

Long-Term Care (LTC) Statistics Branch External Review: One Year Follow-Up

Presented to the NCHS
Board of Scientific Counselors

Presented by Lauren Harris-Kojetin

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U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES
Centers for Disease Control and Prevention
National Center for Health Statistics



Table 1. Description of LTC Services

Supportive services	<ul style="list-style-type: none">• These services are the core of LTC and include help with activities of daily living (ADLs) such as bathing, eating, walking, or going to the toilet (Stone, 2000).• They also include help with instrumental activities of daily living (IADLs) such as household chores, shopping, cooking, managing money, and paying bills (Stone, 2000).
Medical and rehabilitative services	<ul style="list-style-type: none">• People with chronic disabling conditions often need ongoing medical monitoring and intervention.• Some people require rehabilitative services to recover, or to delay a decline in physical or mental functions.
Palliative care services	<ul style="list-style-type: none">• These are services usually provided near the end of life that comprehensively manage the physical, social, spiritual, and existential needs of patients (Kaplan & Urbina, 2000).

Source: Feldman et al, 2005



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Where is Long-Term Care Provided?

Long-term care services can be provided in a variety of settings including one's home (e.g., home care or personal care services), in the community (e.g., adult day care), in residential settings (e.g., assisted living or board and care homes), or in institutional settings (e.g., intermediate care facilities or nursing homes). The term "home- and community-based services" refers collectively to those services that are provided outside of institutional settings.

Panel Members

- **Penny Feldman, PhD**—Visiting Nurse Service of NY (*Chair*)
- **Peter Kemper, PhD**—The Pennsylvania State University
- **Andrew Kramer, MD**—University of Colorado Denver
- **Nancy Mathiowetz, PhD**—University of Wisconsin-Milwaukee
- **Vincent Mor, PhD**—Brown University School of Medicine
- **William Scanlon, PhD**—Health Policy R&D
- **Graham Kalton, PhD**—Westat, Inc. (*BSC Liaison*)
- **Michael O'Grady, PhD**—National Opinion Research Center (NORC) (*BSC Liaison*)

Overarching Panel Recommendations

1. Develop strategic plan
2. Integrate LTC provider surveys into unified set of surveys

Specific Panel Recommendations

1. Engage users
2. Establish regular expert review process
3. Develop inclusive set of sampling frames
4. Develop core content
5. Develop strategy for linkage
6. Field the NSRCF
7. Evaluate changes in data collection
8. Explore sharing sampling frames

National Survey of Residential Care Facilities

National Health Care Surveys



Field National Survey of Residential Care Facilities

- Fielding: March-
November 2010
- Aim: to provide
public use files
in early 2012



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Engage Users

- Center for Excellence in Assisted Living (CEAL) Board members and the National Survey of Residential Care Facilities
- Nursing Home Data Needs for the 21st Century session at the August 2010 National Conference on Health Statistics
- Request feedback at targeted user meetings
- Disseminate feedback form at National Conference on Health Statistics

Engage Users (2)

- All LTCSB staff use e-mail tagline
LTCSB welcomes your questions and comments
by email (ltcsbfeedback@cdc.gov) or phone
(301-458-4747).
- Maintain and assess LTCSB data request
database
- Future “engager” plans
 - Conduct outreach/engage meetings with other
stakeholders (providers, academia)
 - Solicit feedback from federal government
stakeholders

Areas for Improvement Based on User Feedback to Date

- Enhance web page navigation and usability
- Raise awareness of products, web pages, and list serv
- Produce data briefs, fact sheets, and other short, concise products

Racial Differences in Functioning Among Elderly Nursing Home Residents, 2004

Adrienne L. Jones; Nancy L. Sonnenfeld, Ph.D.; and Lauren D. Harris-Kojetin, Ph.D.
Division of Health Care Statistics

Key findings

- Black nursing home residents had poorer functional status than residents of other races.
- Black residents were more likely to be totally dependent in both eating and toileting and to be totally dependent in all five activities of daily living.
- Black nursing home residents were more likely to be incontinent of bladder, bowel, or both.
- Among bladder-incontinent nursing home residents, black residents were less likely than those of other races to have scheduled toileting plans.

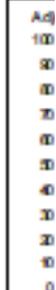
Reduce the number of nursing home residents who are totally dependent in eating and toileting.

In 2004, the U.S. nursing home resident population was 1.5 million, with 1.2 million black and 0.3 million white residents.

Keywords: Incontinence

Racial and Ethnic Differences

Figure 1. United States, 2004



Source: National Nursing Home Survey, 2004

Prevalence and Management of Pain, by Race and Dementia Among Nursing Home Residents: United States, 2004

Manisha Sengupta, Ph.D.; Anita Bercovitz, M.P.H., Ph.D.; and Lauren D. Harris-Kojetin, Ph.D.

