

Towards a Restructuring of the National Long Term Care Survey: A Longitudinal Perspective*

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Abstract

The National Long Term Care Survey (NLTC) is a valuable tool for research in aging and disability. The survey's primary advantage over competitive datasets, its longitudinal sampling of elderly, however, has been underutilized. We suggest (a) changes in content to address comparability with other surveys that include a focus on disability in the elderly population as well as to enhance our understanding of the progression of disability over time, (b) a reallocation of resources for data acquisition with an emphasis on more frequent re-sampling of a smaller set of respondents so that researchers may more effectively study temporal changes in seniors' health and abilities, and (c) the development of shared analytically-oriented files that integrate survey and other linked data on health, medical care utilization, and death, in order to allow a broader array of researchers to more easily utilize the richness of information associated with the NLTC. In addition, because by design the NLTC does not unequivocally provide measurements of *chronic* disability but rather of some combinations of chronic and short-term disability episodes, we addressed this issue by providing suggestions for future longitudinal disability surveys.

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1 Introduction: Why Study Aging Longitudinally?

The National Long Term Care Survey (NLTCS) is both a longitudinal study of the population of the U.S. aged 65 and older, and a series of (correlated) cross sectional surveys. By introducing a new cohort of individuals at each wave to replace those who have died, the NLTCS has been able to produce valid national estimates of disability from the data in each wave. Such cross-sectional analyses have been the focus of most of the reports and papers based on NLTCS data, even when the interest in such publications has been changes of disability over time. Here we argue that the longitudinal information provided by the NLTCS is its primary advantage over other data sources on aging. To best use the NLTCS to understand and characterize the dynamic disability patterns in 40 million Americans, we propose alternative sample designs that involve interviews with fewer subjects, but at a higher frequency than at the present 5-year intervals.

The current NLTCS design, which involves the reinterviewing of study participants every 5 years, is useful for comparing disability rates over time. Such studies have commonly resulted from the NLTCS [29, 30] and other longitudinal [6] and non-longitudinal aging datasets [2, 12, 14, 24, 41, 45]. None of these studies, however, use the longitudinal nature of the data. Although Manton and colleagues [31, 32, 33] and others have written about longitudinal models there has been little in the way of serious implementation.

Fienberg and Tanur [10] have noted: “Implicit in the study of longitudinal data is the recognition that we are interested in the study of change” In the NLTCS this notion is best captured by the development of disability profiles for individuals over time, whereas with repeated cross-sections we can only look at “net change” for ensembles of individuals. Many have talked about longitudinal modeling using the NLTCS but few have actually carried it out. Three very recent examples of focused longitudinal modeling that have made use of the repeated measures within subject to better understand how disability changes with age are papers by Connor [3], Stallard [44], and White [46], although we suspect that there are others as well.

As we alluded to above, there is a clear longitudinal component to the NLTCS. Once individuals have become part of the NLTCS sample, the survey tracks them over time, through complete reinterviews every five years as part

of subsequent waves of the survey, until they die.¹ But the final years of a senior's life often times see rapid and drastic changes. Five-year intervals may be insufficient to measure most of these changes in mental and physical functioning.

Prior published estimates that indicate disability rates are decreasing are typically age and sex adjusted. These adjustments mask the changing demographics of our country, however, and they fail to answer relevant public health questions. We illustrate one such example here.

A major question on population aging is to what extent empirical morbidity trends support expansion, compression or equilibrium of morbidity in a population, and what are the corresponding underlying causal mechanisms. Authors that support the *compression of morbidity* theory [5, 16, 17, 40, 34] hypothesize that healthier lifestyles and medical improvements will delay the onset of disability hence compressing chronically disabled individuals at older ages near the end of life. This thesis paints an ideal scenario for the U.S. population: American seniors live longer and have higher quality lives.

The counter argument, the *expansion of morbidity*, is also based on the fact that early deaths (due to heart disease, workplace accidents, etc.) are decreasing, but concludes that chronic disability may increase as more Americans age further and die from natural deaths at the end of the natural life cycle [36, 37]. Gruenberg [21] made this argument earlier when he predicted that improvements in healthcare would save people from dying without curing them. He labelled this as "the failure of success." He speculated that because the oldest old encounter more severe chronic illness, and because more Americans are living to older ages, a larger proportion of Americans may experience chronic illness and disability in their lifetimes.

