Editorial

Findings From the 1st Round of the National Health and Aging Trends Study (NHATS): Introduction to a Special Issue

Over the last half century, the experience of late-life disability in the United States has been transformed. Medical advances now allow repair of vision loss, replacement of joints, and improved prevention and treatment of chronic conditions. Use of assistive and mainstream technologies is commonplace even at very old ages. For those living with limitations, residential options have expanded beyond traditional community housing and nursing homes to include a variety of alternative settings. There also has been growing recognition that daily life for older adults depends not only on their physical, cognitive, and sensory reserves, but also the social, physical, technological, and service environments around them.

Notwithstanding these advances, the number of older people living with disability is projected to increase markedly in the coming years (IOM, 2007). In 2011, the leading edge of the nation’s large baby boom cohort began to turn age 65. By 2030, the elderly population is projected to be over 72 million (20% of the population), up from about 48 million (15%) in 2015 (U.S. Census Bureau, Population Division, 2012). Recent studies suggest that declines in the prevalence of late-life disability that occurred during the 1980s and 1990s have reached a plateau in the 21st century, and that those now approaching late life have higher rates of disability than previous cohorts (Freedman et al., 2013; Lin et al., 2012; Martin, Schoeni, & Andreski, 2010). Moreover, gaps between racial and socioeconomic groups in disability levels (Schoeni, Martin, Andreski, & Freedman, 2005) and related inequities in medical care (IOM, 2002) and in the supply and quality of long-term care options (Mor, Zinn, Angelelli, Teno, & Miller, 2004) remain concerns.

Recognizing the shifting landscape of late-life disability, in 2008, the National Institute on Aging funded a new national study of disability trends and dynamics as a successor to the 20-plus year National Long-Term Care Survey. The National Health and Aging Trends Study (NHATS) is designed to foster a deeper understanding of national trends in late-life functioning, individual trajectories in functioning and accommodation, how these differ for various population subgroups, and the consequences of late-life disability for individuals, families, and society.

The first round of NHATS, which took place in 2011, gathered information in person from a nationally representative sample of over 8,000 Medicare beneficiaries aged 65 and older. At each round, detailed information is collected on participants’ physical and cognitive capacity; how activities of daily life are carried out; the social, physical, and technological environment; and participation in valued activities. A series of activities performed by respondents provide complementary measures of physical and cognitive capacity. In addition, information is collected on living arrangements, services available and used in residential care settings, economic status and well-being, and aspects of early life. In Round 1, caregivers of NHATS’ participants were interviewed as part of the National Study of Caregiving (NSOC), a supplement funded by the Department of Health and Human Services’ Office of the Assistant Secretary for Planning and Evaluation. Annual reinterviews are carried out with NHATS participants to document change over time. For those who die between rounds, a Last Month of Life interview collects details on place and quality of end-of-life care and daily activities since the prior interview. Replenishment of the sample to maintain its ability to represent the older Medicare population is planned for Round 5 in 2015.

In April 2013, an NHATS Early Results Workshop was held in Ann Arbor, MI jointly with the annual Michigan Center on the Demography of Aging (MiCDA) Disability TRENDS network meeting. The workshop served as a forum for investigators from diverse research perspectives to present initial findings from the first round of NHATS. Presentations covered three broad thematic areas, which are echoed in this issue: opportunities for studying an expanded disablement process that includes the environment, accommodations and related consequences; care and unmet needs for older adults; and common clinical conditions related to disability and functioning in later life. Papers in this volume are largely drawn from workshop presentations.

This paper provides a brief introduction to NHATS. We first review the NHATS’ sample design. We then present NHATS’ conceptual framework for studying disability and a broad overview of NHATS’ content areas, including its reengineered measures of disability. Finally, we close with a brief summary of the contributions in this volume, emphasizing themes that crosscut papers.

Overview of Sample Design

NHATS uses the Medicare enrollment file as its sample frame. The frame is especially well suited for addressing issues related to late-life disability because it represents...
the vast majority (96%; Centers for Medicare & Medicaid Services, 2010; Howden & Meyer, 2011) of adults aged 65 and older living in the United States and includes all residential settings. The 4% of older adults not eligible for Medicare, and therefore excluded from the frame, is mainly comprised of individuals who never qualified for Social Security benefits and those who delay enrollment while they remain on employer-based benefits, most of whom are aged 65–69 years.