Key findings

Data from the National Nursing Home Survey, 2004

- About one-quarter of all nursing home residents reported or showed signs of pain.
- Nonwhite residents and residents with dementia were less likely to report or show signs of pain compared with white residents and residents without dementia.
- Nonwhite residents with dementia were least likely, and white residents without dementia were most likely to report or show signs of pain.
- Forty-four percent of nursing home residents with pain received neither standing orders for pain medication nor special services for pain management (i.e., appropriate pain management).
- Among residents with

Potentially Preventable Emergency Department Visits by Nursing Home Residents: United States, 2004

Christine Gaffrey, Ph.D., Division of Health Care Statistics

Key findings

Data from the National Nursing Home Survey, 2004

- In 2004, 8 percent of U.S. nursing home residents had an emergency department (ED) visit in the past 90 days.
- Among nursing home residents with an ED visit in the past 90 days, 40 percent had a potentially preventable ED visit.
- Injuries from falls were the most common conditions

In 2004, there were over 110 million visits to EDs throughout the United States (1). Older adults, particularly nursing home residents, comprise a large and growing percentage of those visiting the ED (2,3). Prior research has identified conditions that may lead to potentially preventable visits to an ED among nursing home residents (4–11). Fever, chest pain, heart disease (mainly heart failure), mental status changes, gastrointestinal bleeding, urinary tract infections, metabolic disturbances, pneumonia, diseases of the skin, and injuries due to falls have been identified as reasons for potentially preventable visits to an ED. Researchers argue that some of these conditions, such as urinary tract infections, could be more appropriately treated in the nursing home. Other conditions prompting ED visits, such as those related to falls or pneumonia, may have been avoided by preventing the adverse health event itself. Decreasing potentially preventable visits to EDs may reduce health care costs, lessen trauma or complications resulting from medical treatment for nursing home residents, and improve quality of care. This report presents the only national information on potentially preventable ED use among U.S. nursing home residents.



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DATA BRIEF



Home Health and Hospice Care 2007 National Home and Hospice Care Survey

Fact Sheet

This fact sheet provides selected data highlights from the 2007 National Home and Hospice Care Survey (NHHCOS), one in a continuing series of nationally representative sample surveys of U.S. home health and hospice care agencies.

In 2007, 1,036 agencies participated in NHHCOS. These agencies were either certified by Medicare or Medicaid or were licensed by a state to provide services to home health care or hospice care patients. Agencies that provided only homemaker services or housekeeping services, assistance with instrumental activities of daily living, or durable medical equipment and supplies, were excluded from the survey. Data were collected through in-person interviews with agency directors and their designated staffs.

Public-use data files and documentation may be viewed and downloaded from the NHHCOS website: <http://www.cdc.gov/nchs/nhhcs.htm>.

Selected Data Highlights

Number of agencies

- In 2007, there were 14,500 home health care and hospice care agencies in the United States: 75% (10,800) of the agencies provided home health care only, 15% (2,200) provided hospice care only, and 10% (1,400) provided both home health care and hospice care (mixed).
- From 2000 to 2007, the number of home health care only and hospice care only agencies increased, while that of mixed agencies decreased.

Organizational characteristics

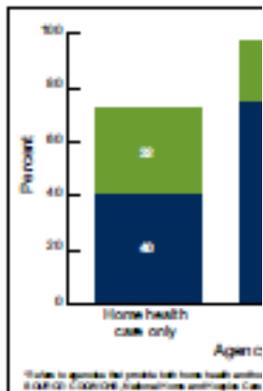
- Home health care only agencies were more likely than mixed agencies to be proprietary (76% and 26%) and located in a metropolitan statistical area (76% and 58%), and less likely to be Medicare- (80% and 98%) or Medicaid-certified (79% and 97%).
- Hospice care only agencies were more likely than mixed agencies to be located in a metropolitan statistical area (73% and 58%).

- No significant difference hospice care only and mixed affiliation, or certification

Number of current patients

- On average, at time of interview agencies served 109 and current home health care patients
- On average, at time of interview agencies served 78 and current hospice care patients

Figure 1. Home health care patient source and agency type: United States, 2007



Selected primary patient referral sources

- Mixed agencies (74%) and hospice care only agencies the primary referral source (Figure 1).
- For over three-quarters of mixed and hospice care agencies, hospital physicians' offices (45%) referral sources of hospice care patients



Home Health Care Patients and Hospice Care Discharges 2007 National Home and Hospice Care Survey

Fact Sheet

This fact sheet provides selected data highlights from the 2007 National Home and Hospice Care Survey (NHHCOS), one in a continuing series of nationally representative sample surveys of U.S. home health and hospice care agencies and their patients.

