U.S. Department of Health and Human Services
Assistant Secretary for Planning and Evaluation
Office of Disability, Aging and Long-Term Care Policy

THE NATIONAL LONG-TERM CARE SURVEYS (1982, 1984, 1989)

March 1992

Office of the Assistant Secretary for Planning and Evaluation

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This report was prepared by HHS's Office of Family, Community and Long-Term Care Policy (now DALTCP). For additional information about this subject, you can visit the DALTCP home page at http://aspe.hhs.gov/_/office_specific/daltcp.cfm or contact the office at HHS/ASPE/DALTCP, Room 424E, H.H. Humphrey Building, 200 Independence Avenue, S.W., Washington, D.C. 20201. The e-mail address is: webmaster.DALTCP@hhs.gov. The Project Officer was Robert Clark.

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OVERVIEW

The 1982, 1984, and 1989 National Long-Term Care Surveys (NLTCS) are household surveys of functionally impaired Medicare beneficiaries age 65 and over.

The surveys provide nationally representative data on:

- the prevalence and patterns of functional limitations, both physical and cognitive;
- medical conditions and recent medical problems;
- health care services used;
- the kind and amount of formal and informal services received by impaired individuals;
- demographic characteristics like age, race, sex, marital status and income;
- out-of-pocket expenditures for health care services and other sources of payment; and
- and housing and neighborhood characteristics.

There are differences among the three surveys.

- The 1982 survey obtained detailed data only non-institutionalized functionally impaired persons. A separate Informal Caregivers Survey (ICS) was conducted.

- The 1984 survey covered functionally impaired non-institutionalized and institutionalized persons. It included persons who aged in (that is, reached age 65) between 1982 and 1984. A next-of-kin interview was conducted for persons who died between 1982 and 1984. There was no separate survey of informal caregivers.

- The 1989 survey also covered non-institutionalized and institutionalized persons. It included persons who have aged in during that period. There was no next-of-kin interview for the deceased. There was an ICS. Also, there was a six-month telephone follow-back survey of institutionalized persons.

The Office of the Assistant Secretary for Planning and Evaluation (ASPE) and the Health Care Financing Administration (HCFA) co-sponsored the 1982 survey. Census collected the data from the impaired elderly. The National Opinion Research Center (NORC) surveyed the informal caregivers.

HCFA and the National Center for Health Services Research co-sponsored the 1984 survey. Census collected the data. Duke University prepared a public use file covering both the 1982 and 1984 surveys and including Medicare Part A bill records. The public use file is available from The National Technical Information Service (NTIS), Department of Commerce, 5285 Port Royal Road, Springfield, Virginia 22161.

The National Institute on Aging sponsored the 1989 survey under a grant to Duke University, which has contracted with the Census Bureau to collect the data. ASPE supplemented funding for the basic survey to provide for the informal caregiver survey, nursing home resident follow-back and addition of supply variables to the respondent record. A public use tape is available from the National Archives of Computerized Data on the Aging, Ann Arbor, Michigan.

THE 1982 NLTCS

The 1982 survey resulted from the Department of Health and Human Services (DHHS) Working Group on Long-Term Care Data, which in 1980 produced a report titled DHHS Statistical Plan for Nationally Representative Data (unpublished). The original purpose of the 1982 survey was to examine the health problems and functional limitations of elderly persons living in the community, and to determine the use and cost of both formal and informal services by this population.

The dual cross-sectional and longitudinal aspects of the 1982 and 1984 surveys along with the linked Medicare records permit analysis of a broad range of questions. It is possible to examine demographic, health and functional status changes in the disabled elderly living in the community along with the trajectory of service use and costs over time. These survey characteristics were further enhanced by the 1989 survey.

SAMPLE DESIGN

The sampling frame from which the 1982 survey sample was drawn is the Medicare Health Insurance Skeleton Eligibility Write-off (HISKEW) file. It included all those enrolled on or before March 31, 1982. The sample was stratified geographically into Long-Term Care Primary Sampling Units (LTC PSU's) which were grouped into 173 long-term care strata.

Thirty-nine of the strata had a single LTC PSU, which was then designated a Long-Term Care Self-Representing Primary Sampling Unity (LTC SR PSU). The remaining 134 strata each had more than one LTC PSU. However, only one LTC PSU was selected from each stratum, converting it into a Long-Term Care Non-Self Representing Primary Sampling Unit (LTC NR PSU).

The initial sampling rate within the selected PSU's, both self-representing and non-self-representing, was 10%. Those under age 65 and those who lived outside the 173 PSU's were eliminated; the remaining persons were sorted into four age strata: 65-74, 75-79, 80-84, 85+. The sample was reduced to approximately 55,000 persons.