Even if disability rates at older ages are decreasing, the sheer increase in population of the oldest old due to the dramatic demographic shift occurring in this country means more Americans may be living to ages where some of these chronic disabilities become nearly inevitable.

Many authors [8, 35] point to the 1997 paper by Manton et al. [29] as the seminal paper proving that the compression of morbidity in the U. S. is, at least over the past 20 years, the correct theory. While the number of chronically disabled has increased, it has done so at a much slower rate due

¹The time between the first and second waves was only two years, but since 1984 the data have been gathered every five years, with the 2004 data collection representing the sixth wave.

to the decrease in disability rates at every age. But the work of Manton et al. [29], based on the NLTCs survey, still only looks at disability rates by age and cohort and indicates that disability rates at all ages are decreasing. It does not indicate that the seniors are afflicted by chronic disabilities for shortening lengths of time. This is typical of cross-sectional investigations of disability that indicate gross changes in particular function areas but can not provide information about the relationship between various disabilities, nor how, within individuals, disabilities compound with age. For example Reynolds, et al. [38] suggest that obesity at age 70 does not decrease expected remaining life, but increases disability throughout the remainder of life. Their analysis, however, simply compared static population proportions for activities of daily living. It did not sequentially monitor seniors' disability as is possible with NLTCs data.

Only longitudinal studies of a large cohort of seniors can provide information on how physical and mental abilities jointly or sequentially deteriorate and how individual disabilities compound with additional disabilities with age. Therefore we look to the NLTCs and other repeated surveys measuring disability status to help us address public health questions such as

1. How many Americans will live with disabilities?
2. What is the distribution of age of onset of disability? Are successive generations more able for longer periods of time?
3. What is the distribution of duration of disability, i.e. how frequently are these disabilities transient or chronic?
4. How will particular disabilities compound with other disabilities?
5. What are the cumulative individual and societal costs associated with these compounding disabilities?

Measurement of the 'severity' of disability is implicit in many of these questions.

We believe that only questions 1 and 2 may be answered with cross-sectional data. All others require subjects to be tracked longitudinally. While the NLTCs can answer these questions, it is uniquely useful answering questions 3-5, identifying patterns of disability and frailty in the elderly population. For measuring the compactness of an individuals' temporal and multivariate pattern of disability, however, sampling every five years is insufficient.

2 Some Issues Involving NLTCs Content

Measurement of chronic disability The National Long Term Care Survey (NLTCs) is designed to address changes in disability among elderly people in the United States through a longitudinal sampling design mechanism. It is evident from several highly visible headlines in scientific journals [30, 29, 19] and in the lay press [15] that the NLTCs provides measures of *chronic* disability. Although the amount of attention these and other publications give to the definition of *chronic* disability employed by the NLTCs varies, they rarely mention the interplay between the basic definition (as a disability lasting more than 90 days) and the complex survey design.

We have explored the operationalization of disability measurement in the NLTCs by examining the design of questionnaires and records on the core disability measures from the 1999 survey wave [7]. Here, we provide a summary of our findings and suggestions.

The operational definitions of *chronic* disability employed by the NLTCs incorporate an interplay between the lower bound of 90 days on the disability duration and the complex longitudinal structure of the survey. These definitions have their roots in the historic development of the survey at the early waves in the 1980s. Unfortunately, existing documentation provides only brusque descriptions of the measurement [26, 29, 30]. Thus, it is not surprising that the protocol of *chronic* disability measurement employed by the NLTCs gets misinterpreted by some of the most knowledgeable researchers in the field. The main argument of a recent publication [19], which points to the overestimation of chronic disability by the NLTCs, is based entirely on an overly simplistic interpretation of the NLTCs measurement protocol.

Through our detailed analysis, we found that the chronic disability measurement in NLTCs is only indirectly related to the basic definition of chronic disability—disability lasting or expected to last 90 days or longer—through the mechanism employed by the screener survey. Impaired individuals who screen-in have at least one problem with either basic or instrumental ADLs, where the actual or expected duration is 90 days or longer. These individuals can be classified as chronically disabled *at the time of the screener survey*. Subsequent disability measurements by the detailed surveys address short-term disability, and these are the measurements that produce the reported disability estimates.

