Estimating the long-term care population: Prevalence rates and selected characteristics

To facilitate manpower and service need estimates, the long-term care population must be defined in terms of dependency on human assistance in daily functioning. Such a definition of dependency is applied to national population data bases, using the 1977 National Nursing Home Survey and the 1977, 1979, and 1980 National Health Interview Surveys.

The four categories of dependency are personal care, mobility, household activities, and home-administered health care services. Although projections to the year 2000 show a doubling of the nursing home population, estimates of the overall prevalence of functional dependency remain smaller than is popularly believed.

Introduction

It has been noted elsewhere that long-term care is a poorly defined concept (Sherwood, 1975). This has confounded efforts at estimating the size of the long-term care population and frustrated estimates of service needs and costs, causing them to vary widely (Baltay, 1977).

This article is intended to do the following:

• Define the long-term care population in terms relevant to public policy considerations.
• Present key characteristics of this defined population, particularly those characteristics relevant to making service need estimates, including institutional care.

Other studies have reported disability and dependency characteristics of the noninstitutionalized national aged population (Shanas et al., 1968; Nagi, 1976) or of a noninstitutional area-specific aged population (Jette and Branch, 1981).1 Berg et al. (1970) surveyed the level of health care needed by the institutionalized and community populations in Monroe County, New York. This study, however, combines national survey data from several surveys to provide national estimates of dependency for the national institutionalized and noninstitutionalized population: the study uses a definition of the long-term care population based on two earlier definitions.

Data sources

Data were drawn from five national surveys: the 1977, 1979, and 1980 National Health Interview Surveys (NHIS's) (Feller, 1981); the 1977 National Nursing Home Survey (NNHS) (Van Nostrand et al., 1979); and the 1980 United States Census (U.S. Bureau of the Census, 1982).

1“Aged” refers to those 65 years of age or over.

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Estimates for the total long-term care population were produced by merging the 1977 NHIS and the 1977 NNHS.

Weighting and sampling issues were considered. It was decided that the two data sets could be merged directly; the weighting for each data set was used because the 1977 NHIS sample was designed to produce estimates of the national community and the 1977 NNHS, to produce estimates of the institutional population (Unger, 1981).

NHIS is administered to a nationwide sample of households each year (Feller, 1981). In addition to asking questions on the prevalence of specific disease conditions, the survey also includes a battery of questions on functioning ability. In 1977, 111,279 individuals were included in the sample. Of these, 11,698 (10.5 percent) were 65 years of age or over. In 1979 and 1980, of 100,530 individuals sampled, 11,730 (10.6 percent) were 65 years of age or over.

NNHS is collected periodically from a nationwide sample of nursing homes, their residents, discharges, and staff (Van Nostrand et al., 1979). But only resident data are used in this article. All types of nursing homes in the Nation are included, regardless of their intensity of service. The 1977 survey used a stratified two-stage probability sample, beginning with selection of sample facilities and subsequent selection of residents, discharges, and staff from the sample facilities. Data on residents came primarily from the patient record, supported by in-person interviews with the nurse most familiar with the patient. When necessary, the nurse also checked the patient, if possible. Items included the need for assistance in a variety of activities of daily living.

Defining long-term care

The most common approach to distinguishing acute from long-term care is to apply a duration cut-off. Most people accept the 1957 distinction offered by the Commission on Chronic Illness that care is long-term when it lasts more than 90 days. This distinction (with minor exceptions) is adopted in the coding definitions employed by the National Center for Health Statistics (NCHS) in both NHIS and NNHS.

Although the definition is convenient, it is difficult to argue that 90 days has any special validity. Looking at the problem from different perspectives is likely to lead to different cut-offs, as evidenced by the
American Hospital Association's definition that calls any hospitalization lasting more than 30 days long-term (American Hospital Association, 1984). More important, such time-based definitions provide little or no help when used as a basis for estimating the type and intensity of services required by the long-term care patient.

Similarly, the widespread approach of counting the number of people with chronic conditions provides an uncertain estimate of service needs because many conditions have few, if any, consequences for behavior (Haber, 1971 and 1973). However, the counting of chronic conditions is essential for other purposes, including medical intervention, prognoses, and utilization and outcome prediction.