This sample was further divided into 101 reduction groups, since it was expected to be larger than needed. To obtain the desired precision of measurement while keeping costs under control it was determined that 6,000 detailed interviews were required. For this purpose, a screening sample of 55,000 was considered too large.

Of the 101 reduction groups, 66 were retained, leaving about 36,000 (actually 35,789) candidates for a screening interview. Of these, about 2,500 persons were found to have died, entered an institution or become ineligible for some other reason by the time the sample was drawn. Almost 6,400 persons qualified for detailed interviews. Approximately 300 of these refused or were otherwise unavailable.

The procedures for administering the survey to the 36,000 persons in the screening sample were as follows:

1. Sending an introductory letter to each sample person to acquaint him/her with the survey.

2. Administering a short screening interview by telephone (for 70% of the cases) to delete those who had no functional limitations, who had died, or who had entered an institution.

3. Sending a second introductory letter to persons whose responses to the screen indicated that they had functional limitations.

4. Using a control card to collect demographic information and to record all contacts with the household.

5. Administering the detailed interview to persons living in the community with (according to the screen) functional limitations.

6. Interviewing in a later separate survey the informal caregivers of those with functional limitations.

On the screen, nine activity of daily living (ADL) related questions and seven instrumental activity of daily living (IADL) related questions were asked. Basically, respondents were asked whether they had any problem with individual ADL's and IADL's that has been present or was expected to be present for a period of three months or longer. This time frame was used to screen in persons with long-term impairments. An impairment of this duration on any ADL or IADL fulfilled the requirement for the person's inclusion in the survey. Of the 6,349 persons found to be functionally disabled based on their responses to these questions, 1,462 were ADL-only impaired, 1,277 were IADL-only impaired and 3,610 were ADL and IADL impaired.

The detailed community survey covered the following areas: (a) functional status, as measured by ADL's and IADL's; (b) other functioning (e.g. physical, mental, and social); (c) housing and neighborhood characteristics; (d) health insurance; (e) medical

providers and prescription medicines; (f) cognitive functioning (as measured by the Short Portable Mental Status Questionnaire); and (g) military service, ethnicity, income and assets.

Within the functional status category, there were questions about informal caregivers, formal service use and sources of payment.

On the detailed survey, the ADL's were eating, getting in and out of bed (transfer), getting around inside, dressing, bathing, toileting and continence. For each ADL, seven or eight separate questions were asked. Both performance and capacity were measured.

The IADL's were heavy housework, light housework, laundry, meal preparation, shopping, getting around outside, going places outside of walking distance, money management, taking medicine and use of the telephone. Both performance and capacity were measured directly.

Detailed in-person interviews began in June 1982 and ended in early October. Of 6,393 persons screened in to the sample, based on being chronically dependent in one or more functions, detailed interviews were completed for 6,088, for a 95.2% response rate.

The Census Bureau constructed weights to correct for three factors that prevent the screener survey from representing the universe accurately: (a) persons in the sample who could not be interviewed; (b) population distributions in the LTC PSU which differed from those of the strata from which they were drawn; and (c) total population in the universe differing from that provided by independent Census estimates of the population.

THE 1982 ICS

In addition to a survey of the functionally impaired elderly living in the community, there was conducted a separate but linked survey of the informal caregivers of these persons. Because of funding limitations and the belief that helping with ADL's was more time-consuming and stressful than helping with IADL's, the sample was limited to those providing assistance with ADL's.

NORC did the field work for the survey, using informal caregivers identified on the Census Bureau's control cards for the interviews with the functionally impaired elderly.

A caregiver was defined as someone aged 14 and over who gave unpaid assistance with at least one ADL to a sample member.

The intended sample size was approximately 2,000. To achieve this, a subsample of NLTCS respondents was selected, first, by selecting a subsample of LTC PSU's and, second, by identifying a subsample of impaired persons within the selected PSU's. All caregivers who assisted a given NLTCS sample member were interviewed where possible.

The questionnaire included information on:

- the relationship of the caregiver to the sample member;
- changes in the health of the sample member since his/her interview;
- the kinds of care given to the sample member;
- costs in terms of out-of-pocket expenditures, time and inconvenience;
- restrictions on the caregiver's mobility due to providing care;
- restrictions on working due to providing care;
- feelings about providing care and about nursing homes;
- the mental competence of the caregiver; and
- demographic and socio-economic data on the caregiver.

The principal questionnaire was used for those still providing care and a slightly modified one for those who had ceased providing care. Interviews were conducted between October 15, 1982 and January 22, 1983.

A total of 2,349 individual caregivers were assigned for interview. Of these, 1,925 interviews were completed, 260 were classified as ineligible and 164 were not completed for reasons other than ineligibility (e.g. respondents could not be located, were too ill, refused, or had died). The response rate was 81.9% for all cases and 92.1% for eligible cases.