In 2007, data were obtained for 4,683 current home health care patients and 4,733 hospice care discharges. Eligible agencies were either certified by Medicare or Medicaid or were licensed by a state to provide services to home health care or hospice care patients, currently served home health care patients, or currently or recently served hospice care patients. Agencies were excluded from the survey if they provided only homemaker services or housekeeping services, assistance with instrumental activities of daily living, or durable medical equipment and supplies. Data were collected through in-person interviews with agency directors and their designated staffs. Public-use data files and documentation may be viewed and downloaded from the NHHCOS website: <http://www.cdc.gov/nchs/nhhcs.htm>.

Selected Data Highlights

Current home health care patients

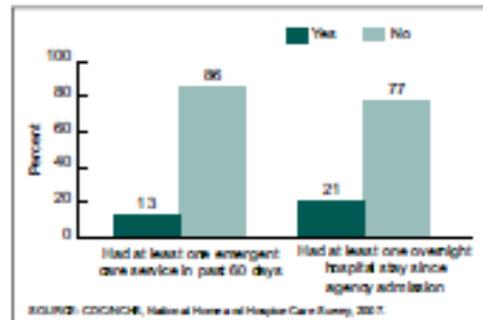
Demographic characteristics

- On any given day in 2007, there were 1.46 million current home health care patients in the United States.
- Home health care patients tended to be aged 65 and over (69%), female (64%), and white (82%).

Emergency and hospital care use

- More than one-tenth (13%) of current home health care patients had used emergency care in the 60 days before the agency interview (Figure 1).
- More than one-fifth (21%) of current home health care patients had at least one overnight hospital stay since admission to the home health care agency.

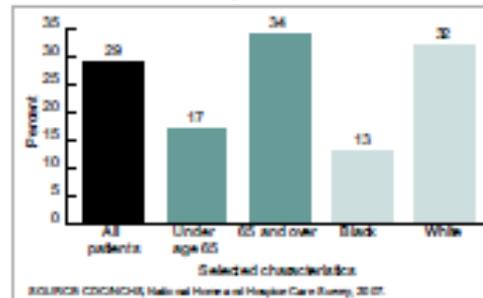
Figure 1. Use of emergency care services and overnight hospital stays of current home health care patients: United States, 2007