Inventories of the number of people who report limitations in their usual activity are a useful measure for some epidemiological purposes. But "usual activity" varies with age, occupation, work-force participation, and self-perceived role; this variation raises serious questions concerning validity and reliability of the term when used as a survey item with a retired population.

Similarly, an NHIS item that asks whether or not an individual stays in bed most days because of a chronic condition has little consequence for manpower-need estimates. This is so because it is not clear that human intervention would alter those individuals' conditions, and they are a small group. In 1980, only 17,000 nondependent persons, or less than one-tenth of 1 percent of the aged population, reported a chronic condition.

The notion of functional disability as the criterion for inclusion in the long-term care population comes closer to the mark by focusing on behavior (Department of Health, Education, and Welfare, 1981). But when functional disability is defined, the nature of functional disabilities to be included are unspecified, thereby offering no guidelines for quantification.

Two definitions that have proved useful in trying to develop estimates of the size of the group needing long-term care services are one by Sherwood (1975) and one by the joint effort of the staff of the National Center for Health Statistics and the National Center for Health Services Research (Weissert, 1978).

According to Sherwood's definition:
"Someone is a long-term care person who has reached, either suddenly or gradually, a state of collapse or deterioration in human behavioral functioning which requires—for survival, slowing down the rate of deterioration, maintenance, or rehabilitation—the services of at least one other human being."

According to the second definition:
"Long-term care consists of those services designed to provide diagnostic, preventative, therapeutic, rehabilitative, supportive, and maintenance services for individuals of all age groups who have chronic physical and/or mental impairments, in a variety of institutional and noninstitutional health care settings, including the home, with the goals of promoting optimum levels of physical, social, and psychological functioning."

The following are among the virtues of these definitions: The first focuses on the behavioral and measurable phenomenon of functional limitation and the need for human service assistance; the second provides a comprehensive listing of types and varieties of services involved in long-term care. Yet both have important shortcomings. The first seems to exclude those who were born with their conditions; the second avoids such exclusion, but at the cost of giving no guidance as to the characteristics, other than chronicity, of the population to be served.

For this study, elements of both definitions were accepted: from the Sherwood definition, focus on the need for human assistance because so much of supply estimation involves manpower estimates; from the second definition, expanding the population—to include the nonaged—and not excluding those with congenital impairments. In addition, a definition of use for public policy should meet the following minimum conditions: It should be compatible with available data and measures, to the extent feasible; it should be easily translated into service and manpower estimates. Such estimates can then be easily translated into costs (Weissert et al., 1983).

Accordingly, the following definition guided estimates made in this article:
"The long-term care population consists of all persons, regardless of age or diagnosis, who, because of a chronic condition, require or receive human help in personal care, mobility, household activities, or home-administered health care services. Personal care includes eating, continence, transferring (e.g., moving from bed to chair, or bed to floor), toileting, dressing, and bathing. Mobility includes walking and going outside. Household activities include meal preparation, money management, shopping and chores, excluding yard work. Home-administered health care services include injections, dressings, physical therapy, and other health care services."

From an analytical perspective, this definition proved quite useful. But like all others, it is flawed. One group this definition leaves out is all people who suffer psychological deficiencies unaccompanied by functional dependency. This group could include some or all of the 54,000 self-reported psychotics and 384,000 self-reported neurotics counted by the 1977 NHIS as well as an unknown number of people who suffer no functional dependency but who nonetheless could benefit by human intervention of some sort (e.g., those who need the help of friendly visitors, telephone reassurance programs, bereavement counselors, pastoral counselors, or others). There may also be people who suffer from mental impairments, such as Alzheimer's disease, whose mental impairment has not yet affected their physical functioning.

Although an effort was made to avoid including in the definition those people whose dependency could be alleviated by equipment alone (e.g., canes, wheelchairs, more accessible transportation systems, or telephones without dials or with large buttons), changing technology would make some people independent.
in future counts who are now dependent for household activities and home-administered health services. Consequently, the study definition and the resulting estimates should be regarded as interdependent and judged as appropriate or not depending on the uses to which the estimates are to be put.