A key goal of the sample design is to support analyses of disability trends and trajectories by 5-year age groups. Recognizing the burgeoning number of adults in the United States reaching the age of 90 (U.S. Census Bureau, 2011), NHATS over-samples persons aged 90 and older. An oversample of Black non-Hispanic individuals allows for investigation of disparities. Cases were selected for Round 1 using a stratified three-stage design, which selected counties or groups of counties from the contiguous United States, ZIP codes or fragments within these primary sampling units, and finally beneficiaries enrolled as of September 30, 2010.

Round 1 of NHATS has two interview instruments: the Sample Person (SP) interview conducted with study participants (or proxies if sampled persons were not able to self-report), and, as described in more detail below, a Facility Questionnaire (FQ) administered to participants living in nursing homes and other residential care settings. In Round 1, only the FQ was administered for nursing home residents. Of the 12,411 cases sampled for Round 1, 8,245 individuals had either a complete SP or FQ interview, for a response rate of 71%. For more details on NHATS Round 1 sample design and selection, see Montaquilla, Freedman, Edwards, and Kasper (2012).

An important contribution of NHATS is systematic identification of the type of setting in which older adults live so that community, residential care setting other than nursing homes, and nursing homes are delineated. Rather than rely solely on participants’ (or in some cases their proxies’) reports, NHATS relies on an interview with a facility staff member to confirm the type of place, and for places with more than one level of care, the level in which the sampled person currently lives (e.g., independent, assisted, special care unit, nursing home). The facility interview is designed to be triggered through a series of questions in the SP interview. It is administered to a staff person when a sample person is determined to be living in a residential care setting of any type, including nursing home, assisted or independent living, personal care, group home, and places with combinations of settings such as continuing care retirement communities. In addition to type of place, facility respondents are also asked about services available at the sampled person’s level of care and sources and amounts of payment.

Starting in Round 2, the design supports investigation of care received by older adults at the end of life. An interview with a proxy respondent, typically a family member, is administered for participants who die between rounds. Questions on settings and quality of care are modeled after instruments developed by Teno (2000) and provide a rich, national resource on end-of-life experiences for this population.

As of this writing, Rounds 2 and 3 have been completed (with response rates of 86% and 88%, respectively) and Round 4 is in the field. Plans are underway to replenish the sample in Round 5, so that it yields Round 1 totals by age and race, to conduct follow-up Rounds 6 through 8 with both the original and replenishment samples, to add collection of biologic material, and to field a second NSOC.

**NHATS Conceptual Framework**

NHATS has adopted a conceptual framework for studying disability that blends language and concepts from existing models (see Figure 1: Freedman, 2009). Much of the language used in NHATS is from the World Health Organization’s International Classification of Functioning (ICF; WHO, 2002). For instance, like the ICF framework, NHATS uses the term disability as an umbrella term rather than as a final outcome in the disablement process. Concepts are drawn from both the ICF and from the classic Nagi model of disablement (Nagi, 1965). The main pathway resembles both the well-known disablement process in which pathology leads to impairments, which in turn lead to functional limitations, and finally to disability (Verbrugge & Jette, 1994) as well as the main pathway of the ICF framework, in which health conditions influence body functions and structures, which in turn influence activities and participation.

NHATS’ framework extends existing approaches in several key respects (Freedman, 2009). Most important, the framework underscores the distinction between “capacity” of individuals to carry out activities and complex tasks and “accommodations” that individuals make to enhance their capacity. In this approach, capacity is defined as an individual’s physiological, cognitive, and sensory capabilities that form the building blocks to carry out activities. As described in more detail below, NHATS assesses this domain through a combination of self-reported items about ability to carry out tasks (by oneself and without devices) and performance-based measures. Accommodations are identified in a separate domain that captures behavioral responses to changes in capacity—in essence, how activities are carried out. Persons with higher levels of capacity, for example, may use a variety of compensatory strategies (Weiss, Hoenig, & Fried, 2007): take up assistive technology (e.g., start using a cane), change the physical environment in which an activity is performed (e.g., add a grab bar), change the demands of the activity (e.g., clean up at the sink instead of taking a bath), or reduce the frequency of an activity to maintain their ability to carry out activities by themselves. For those with lower levels of capacity, accommodation may take the form of assistance from another person alone or in combination with other strategies. Broadly construed, accommodations may also include
various transportation options that facilitate daily life and participation in valued activities (Satariano et al., 2012).