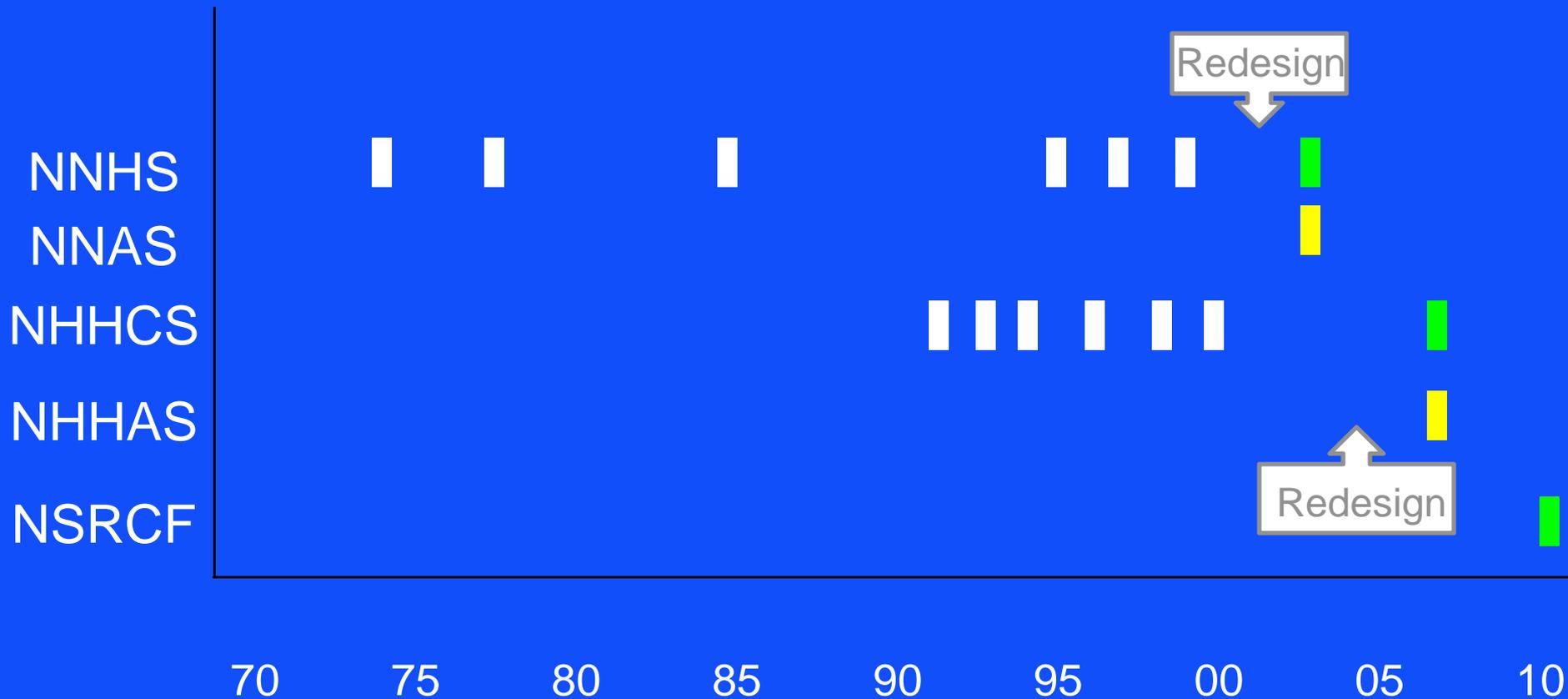
Advance directives

- In 2007, 29% of current home health care patients had at least one advance directive (Figure 2).
- Home health care patients who were aged 65 and over were twice as likely as younger patients to have an advance directive (34% and 17%).
- White home health care patients were more than twice as likely as black patients to have an advance directive (32% and 13%).

Figure 2. Current home health care patients with at least one advance directive on record: United States, 2007



NCHS LTC Provider Survey Data Collection, 1973 - 2010



NCHS LTC Provider Surveys at a Crossroads

- Challenges with the current LTC provider surveys approach
 - **Content**—Value of NNHS and NHHCS relative to Centers for Medicare & Medicaid Services (CMS) administrative data
 - **Data currency**—periodic data collection, getting back into field uncertain, less appealing to potential partners
 - **Scope**—Gaps in coverage of LTC providers and recipients
- What strategy can work toward addressing these challenges in a sustainable way with limited resources?

National Long-Term Care Providers Survey

- Content
 - Small **core** of information on provider characteristics, practices, and staffing
 - **Link to administrative data wherever possible**
 - CMS data on nursing homes, home health agencies, hospices
 - Primary data collection only when administrative data not available
 - Residential care facilities, adult day programs, home care agencies
 - **Less expensive modes** (mail/phone/web) than in-person surveys

National Long-Term Care Providers Survey (2)

- Data currency
 - Annually or bi-annually
- Scope
 - Broaden range of providers routinely covered
 - Nursing homes
 - Home health agencies
 - Hospices
 - Residential care facilities
 - Adult day programs
 - Home care agencies
 - Ability to add other providers as they emerge

What Core Might Provide (Selected Examples)

- Use frame, administrative data, and primary data
- Trends over time in the numbers and composition of LTC providers (**supply**) and encounters (**use**)
 - Distribution of providers and encounters by geography, chain status, size, ownership, services offered
 - Growth or decline in providers and encounters overall, within, and among provider types
 - Distribution of encounters by age, race, gender, payment sources
- Monitor the effects of policy changes

Selected Examples of Provider Characteristics

- Health information technologies
- Transition to community
- Referral patterns
- Diversification of services
- Contracts with outside providers
- Revenue sources
- Monitoring infections
- Culture change practices
- Staffing
- Interdisciplinary teams
- Vaccination practices
- Emergency preparedness

Vision

Care recipient characteristics beyond the core

Administrative records

Primary data

Primary data

Provider characteristics beyond the core

Administrative records

Primary data

Primary data

Primary data

COMMON CORE

(Provider and aggregate-level care recipient characteristics on samples)

Via **administrative records**

Via **primary data**

Frame(s) (e.g., numbers, geographic distribution, size)

PROVIDER TYPES

Hospices

Nursing Homes

Home Health Care Agencies

Residential Care Facilities

Home Care Agencies

Adult Day Programs

Potential Products

- Data briefs or fact sheets
 - LTC provider spectrum
 - Specific types of providers
- Report giving overview of LTC supply and use
- Public use file

Next Steps

- Select common core—expert meeting
- Decide frequency of frame maintenance and data collection assuming \$1M/year
- Determine 2011 activities
 - Which frame(s)—e.g., update 2009 NSRCF?
 - Sample design
 - Data collection mode(s) and methods work
- Develop request for contract for 2011
- Make arrangements with CMS to obtain administrative data