**Measures and methods**

The criteria included in the previous definition were applied in ways which were compatible with the NHIS and NNHS data sets. The 1977 NHIS includes two sets of functional limitation items. They are:

- Activity of daily living items (need for human help bathing, dressing, toileting, or eating).
- Mobility items (need for assistance in getting around inside the house, outside the house, or outside the neighborhood).

NNHS includes the first set and an item on walking assistance that can be substituted for the second. The 1979 and 1980 NHIS also include additional home care items, household activities, and home-administered health care services, discussed later.

The first group of dependencies, the activities of daily living (ADL) items, reflects the considerable work of Katz and his colleagues (Katz et al., 1970). They defined and measured the consequences of impairment among the chronically ill by ability to perform activities of daily living. The items collected by the 1977-80 NHIS are four of the six commonly included in the Katz scale (continence and transferring are missing from NHIS, but all six are included in NNHS). However, when properly defined, the items in the Katz scale form an effective Guttman scale, a hierarchical pecking order, which means that it can be assumed that for most individuals, limitation in a more primitive function (e.g., feeding) includes limitation in a more developed function (e.g., bathing or dressing). Analysis of assistance needs within the

| Type of assistance need | Percent also needing help | Getting around |
|-------------------------|---------------------------|----------------|
| Eating                  | 83.6                      | NA             |
| Toileting               | NA                        | 91.4           |
| Dressing                | NA                        | 82.7           |
| Bathing                 | NA                        | NA             |

**Table 1**

Hierarchy of assistance needs of the chronically ill within the National Health Interview Survey data set

| Age                  | Number in thousands | Percent | Number in thousands | Percent |
|----------------------|---------------------|---------|---------------------|---------|
|                      | Total               | 4,913   | 2.3                 | 2,894   | 1.3     | 2,019 | 0.9 |
| Under 65 years       | 1,637               | 1.0     | 840                 | 0.5     | 797    | 0.5   |
| 65 years or over     | 3,276               | 15.4    | 2,054               | 9.6     | 1,222  | 5.7   |

**Table 2**

Number and percent of civilian Americans needing personal care and mobility assistance

NOTE: NA means not applicable.

"Very aged" refers to those 85 years of age or over.

**Dependency prevalence**

An estimated 2,019,000 civilian Americans suffered dependency in mobility and 2,894,000 suffered dependency in personal care in 1977, according to analysis based on the combined National Health Interview and National Nursing Home Surveys for that year (Table 2).

As expected, those over 65 years of age formed the bulk of this population, especially of the personal-care dependent population. From Table 2, it can be calculated that nearly 71 percent of those dependent in bathing, dressing, toileting, feeding or a combination of these and other dependencies were 65 years of age or over. In addition, even among the population dependent only in mobility, those 65 years of age and over predominated by more than 61 percent.

As shown in Table 3, females predominated over males in dependency, reflecting, in part females' greater representation among the ranks of the very aged. More than twice as many females as males were dependent.

In addition, as expected (Table 4), white people predominated among the dependent population by virtue of their greater prevalence in the population at large and because white people tend to live longer, increasing the probability of dependency: 4,301,000 white people were dependent compared with 612,000 members of all other races. But among those surviving to old age, the rate of dependency was lower for white people than for members of all other races.

Rates of dependency (that is, the percent of the population that is dependent) are also shown in Tables 2-4. Overall, 0.9 percent of the population suffered dependency in mobility, and 1.3 percent suffered dependency in personal care. As expected and consistent with the higher numbers of aged dependent compared with nonaged dependent, the aged suffered much higher rates of dependency than the nonaged: 5.7 percent in mobility and 9.6 percent in personal care, compared with the much smaller rates of 0.5 percent for both mobility and personal care dependency for the nonaged. The aged were more than 10 times more likely than the nonaged to suffer mobility dependency and almost 20 times more likely than the nonaged to suffer personal care dependency.
Aged females were substantially more likely to suffer mobility and personal care dependency than aged males.

Most dramatic, however, are the rates of dependency among the most aged groups, especially females from races other than white among the very aged group (Table 5): 52 percent of these females 85 years of age or over are dependent in personal care, nearly double and triple the rates for white and nonwhite males. White females, too, have a considerably greater dependency rate than all males. Possibly, dependent males die sooner than females, and many males die before the age of onset of dependency.

Overall, the rates suggest a close relationship between age and dependency.