Following the ICF; and as empirically demonstrated by Jette and colleagues (Jette, 2009; Jette, Haley, & Kooyoomjian, 2003), the framework also makes a distinction between the ability to carry out by oneself essential activities, including mobility and self-care activities (analogous to activities of daily living) and household-related activities (also called instrumental activities of daily living), and the extent of participation in valued but elective activities that represent social, generative, and community realms. Finally, explicit recognition is given to the view that a person’s environment—broadly defined to include physical, social, technological and service-related aspects—influences the entire process.

These extensions in conceptualizing disability open up new avenues for investigation. Articles in this issue explore, for example, how the built environment and accommodations influence activity limitations and participation restrictions; the link between various types of accommodations and well-being; the role of insomnia in late-life physical capacity, household activities, and participation; the residential environment and its relation to unmet need for assistance; unmet need for assistance among those dually eligible for Medicare and Medicaid; and various aspects of the family’s role in informal caregiving. As more rounds of NHATS are completed, analysts will be able to draw upon this framework to study the dynamics and interrelationships of these domains of disability within individuals over time. As the sample is refreshed, researchers will also be able to track national trends in the various domains, to better understand the forces behind these trends, and to explore their consequences for individuals, their families, and society.

**NHATS’ Content**

NHATS’ content was developed by a multidisciplinary team of researchers from the fields of demography, geriatric medicine, epidemiology, health services research, economics, and gerontology. Table 1 provides an overview of sections that appear in the NHATS interview. More than two dozen sections form the NHATS core disability instrument; remaining content areas focus on precursors and consequences of disability for individuals, their families, and society. In addition, 11 sections were administered as part of the Last Month of Life interview beginning in Round 2.

NHATS’ core disability instrument was developed over a 2-year period. The process involved obtaining input from the scientific community, several rounds of cognitive testing, and a validation study, which established the reliability and validity of the core activity, participation, and accommodations measures (Freedman et al., 2011; 2013). Through this process, NHATS reengineered existing self-report measures of physical capacity and activity limitations and developed new items to measure participation and restrictions in valued activities. Here, we provide a brief overview of key measures in the protocol (with two-letter abbreviations for the interview sections that are the source) upon which the articles in this issue draw. For more details, see Kasper and Freedman (2014).
Health Conditions (HC)

This section asks about self-rated health, self-reported diseases and chronic conditions, hospital stays and surgeries, and a number of common clinical concerns in later life including falls, depressive and anxiety-related symptoms, and sleep quality.

Sensory and Physical Impairments and Symptoms (SS)

NHATS asks about vision, hearing, ability to chew and speak, and impairments in several body systems (breathing, upper and lower body strength and movement, balance/coordination) in the last month. In addition, there are questions about pain and fatigue in the last month.

Physical Capacity (PC, PE, AB)

Capacity measures in NHATS include both self-report items, modeled after traditional Nagi functional limitation measures (1965), and performance-based measures. Self-reported physical capacity is ascertained with questions about ability in the last month by oneself, and if relevant without devices, to carry out six pairs of less and more challenging tasks—walking 3 and 6 blocks, going up 10 and 20 stairs, lifting and carrying 10 and 20 pounds, bending over paired with kneeling down, reaching up over head without holding on paired with putting a heavy book on a shelf overhead, and using fingers to grasp small objects paired with opening a sealed jar with just one’s hands (Freedman et al., 2011). Respondents able to do the more challenging task skip the question about the less challenging task. Five performance-based measures of physical capacity are also administered to eligible participants, including three that form the Short Physical Performance Battery (Guralnik et al., 1994): a set of five increasingly challenging balance tests; a single and then up to five rapid chair stands; a 3-m walking course (performed twice); two measures of grip strength using a dynamometer; and two measures of peak air flow taken with a peak air flow meter (see Kasper, Freedman, & Spillman, 2011 for details).