The weighting procedures are complex, involving seven factors: (a) overall selection probabilities for the long-term care sample; (b) non-response during the screen; (c) discrepancies from the population arising from the selection of the LTC PSU's; (d) independent estimates of the population size; (e) non-response during the main long-term care interview; (f) subsampling probabilities for the ICS sample; and (g) non-response during the ICS interview.

THE 1984 NLTCS

The 1984 survey used a questionnaire for the community-based impaired elderly that was virtually identical to the 1982 community questionnaire. A separate questionnaire was administered to persons in institutions. There was no informal caregiver survey. Survey work was conducted between June and October 1984.

The sampling procedure for the 1984 survey differed from the 1982 survey in several respects.

- All surviving persons: (a) who had reported chronic disability on the 1982 screener; or (b) who had not been not screened in due to being institutionalized on April 1, 1982 were interviewed regardless of their 1984 functional status.

- From the original 25,541 persons who had not reported functional impairments in 1982 (and who were not institutionalized), a 47% random sample (approximately 12,100 persons) was drawn and subjected to the screening procedure used in 1982.

- 4,916 persons who aged in, i.e. turned age 65 between 1982 and 1984, were screened so that, in addition to having a longitudinally followed sample in 1984, the full cross-section of functionally impaired persons age 65 and over in 1984 could be assessed.

- From these four "sources"--(1) 1982 community disabled, (2) 1982 institutionalized, (3) 1982 non-disabled but screened in 1984, and (4) aged-in persons--6,264 community-based disabled elderly were identified. Detailed interviews were completed for 5,934 persons.

- Persons who were in institutions in 1984 were interviewed with a separate instrument that contained a number of questions on institutional use in the interim period and the sources of payment for those services. Of 1,773 persons in institutions in 1984, interviews were completed for 1,690.

- A "next-of-kin" interview was conducted for persons who died between 1982 and 1984. Of 3,214 persons who had died, interviews were completed for 2,475 next-of-kin.

From a design standpoint, all persons either disabled or institutionalized in 1982 were interviewed in 1984 without screening.

This has the advantage of providing data on persons who became non-disabled over the two year period. It has the disadvantage that one cannot obtain a set of persons exactly comparable to the 1982 "screen-in" sample of 6393 persons. To get a comparably defined disabled population in 1982 and 1984, one must use criteria based on questions from the detailed community survey.

Medicare Part A bill data for the period from January 1978 through June 1986 has been appended to the 1982-1984 survey file. These data are included on the public use tape which was released by HCFA in February 1989 and is available from NTIS.

There are several weights in the survey file. For most straightforward tabulations, the sample weights on the data record are appropriate. So long as one is doing a cross-sectional analysis of the results of a particular survey instrument, the weights associated with that instrument are appropriate.

For a cross-sectional tabulation of the 1982 or 1984 community survey for persons who completed the detailed survey, one should use the 1982 or 1984 final detail weight. Other more complicated analyses will require other weights. Various memoranda from the Census Bureau included with the tape documentation can be consulted for help in constructing the appropriate set of weights.

The samples for the surveys are not simple random samples, but are drawn with a pre-specified probability to increase the precision of the estimates for certain rare populations. This affects the estimate of error variance which is used in various test statistics to determine whether to accept or reject a particular hypothesis. The documentation includes a table of adjustment factors that can be used to compensate for these design effects.

THE 1989 NLTCS

The 1989 survey was administered to the following groups:

- A subsample of persons found to be non-disabled in the 1984 survey, plus all persons age 75 and over who were found to be non-disabled in the 1984 survey and who are not the prior subsample.

- A sample of persons from Medicare files who aged in (i.e., became age 65) since the 1984 survey. The sample size was 4,910 persons.

- All persons assigned a detailed community interview in the 1984 survey. The sample size was 6,264 persons.

- All persons assigned a detailed institutional interview in the 1984 survey. The sample size was 1,773 persons. A six-month follow-back telephone survey was also be conducted for this group.

- A subsample of caregivers or next-of-kin of the impaired elderly.

The instrumentation for the community-based elderly was very similar to the questionnaires used in the 1982 and 1984 surveys. There were some modifications, e.g. in the area of income and assets where the Survey of Income and Program Participation questions were adapted to the survey. The institutional questionnaire also resembled closely the 1984 questionnaire.

The caregiver survey was similar to the 1982 ICS questionnaire, though somewhat shortened. The six month telephone follow-back for institutionalized persons was a very brief survey focusing mainly on income and asset questions.

The 1989 survey will be linked to Medicare Part A and Part B files and the National Death Index.

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