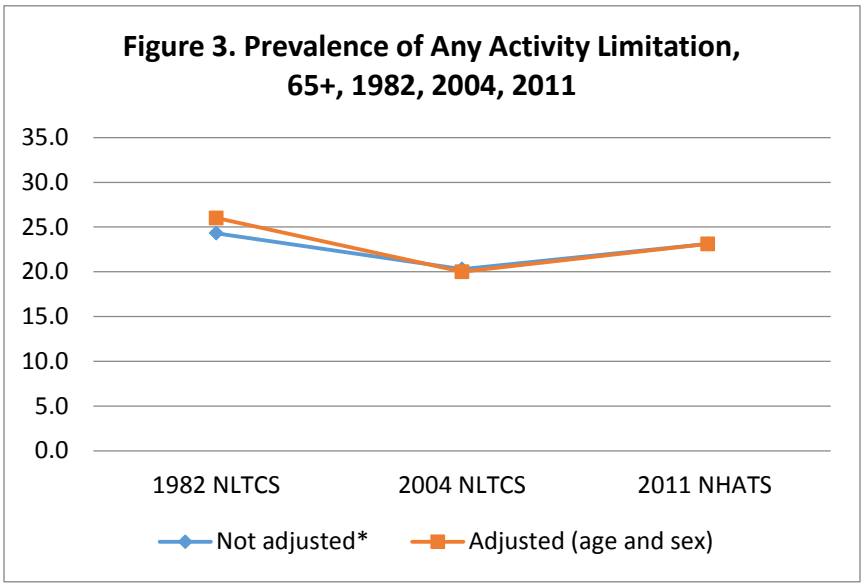


Figure 2. Prevalence of Any Activity Limitation: Women by Age Group (1982, 2004, 2011)
100.0
80.0
60.0
40.0
20.0
0.0
6569
7074
7579
8084
8589
90+
1982 NLTCS
2004 NLTCS
2011 NHATS



*Not adjusted =Only 2011 NHATS standardized to Census 2010 age-sex distribution. Adjusted=All three waves standardized to Census 2010 age-sex distribution.

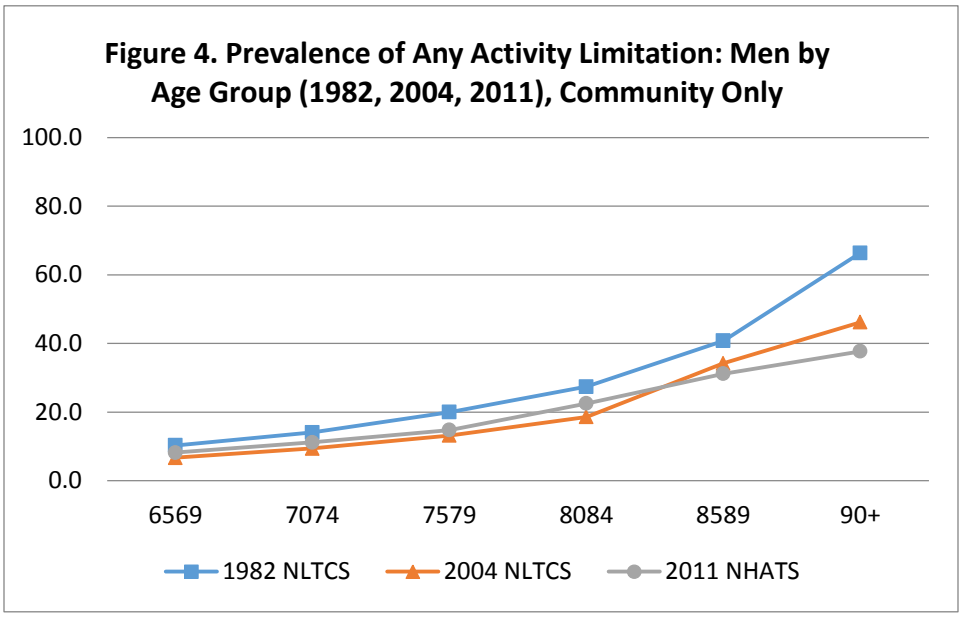


Figure 4. Prevalence of Any Activity Limitation: Men by Age Group (1982, 2004, 2011), Community Only
100.0
80.0
60.0
40.0
20.0
0.0
6569
7074
7579
8084
8589
90+
1982 NLTCS
2004 NLTCS
2011 NHATS

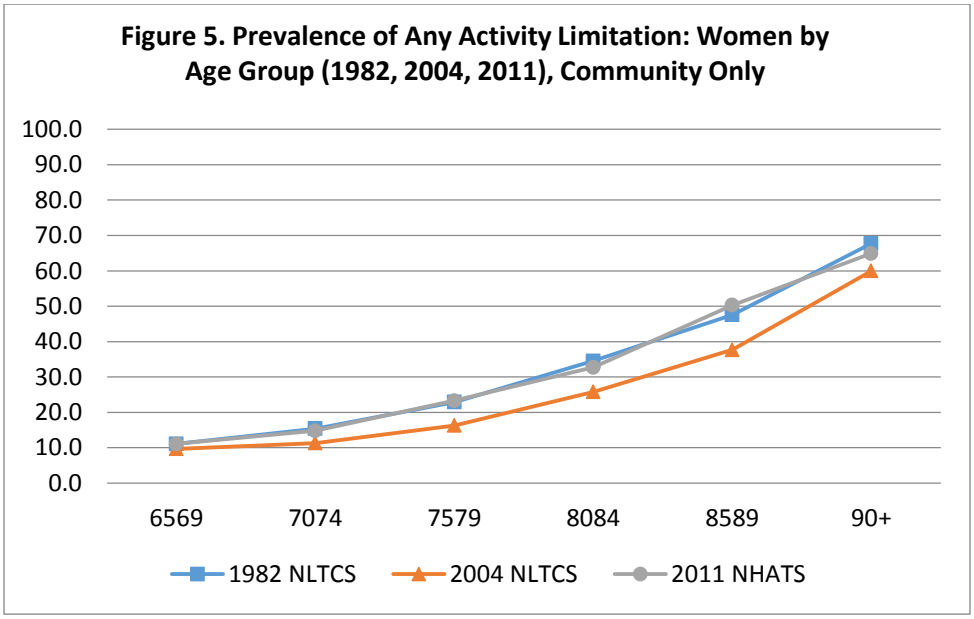


Figure 5. Prevalence of Any Activity Limitation: Women by Age Group (1982, 2004, 2011), Community Only
100.0
90.0
80.0
70.0
60.0
50.0
40.0
30.0
20.0
10.0
0.0
6569
7074
7579
8084
8589
90+
1982 NLTCS
2004 NLTCS
2011 NHATS

Table 2. NHATS Hierarchial Activity Limitations Measure by NLCTS Screener Items		
	Any Limitations: NLTCS Screener	
Limitation Level	No	Yes
Fully Able on all activities	98.6%	1.4%
Device use/Less often, but no difficulty	97.2%	2.8%
Difficulty, but no help	89.7%	10.3%
Help	29.2%	70.8%

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