Cognitive Capacity (CG, CP)

Cognitive capacity is assessed through both reports of cognitive status and brief activities. Sample persons are asked to rate their memory and to perform a memory-related activity (immediate and delayed 10 word recall), to respond to items related to orientation, and to perform activities related to executive function (clock drawing test in each Round, a computerized Stroop Test in Round 2). In addition, when a proxy interview is being conducted, the proxy respondent is asked to rate the sample person’s memory and to answer an 8-item screening instrument designed to screen for possible dementia (the AD8; Galvin et al., 2005; Galvin, Roe, Xiong, & Morris, 2006). Items may be combined to form a validated indicator of probable dementia (Kasper, Freedman, & Spillman, 2013).

Ability to Carry Out Essential Activities by Oneself (MO, SC, MC, HA)

NHATS includes questions about mobility, self-care, and household activities. Measures of mobility and self-care limitations focus on the ability in the last month to perform activities by oneself, with whatever aids or devices are used.
(e.g., grab bars in the bathroom; a walker). For household activities and managing medications, the NHATS protocol first assesses how household activities are carried out (in the last month: always by yourself, always with someone else, someone else always does it with you or for you, or it varies). Follow-up questions are tailored to this initial response. If the respondent ever did the activity by her/himself, the level of difficulty is assessed. A person who indicates someone else did the activity with or for them is asked whether the reason is related to their health or functioning. Self-care and mobility activities include: eating, bathing or showering, toileting, dressing, getting out of bed, getting around inside one’s home (or building if in a multi-unit setting), and leaving one’s home (or building if in a multi-unit setting). Household activities include: doing laundry, shopping for groceries, making hot meals, handling bills, and banking and handling less common money matters (such as opening or closing accounts, applying for loans). Keeping track of medications is asked in the medical care section.

Accommodations (MD, MO, DM, SC, DS, DT, HA, MC)

For self-care and mobility activities, respondents are asked whether in the last month they used specific assistive devices while doing a particular activity and whether they received help with the activity. Self-care devices include adapted utensils, grab bars in the bath/shower, a bath/shower seat, grab bars around the toilet, a raised toilet, and items to help with dressing such as a button hook or clothing that is easy to get on or off. Mobility devices include canes, walkers, wheelchairs, and scooters. Information on duration of help with self-care, and duration of help and device use for mobility activities, is also collected. For household activities, NHATS collects information on whether health or functioning is the reason the activity is done with or by someone else and on the use of computers for selected activities, such as banking and shopping. Assistance from another person with managing medications, doctor visits, and selecting health insurance plans is also assessed as part of the section on medical care activities. For getting outside, getting around inside, bathing, dressing, and household activities, respondents are also asked whether, compared to a year ago, they carry out the activity more often, less often or about the same.

NHATS also offers users the opportunity to explore how transportation options facilitate or impede late-life activities and participation. Transportation measures include driving habits, how participants get to places, and whether a transportation problem limits their participation in various activities. For participants who live in residential care settings, NHATS also collects whether transportation services are available to residents and if they were used in the last month. For additional details on transportation-related items in NHATS, see Skehan, Kasper, and Freedman (2014).

Participation and Restriction in Valued Activities (PA, LF)

For each activity, persons are asked whether they participated in the last month, whether their health or functioning limited their participation, and how important it is to the respondent to be able to participate (a lot, some, not at all). For select activities, NHATS also assesses whether a transportation problem limits participation. Eight types of activities are queried: talking on the phone, emailing or texting, socializing in person, attending religious services, attending organized club meetings, going out for enjoyment, caring for another person, and volunteering. For persons who work, details about current work are collected in a section on labor force participation.

Measures of the Environment (HT, SE, HH, CS, SN, HO, EM, CM, TE, FQ, IR)

NHATS collects details about the social, physical, technological, and service environments in which older adults carry out their daily lives. The social environment is captured through a roster of household members, living children (including biologic and step), up to five social network members, and a count of living siblings and through items about the community in which the sample person lives. The physical environment is captured through questions about characteristics of the home features (e.g., floors, stairs) and modifications the sample person has made to the home (e.g., addition of grab bars) and observations by the interviewer of the home environment. The service environment is captured through questions about the type of housing (which trigger a FQ if needed) and services offered to and used by persons in residential care settings other than nursing homes. Questions about the technological environment capture use of the internet in daily activities and forms of communication such as email and texting.