Moreover, we have observed a large impact of the differences in the operational definitions employed in recording binary ADL and IADL outcomes

between the screener and the detailed parts of the survey. The detailed survey detects higher disability levels than does the screener survey. In addition, the ADL and IADL lists in the two survey components overlap but are not identical. Finally, time lags between the screener and the detailed interviews, various skip patterns that result in no ADL/IADL questions asked by the screener for certain subsets of individuals, and substantial chronic disability recovery rates make it problematic to accept the disability measurement in the NLTCs as the measurement of *chronic* disability.

Ideally, a longitudinal survey composed of a screener and detailed survey that aims to measure chronic disability based on the results of the detailed component should:

1. Include core disability questions that result in binary ADL and IADL outcomes each time the screener survey is administered.
2. Keep core disability questions that result in binary ADL and IADL outcomes consistent between the screener and the detailed surveys.
3. Administer disability duration questions in the screener and the detailed surveys in the same way.

These requirements will assure proper tracking of *chronic* disability status of the elderly. In addition, such data collection will be more efficient in that those individuals who have the screener and the detailed parts of the survey on the same day only need to answer one set of the ADL/IADL questions. Moreover, compatibility between the screener and the detailed survey will provide researchers who are interested in studying transitions in disability with additional longitudinal records obtained for those who experience time lags between the screener and the detailed surveys.

We appreciate the importance of keeping the survey structure intact insofar as it relates to the need for making core disability questions consistent with those employed in prior waves of the survey. Thus there is not much that can be done with future NLTCs waves to fully accommodate our concerns. But we would argue for closer compatibility between the screener and the detailed surveys through the use of additional “bridging” questions.

Comparability with other surveys There are a number of other surveys that attempt to measure disability among the elderly, and we also believe in

the importance of adding questions to improve the comparability of NLTCS findings with those from these other surveys.

As we noted above there is conflicting evidence in the literature regarding declines in severe disability, i.e., disability in activities of daily living (ADL) in the U.S. elderly population. As Freedman et al. [13] note in their review, “of the surveys of fair and better quality for evaluating trends, only the NLTCS found declines; the remaining surveys showed increases or no change.” Among potential explanations for these differences, Freedman et al. name “differences in how questions are worded” and differences in “defining specific ADL activities.” If the NLTCS can incorporate elements that allow one to compare its results with those from other surveys without large increases in survey burden, especially on the important concept of severe disability, then this should be one of the priorities. Changes may include additional questions that allow for better correspondence with main disability and morbidity questions in the Supplements on Aging to other surveys such as National Health Interview Survey and Medicare Current Beneficiary Survey. Although researchers are aware of inconsistencies on some level [11], further work needs to identify the changes and opportunities for obtaining closer correspondence with other surveys. Alternatively, cognitive research might be needed to address the issue of comparability of findings.

3 Optimal Design For Choice of Time Intervals for Longitudinal Statistical Models

Despite the fact that the NLTCs measures individuals' disability at discrete points in time, what we are really interested in are continuous-time models for disability that characterize individual disability profiles. A key issue, first elucidated by Singer and Spillerman [42, 43] over 30 years ago, is whether we can estimate the parameters of the continuous-time model from the discrete-time measurements. This is what they referred to as the problem of *embeddability*, and they and others have explored the issue in the context of the modeling of social phenomena by continuous-time Markov structures. See also the related work of Kalbfleisch and Lawless [22]. This issue of embeddability arose in the early 1990s in the context of the NLTCs because of the anomalous 2-year initial gap between waves 1 and 2, e.g., see Manton et al. [28], and the related discussion in [14].

Fienberg, Singer, and Tanur [9] discuss the implications of estimation from such models for longitudinal collection of data. In particular, they note that the usual strategy of collecting data at equally-spaced points in time may be inefficient compared with the “optimal design” for sampling when our focus is on the estimation of the parameters in the underlying stochastic model. Given the lack of convincing longitudinal stochastic models for disability in the elderly, we need to approach the timing of new waves for current cohorts in the NLTCs from a heuristic perspective. When do we expect the differences between individual disability profiles to be greatest? If we are measuring changes in curvature of profiles, for which individuals do need to have more frequent measurements to capture major shifts in curvature? We argue for more frequent measurements for the older cohorts below, using a related substantive heuristic.