**Dependency and institutionalization**

In Table 6, the distribution of dependent Americans by residence in nursing homes versus the community is shown. Overall, 26.1 percent of dependent persons were in nursing homes in 1977. However, nursing home residency was considerably more likely among those dependent in personal care than among those dependent in mobility. Among those dependent in toileting or eating, 51.5 percent were in nursing homes, and among those dependent in bathing or dressing, 29.5 percent were in nursing homes. In contrast, among those dependent only in mobility, nearly 20 times as many were dependent in personal care as in mobility. The 125,000 persons, about 9 percent of nursing home residents, who are in nursing homes but have no personal care or mobility
dependency will be studied in a separate analysis. They are younger, with mental disorders; many are males.)

### Dependency and home care

Because the 1979 and 1980 NHIS's contained a special home care supplement, administered to all persons who passed a minimal impairment screen, categories of dependency are more refined in these later estimates compared with those in 1977. The additions include (1) the Lawton and Brody (1969) Instrumental Activities of Daily Living Scale (the shortened version is used by NHIS), which measures need for human help in household activities; and (2) need for human help in administering home-administered health care services such as injections and sterile dressing changes.

In Table 7, a dependency breakdown for the 1979-80 noninstitutionalized population is given. (There has been no post-1977 NNHS.) Again, the hierarchical classification of persons by their most severe dependency was employed: Personal care includes assistance in eating, continence, transferring, toileting, bathing, and dressing (those whose only problem was incontinence were excluded, again because they require no human assistance, e.g., stress incontinence in young women). Mobility includes assistance in walking and in going outside. Household activities include meal preparation, shopping, chores other than yard work, and financial management. Health services is a respondent-defined category. The most frequent response was injections, followed by changing of sterile dressings and a large number of very low prevalence items, including specific therapies.

As shown in the table, when this broadened definition of long-term care is used, it captures nearly 5.5 million people, nearly 3 million of whom are aged. Regardless of age category, personal care dependency (the most severe type of dependency) and household activity dependency (less severe dependency) are the largest categories. Among the noninstitutionalized aged, there is a total of more than 1 million people in each category. Mobility dependency and health services dependency, when combined, equal less than three-quarters of a million aged. The assumption that those who are dependent in mobility are also dependent in household activities and home-administered health care services was validated in cross-tabulations.

Overall, among the total noninstitutionalized population, these four types of dependency affect about 2.6 percent of people of all ages. Among the aged, the overall dependency rate is nearly 12 percent.

Distribution of the 1979-80 noninstitutionalized dependent population by marital status, living arrangement, and poverty, as defined by the U.S. Bureau of the Census (1982), is shown in Table 8. In general, individuals in the other dependencies category tended to be worse off in all respects than either the personal care dependent or the independent, presumably because people who are personal care dependent and lack social and economic resources are more likely to die, move in with others, or be institutionalized; independent persons may be better off in all respects because they have not yet lived long enough to reach the ages of highest probability of physical dependency, death of spouse, death of friends and relatives, and diminishing economic reserves. Independent people averaged 74.8 years of age, with 77.6 of age among the personal care category and 78 years of age for the other dependency category.

In Tables 9 and 10, dependency for the years 1985 and 2000 are projected by applying the 1977 institutionalization rates and 1979-80 dependency rates among the aged population to the U.S. Bureau of the Census (1982) age, sex, and race estimates for the years 1985 and 2000.

These estimates are potentially more valid for overall dependency prevalence than they are for the distribution of dependent persons between institutional and noninstitutional settings. These are merely point estimates for institutionalization rates among the dependent population in 1977, projected forward to the year 2000, with no allowance for the well-known long history of increases in rates of nursing...
Table 7
Number and percent of noninstitutionalized dependent persons, by type of dependency and age

| Age           | Total dependent | Personal care | Mobility | Household activity | Health services |
|---------------|-----------------|---------------|----------|--------------------|-----------------|
|               | Number in thousands | Percent | Number in thousands | Percent | Number in thousands | Percent | Number in thousands | Percent |
| Total         | 5,455           | 2.6         | 1,877    | 0.9               | 775            | 0.4     | 1,969               | 0.9     | 833              | 0.4 |
| Under 65 years| 2,626           | 1.4         | 820      | 0.5               | 240            | 0.1     | 937                 | 0.6     | 629              | 0.3 |
| 65 years or over | 2,829          | 11.7        | 1,057    | 4.4               | 535            | 2.2     | 1,032               | 4.3     | 204              | 0.8 |
| 75 years or over | 1,955          | 20.6        | 745      | 6.4               | 165            | 1.3     | 140                 | 2.8     | 47               | 0.7 |

*Approximate standard errors for this row of estimates are as follows: 3.4 percent, 2.1 percent, 2.3 percent, 2.1 percent, and 0.8 percent.