Papers in This Volume

Papers in this volume collectively focus on components and consequences of late-life disability. At the time of the Early Results workshop, when many of the papers were first presented, only the first round of NHATS was available. Hence, the collection explores new territory both conceptually and empirically but is largely descriptive. As a group, the papers set the stage for more dynamic investigations as future rounds of NHATS become available. Here, we synthesize the main contributions of the collection.

Three of the papers (by Clarke; Lin and Wu; and Skolarus et al., in this issue) take advantage of NHATS’ expanded conceptual framework to address the role of the environment and/or accommodations in older adults’ daily lives. Clarke investigates the intersection of the physical environment and mobility accommodations on reports of difficulty going outside by oneself. She finds that entrance stairs pose a barrier to getting outside for those using a walker. Ramps
on the other hand facilitate outdoor mobility for those using wheeled devices but increase the risk of difficulty going outdoors for those who do not use any mobility device. This nuanced understanding of the intersection between environmental demands and accommodations is critical for the planning and development of age-friendly environments that promote aging in place. Lin and Wu and Skolarus and colleagues both investigate the role of alternative accommodations (or "coping") strategies—using no devices or personal assistance, using assistive devices, or using personal care—on two distinct sets of outcomes. Lin and Wu focus on the role of such coping strategies in maintaining older adults’ well-being and find that among persons with self-care limitations, use of assistive devices is associated with greater well-being, while personal help is negatively related. Skolarus and colleagues investigate the role of accommodations in poststroke disability management. Their main finding underscores that although accommodations are commonly used by older adult survivors, unmet need is also substantial. Both studies make the important point that having accommodations in place may not be sufficient to address gaps between capacity and doing activities that are necessary or valued, and that much is still to be learned about which accommodations are effective and for whom.

Spira and colleagues also take advantage of the expanded disablement framework to explore the association between insomnia symptoms in later life and three measures of disability: underlying physical capacity, household activity limitations, and participation. They find that, although insomnia symptoms are not associated with measures of physical capacity, they are associated with being less independent in activities important for community living and with restrictions in doing valued activities that contribute to quality of life. Their findings highlight the importance of distinguishing among different domains of disability.

The remaining papers focus on consequences of disability, and in particular, care-related issues and unmet needs for assistance in the older population. Freedman and Spillman address the residential landscape for older adults with care needs. They find that 15% of older adults live in settings other than traditional community housing: retirement and senior housing communities, assisted and independent living settings, and nursing homes. These settings form a continuum with regard to population care needs. They find that unmet needs are prevalent among older adults with limitations across all settings. However, after controlling for differences in resident characteristics across settings, those in retirement or senior housing communities have a higher likelihood of unmet needs than those in traditional community housing, while those in independent or assisted living settings have a lower relative likelihood.

Allen and Mor (in this issue) examine adverse consequences linked to unmet needs for assistance for a particularly vulnerable subset of older people, Medicare beneficiaries who are low income and also qualify for Medicaid. Their investigation highlights that among those who receive help or have difficulty with mobility, self-care, or household activities, persons who are dually eligible have higher rates of adverse consequences than other Medicare beneficiaries.

The final two papers address aspects of informal caregiving, including the role of the availability of family caregivers in the receipt of assistance with daily activities (Wolf) and the involvement of family members in navigating medical care (Wolf and Spillman). Wolf examines the relative role of supply of informal caregivers in the demand for care, using children of unmarried older adults as the focus, and finds little evidence of a supply-driven effect on receipt of any help. However, caregiver-supply factors are associated with the number of helpers and total hours of help received. He concludes that foreseeable trends in the number of children available to care for older adults will influence patterns of receipt of help in the future. Wolff and Spillman examine the role of helpers in navigating health care for older adults. Their analysis shows that more than one third of older adults receive assistance primarily from family members, who attend and participate in physician visits, help with prescribed medication management, or do both. The 3.3 million older adults who receive both types of help are a high-need subgroup who also receives substantial levels of assistance from caregivers with mobility, self-care, and household activities.

The papers in this volume represent intriguing initial findings from the first round of NHATS. They illustrate the breadth and depth of the NHATS content and how it can be applied to investigate new questions regarding late-life disability. As NHATS moves forward and develops as a unique longitudinal resource, we hope this volume inspires others to contribute to the study’s overarching aim to guide efforts to reduce disability, maximize functioning, and enhance quality of life of older Americans.

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