If the focus of longitudinal models for the NLTCs is on disability profiles derivable from continuous-time stochastic processes, then for many statistical purposes there is at best a limited rationale for the use of survey weights as part of estimation strategies, c.f., the discussion in [10].

4 Alternative Data Collection Approaches for the NLTCs

The NLTCs began with 20,000 subjects in 1982 and has typically added 5,000-8,000 subjects per wave to replace those who've died, both oversampling the oldest old, and ensuring that there is a new cohort of seniors who have just turned 65 years of age. Therefore, if we “define” a generation somewhat arbitrarily as 25 years, new cohorts are introduced into the NLTCs every one-fifth of a generation.

We believe that, given the current age-period cohort of the NLTCs, up through the 2004 wave, we could learn more about disability profiles were new cohorts introduced less frequently, for example every one-third to one-half generation, but sampled more frequently. For instance at 5-year intervals 11% (1984-89) to 14% (1989-94 and 94-99) of subjects reporting no disabilities (requiring help with no activities of daily living and no instrumental activities of daily living) report 3 or more ADLs, institutionalization or death by the next wave. These are significant changes in functional health in 3.5 million Americans. Long assessment intervals do not promote full understanding of the dynamic nature of disability. Benefits of more frequent assessments of functional status in the elderly could include “more precise estimates of active life expectancy, more precise estimates of risk in etiological studies of disability, and an improved understanding of the course and overall burden of disability in a burgeoning population of older persons” [18]. To better understand the dynamic pathway of disability, we need to track subjects more frequently.

A more common transition is from no trouble performing activities of daily living (ADLs) but problems performing one or more instrumental activities of daily living (IADLs) to disability including 1 or more ADLs or death. Over 60% of subjects with no ADLs but one or more IADLs see increases in disability or death at the next wave. Likewise over 50% of subjects with the inability to independently perform 1 or 2 ADLs experience increases in disability by the next wave.

To understand the rapid changes in disability, increased observation is necessary. This is particularly true if health policy researchers need to identify particular patterns or combinations of disability that require special attention. Because it is unlikely that simply more frequent data collection will be possible given the budget and interview burden constraints, selec-

tion strategies become more important: whom and how frequently to follow subjects in a sample that changes dramatically over time. We believe that introducing a new cohort every 5 years may be more often than is necessary. Instead the NLTCs can focus on a more frequent study of its existing cohorts of seniors and focus less on regularly spaced cross-sectional estimates of the disabled elderly population.

Introducing new cohorts every one-third of a generation will still provide sufficient frequency for identifying changing patterns of disability over time. But increased monitoring of those sampled will provide researchers the ability to identify individual longitudinal patterns of disability and better determine how changes in disability compound.

Because already disabled seniors typically experience further increases in disability more frequently, a design 2 or 3 years between the waves for current cohorts will enable researchers to more closely monitor a subset of the chronically disabled who are experiencing rapid decreases in function. At the moment, the NLTCs sample contains major components that include chronically disabled individuals over 65 years of age plus the oldest-old (95+) supplement and the healthy supplement (a subsample from those who were found unimpaired according to the screener survey).

It is also worth considering the introduction of intermediate short follow-up surveys that would especially target the following categories:

1. Those already in the detailed survey who are at a lower risk for disability (e.g., those who became “healthy” over time after passing the NLTCs screener survey at some point), and
2. Those who are at a high risk of dying in the next few years.

The two supplemental components of the NLTCs, healthy and the oldest-old, closely relate to these candidate groups for more frequent follow-up.