SOURCE: National Center for Health Statistics: Data from the National Health Interview Surveys, 1979 and 1980.
Table 8
Number and percent of noninstitutionalized aged who are unmarried, live alone, or are poor, by dependency level

| Status     | Number of persons | Percent of all elderly |
|------------|------------------|------------------------|
| Unmarried  | 486              | 46.0                   |
|            | 2.1              |                        |
| Live alone | 170              | 16.1                   |
|            | 0.8              |                        |
| Poor       | 200              | 18.9                   |
|            | 0.9              |                        |

1Noninstitutionalized personal care dependent elderly.
2Noninstitutionalized elderly dependent in activities other than personal care.
3Noninstitutionalized independent elderly.

SOURCE: National Center for Health Statistics: National Health Interview Surveys, 1979 and 1980.

Table 9
Predicted prevalence of dependency and institutionalization for the year 1985

| Age         | Total | Institutionalized | Personal care dependent | Other dependent |
|-------------|-------|-------------------|-------------------------|-----------------|
| Number of persons in thousands |       |                  |                         |                 |
| Total       | 6,330 | 2,367             | 1,889                   | 2,074           |
| 65-69 years | 547   | 89                | 172                     | 286             |
| 70-74 years | 839   | 179               | 237                     | 423             |
| 75-79 years | 1,197 | 324               | 359                     | 514             |
| 80-84 years | 1,163 | 468               | 504                     | 171             |
| 85 years or over | 2,584 | 1,267             | 617                     | 680             |

Table 10
Predicted prevalence of dependency and institutionalization for the year 2000

| Age         | Total | Institutionalized | Personal care dependent | Other dependent |
|-------------|-------|-------------------|-------------------------|-----------------|
| Number of persons in thousands |       |                  |                         |                 |
| Total       | 6,330 | 2,367             | 1,889                   | 2,074           |
| 65-69 years | 547   | 89                | 172                     | 286             |
| 70-74 years | 839   | 179               | 237                     | 423             |
| 75-79 years | 1,197 | 324               | 359                     | 514             |
| 80-84 years | 1,163 | 468               | 504                     | 171             |
| 85 years or over | 2,584 | 1,267             | 617                     | 680             |

Reliability of estimates

To address the issue of reliability, estimates of the prevalence of bathing, dressing, toileting, and eating dependency were each compared for 1977, 1979, and 1980. These estimates remain very close year to year despite slight differences in definitions used in 1977 and expected sampling variations. Similar comparisons were made between the NHIS estimates and estimates for aged persons participating in the well-known Framingham Massachusetts Heart Disease Epidemiological Study (Jette and Branch, 1981). For home utilization experienced among the aged (Weissert and Scanlon, 1980; Russell, 1981). Yet, surprisingly, the estimate produced for nursing home use is considerably higher than projections made by Russell (1981) and the Health Care Financing Administration (1981) who projected institutional residency rates in the year 2000 to be 1,965,000 (Russell) and 1,952,190 (Health Care Financing Administration, 1981) based on rates of increase in utilization in past years (e.g., Russell's data began with 1950). The estimate produced here is 2,367,000 (Table 10), reflecting what should be a conservative assumption that the proportion of the dependent population in nursing homes in the year 2000 will be no higher than it was in 1977.

As others have suggested (Greenberg and Ginn, 1979; Colvez and Blanchet, 1981), these dependency rates may not necessarily remain stable. For example, improved health care access and early retirement or major medical breakthroughs, such as a cure for cancer or heart disease, might extend life to its hypothesized "limit" (Fries, 1980) or female labor force participation or smoking could alter female life expectancy. (An excellent review of the differing views on the future relationship between longevity, chronicity, and disability is given by Manton, 1982).