Newly disabled older persons can recover independent functioning at high rates [20]. Elderly who become “healthy” over time can be considered at a lower risk for disability than those who stay disabled continuously. Studying low-risk older persons, Gill, Hardy and Williams [18] concluded that for this category of the elderly, disability should be considered as an acute reversible event more similar to falls than to progressive disorders more frequently associated with general processes of senescence [29]. Individuals do transition back and forth between disabled and healthy status, rather than proceeding sequentially from healthy to disabled to deceased [25]. As such, it would

be of interest to study factors related to predicting recovery from disability. However, it is difficult to learn about recovery in the context of a survey with long assessment intervals that mainly targets the occurrence of disability. Moreover, the current NLTCs with 5-year spacing between the waves can provide little information regarding the duration of disability.

Older persons who are more disabled are less likely to have follow-up assessments because of their high mortality and dropout rates [26]. This brings us to another subset of the elderly that will be important to study with more frequent assessments. Namely, those who are at a high risk of dying before the next 5-year wave would normally take place. Research has shown that health care expenses are the greatest at the last phases of life. Thus, about one-quarter of aggregate annual health care expenses is accounted for by the people in their last year of life; moreover, different studies from a range of countries indicate that high care consumption at the last years of life is irrespective of how long people live (see Batljan and Lagergren [1], and references therein). Obtaining more frequent data on the elderly in the last phases of life will provide better understanding of the dynamics of disability which in turn will facilitate better predictions for the cost of medical care.

Finally, more frequent monitoring may indicate the subtle markers indicative of institutionalization. Institutionalization is a large cost for chronically disabled seniors. Therefore providing assistance to those with disabilities, via increased community services or via assistive devices, will help seniors delay institutionalization and limit their health care costs. We might believe that to partially alleviate the need for long-term care, either disabilities need to be delayed or technologies that permit independent living with disabilities need to be developed. While this is true, one recent study estimates that 35% of seniors live without would-be-useful assistive devices or tools [27]. Therefore identifying populations who might benefit from available technology would also decrease institutionalization and health care costs.

To oversample individuals in high risk groups that may be about to see dramatic increases in disability shortly before death, we must be able to identify such individuals. Using a combination of demographic and health indicators might provide some guidelines for such selection. For example, one component to consider is data that are already available on activities of daily living (ADL). Studying severe disability (as defined by disability in ADL), Lynch et al. [25] observed some tendency toward terminal decline; that is, those near death can suffer an irreversible momentum toward death that minimizes the tendency to recover from disability status. During a 2-

year study of nondisabled older persons, Gill and Kurland [20] found that decedents were more likely to have developed disability, however, death was not always preceded by disability. Moreover, Medicare data can be used between waves to select whom to follow up based on major health transitions. Thus any sample selection scenario will have to address ethical issues in a careful fashion.

We leave open what to measure and how in the options involving different forms and frequencies of follow up. But we believe that the idea of modularization of the NLTCs to allow for different kinds of follow up and testing of alternative questions is worth considering. After all, as others² have pointed out the use of a screener is already a start towards modularization. But it may not go far enough along the pathway.

One of the goals of this paper is to lay out design options for a future NLTCs. Thus, we take as the first option the current design, perhaps with reduced sample sizes if funding is inadequate for continuation at present levels:

0. Status quo.

Next, we provide four examples of sampling designs that could increase the frequency of observation while maintain sampling costs.

1. Add a new cohort of subjects less frequently, i.e. every 8 years, while sampling every 2 years.
2. Add a new cohort of subjects less frequently, i.e., every 8 years, while resampling every 2 or 4 years depending upon prior levels of disability. Assign higher probabilities of being sampled with the 2-year follow-up to two categories: subjects who were screened-in but showed no ADL/IADL disabilities in the previous wave and subjects who were ADL disabled in the previous wave. Those who showed no disability in the previous wave may only need to be interviewed with the core survey questions pertaining to ADL/IADL unless found disabled.
3. Add a new cohort of subjects less frequently, i.e. every 8 years, while resampling every 2 or 4 years depending upon prior levels of disability. Assign higher probabilities of being sampled with the 2-year follow-up

²Robert Groves discussed this notion at the February 2006 expert meeting at the National Research Council.

to more disabled subjects, e.g., those who were ADL disabled in the previous wave.

4. Add a small new cohort of subjects every five years (current plan) and resample more disabled patients halfway through the 5-year cycle according to the weighted design described in 2.