On the other hand, there is some reason to believe that institutionalization rates have reached a structural limit. They now are being held down by supply restrictions to such a level that effectively only the most severely ill, socially unsupported, and dependent can or (if privately paying) wish to gain admission. Nor can the rates go much lower given the reality that at some level of dependency and frailty there is no cost-effective option other than congregate round-the-clock supervision and care.

Discussion

Data in this study confirm earlier small sample findings that the proportion of the American population that reports the need for human help in performing activities basic to daily life is small relative to the total population: only 2.3 percent of the total (all
ages) institutionalized and noninstitutionalized population in 1977 were dependent in personal care or mobility. Even among the aged, only about 15 percent were dependent in these two types of activities.

When other types of dependencies are included, i.e., household activities and home-delivered health care services, the percent dependent is raised to 2.6 percent of the noninstitutionalized of all ages and another approximately 0.5 percent of all Americans in nursing homes (most of whom are dependent in personal care).

Focusing on the 1979 and 1980 aged alone, 11.8 percent lived in the community and were dependent in personal care, mobility, and household activities, or home-administered health care services; another 4.8 percent, most of whom suffered personal care dependency, were institutionalized.

In short, the vast majority of the population, young and old, appears to be free of dependency on other human beings for help in daily functioning. This will remain true in the year 2000 even though the very old portion of the aged population is rapidly growing. Assuming the same age-race-sex specific rates of dependency prevail, in the year 2000, the dependent aged population will number nearly 6.5 million people, more than one-third of whom will live in nursing homes.

Bearing in mind that the size of these figures is a function of the rather restrictive definition used, these estimates nevertheless offer a useful antidote to widely held beliefs that now, and even more so in the future, the Nation will be dominated by an aged dependent population. That is not the case.

On the other hand, a doubling of the nursing home population is projected. This is a staggering prospect for the Medicaid program, which currently pays nearly one-half of all nursing home charges (accounting for nearly one-half of Medicaid program outlays).

What these estimates permit is a sober planning process for delivering long-term care to those who most need it. Using the scales and measures adopted by NHIS, analysts can define and measure the long-term care population, specify service needs, and make synthetic estimates to statewide and perhaps smaller planning areas (Unger and Weisert, 1983).

For a city of 100,000, with the national average mix of age, sex, and race factors and no special health status characteristics, for example, the 1985 aged long-term care population can be expected to be roughly 2,000 people, of whom, depending on bed supply and climate, some 600 can be expected to be institutionalized. Somewhat fewer than one-third (about 500 persons) are likely to suffer personal care dependency, meaning that their needs are most profound and comprehensive. It is for the most part only a subset of this group that is likely to meet criteria now (justifiably or not) being adopted by many community care programs. Under the Medicaid community care authority, for example, programs are required by law and regulation to serve only those who, without such services, would be highly probable candidates for institutionalization. Basically, that is a subgroup of the personal care dependent.

While local health conditions and age mix could cause these estimates to vary, they give a ballpark standard against which long-term care planners can consider the potential magnitude of this special population. These relatively small numbers may explain, in part, why many community long-term care demonstration projects have had difficulty achieving projected population sizes of dependent persons. Furthermore, not all of those who require help would necessarily seek it from a community care program. Many community care programs have been operated only in sections of cities where projections of this type would suggest that no more than a few hundred aged people are dependent for personal care. Considering the transportation limitations on the portion of a city that can be included in a program's catchment area, it is no wonder that day care, homemaker, and other programs in small cities have experienced difficulty in attracting large patient populations. This suggests caution in developing community care programs that require large participant populations to share high fixed costs if charges are to be kept reasonable.

Indeed, perhaps the most encouraging conclusion suggested by these numbers is that even if long-term care planners adopt a rather broad definition of dependency as a definition of the long-term care population, the numbers produced appear to be sufficiently small so that our Nation of 230 million people can afford to serve this small subgroup adequately. This, of course, is a policy judgment not inherent in the data. But policy is influenced by perceptions, and, in this case, the perception that long-term care is so large a problem that it must continue to be substantially ignored by public policy appears to be unwarranted by the numbers.

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