These options could be characterized as versions of a “smaller but richer” NLTCs. Because our understanding of underlying statistical models and biological processes regarding disability over time is still at a rudimentary level, we have not attempted to derive optimal timing of followups. Some attention to the “best” choices for such followups prior to the funding of the next NLTCs cycle would likely reap major benefits.

Other more radical options that in some ways are natural extensions of the ones above include:

5. “Continuous” monitoring of subsets of those already included in the survey in prior waves. Here, “continuous” monitoring means relatively frequent interval measurement that is the same for all individuals in the selected subset, perhaps with increasing frequency towards older ages.
6. “Event-based monitoring” of subsets triggered by specific health-related events. Here, frequency of measurement would vary across people.

Any form of continuous monitoring involves greater administrative costs than periodic measurement and it requires a nimble and responsive survey organization. As with the other scenarios, these monitoring options are fully compatible with the introduction of new cohorts at less-frequent intervals, and/or of smaller sample sizes depending on resources available. Thus there are really far more than seven options implicit in the alternatives suggested above. What all of these but the status quo share, is that they involve tradeoffs between reduced frequency for the introduction of new cohorts, and targeted higher-frequency sampling for selected groups already in the survey. Such tradeoffs can be exploited with either level or reduced funding in a future NLTCs cycle.

We also can see a strong argument for the elimination of the buccal samples and other genetic and/or physiological measurements from future regular NLCS waves, or at least their uncoupling from the core survey measurement

components. Genetic and laboratory measures permeate the biomedical literature and we have yet to see a sound rationale for their inclusion in the NLTCS. Physiological measurements increase cost and complexity of the survey and remain exploratory. There are currently two waves of such information (1999 and 2004) that have gone virtually unanalyzed. The gathering of such biologic specimens could still be funded separately if a sound scientific argument based on data already collected can be made. We believe, however, that the core NIA resources devoted to the collection of such information in recent waves could be put to better use in more frequent measurements of disability of current cohorts.

5 Record Linkage and Analytical Longitudinal Data Files

To maximize the NLTCS's role and visibility in health policy debates, researchers must study health care costs associated with changing disability patterns. This requires the number of researchers contributing studies based upon the NLTCS and other administrative databases to increase. Therefore researchers outside the inner circle of NLTCS researchers must have uncomplicated access to de-identified Medicare records linked to subjects in the NLTCS survey. Even then however, the NLTCS, as currently maintained, may not provide frequent enough information to be relevant. Even the Center for Medicare and Medicaid Services (CMS) has claimed the NLTCS is sampled too infrequently to be useful in their health policy studies.

Links to medical utilization data may also provide validation to results from measures within the survey. Cox and Cohen [4] found in the 1980 National Medical Care Utilization and Expenditure Survey that a comparison of reported medical conditions by both patient and provider showed a weaker relationship than assumed by most researchers. This point relates to the issue of making at least some of the information from linked Medicare data accessible in the same analytical data files released to researchers without a special permission. Furthermore, NLTCS records need to be more easily linked to death records and cause of death since death and its cause are frequently a primary study outcome. Many of those who come to the NLTCS to carry out secondary analyses get a rude awakening when they discover that they do not have easy access such crucial information.

The preparation of such linked analytical files needs to be done for prior waves wherever possible, not simply going forward to a new wave.

6 Summary

The NTLCS provides important information for health science researchers. But thus far researchers have underutilized the longitudinal information available in the dataset. This year the sixth wave of data will be released but nearly all publications emanating from the NLTCs have only inspected the data cross sectionally. By increasing the frequency of measurements, the longitudinal information will become more valuable as sampled seniors' health status is measured more frequently. We have suggested a rethinking of the sampling strategies for collecting data for the NLTCs that would support such a longitudinal perspective.

In addition, we found that by design the NLTCs does not unequivocally provide measurements of *chronic* disability but rather of some combinations of chronic and short-term disability episodes. We have provided suggestions for future longitudinal disability surveys for proper tracking of *chronic* disability. Although not much improvement can be done at the moment to accommodate these concerns while preserving the core survey structure, it is important to understand the limitations of the NLTCs in that regard. Finally, we have suggested some changes to the content and data reporting/access strategies that would facilitate and perhaps even encourage longitudinal modeling.

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