Estimates of the Incidence, Prevalence, Duration, Intensity and Cost of Chronic Disability among the U.S. Elderly*

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Abstract

Objectives: To estimate the burden of chronic disability on the U.S. elderly population, using sex-specific measures of long-term care (LTC) service use, intensity and costs.

Methods: Multistate life-table analysis of adjacent rounds of the National Long-Term Care Survey (NLTCS) from 1984, 1989 and 1994, using criteria introduced in the Health Insurance Portability and Accountability Act (HIPAA) of 1996 to stratify the disabled population according to level of disability based on ADL and cognitive impairment criteria. Rates of transition to/from non-disabled to disabled states and from all states to death were computed and analyzed for differences by age and sex. Rates of service use, intensity and costs were computed conditional on age and sex.

Results: Approximately 20 percent of the residual life expectancy at age 65 for males and 30 percent for females were spent in a state of chronic disability. For both sexes, the years of chronic disability above age 65 were split evenly between mild/moderate and severe disability. The expected costs of purchased LTC services were $59,000 (includes home/community care and institutional care, in constant 2000 dollars), with substantial sex differences—$29,000 for males versus $82,000 for females.

For both sexes, the overwhelming majority (92 percent) of the LTC costs were incurred during episodes of severe disability, with the remaining (8 percent) incurred during episodes of mild/moderate disability. Residual lifetime unpaid home/community care averaged 3,200 hours for males and 4,000 hours for females, with approximately one-third of those hours incurred during episodes of mild/moderate disability.

Differences in the costs of acute health care were substantial for the different levels of disability and associated differences in survival.

Conclusions: The criteria for identifying severely disabled persons introduced by HIPAA effectively targeted the high-cost disabled subpopulation. This group accounted for the overwhelming majority of purchased LTC services, and a large majority of unpaid LTC services,

over age 65. Sex differences in expected per capita lifetime LTC costs were substantial, with females outspending males 2.8 to 1.

1. Introduction

Chronic disability among the elderly is commonly defined as the inability to independently perform one or more activities of daily living (ADLs) or instrumental activities of daily living (IADLs) for a period of 90 days or more; chronic disability also includes cognitive impairment (CI) associated with Alzheimer's disease and other dementias, with or without ADL/IADL limitations. The chronic nature of the disability induces a degree of permanence that distinguishes these health states from short-term medically unstable health states typically associated with acute health care. The chronic nature of the disability also tends to shift the focus away from the underlying chronic medical conditions responsible for disability and towards the long-term care (LTC) needs of the disabled individual. The stability of these chronic health states makes them suitable for analysis by a broad range of demographic methods.

This paper uses multistate life-table methods to analyze sex-specific incidence, prevalence and duration of chronic disability in the 1984, 1989 and 1994 rounds of the National Long-Term Care Survey (NLTCS). Six states were defined: non-disabled, mildly disabled, three levels of severely disabled and dead. The three levels of severe disability were defined using ADL and CI thresholds (singly, and in combination) consistent with the Health Insurance Portability and Accountability Act of 1996 (HIPAA—Public Law 104-191, Aug. 21, 1996) which governs the tax treatment of LTC services and insurance under private LTC insurance policies. Estimates of the prevalence and intensity of care were generated for all disability states. The non-disabled state contained the at-risk population for the disability transitions.

The remainder of the paper contains eight sections:

- "Background" provides basic definitions used to characterize and stratify the disabled population according to the severity of disability, using criteria introduced by HIPAA.
- "Data" describes the NLTCS.
- "Disability Classification" presents the methods used to classify NLTCS sample respondents according to severity of disability, using the HIPAA criteria.

- “Disability Prevalence” presents cross-sectional disability estimates from the 1984, 1989 and 1994 NLTCS.
- “Disability Incidence” presents unisex and sex-specific disability transition rates obtained from pooled longitudinal analyses of the 1984–1989 and 1989–1994 observation intervals in the NLTCS.
- “Disability Duration” presents the multistate life-table methods and results. The consistency of the results with external data on survival and with cross-sectional NLTCS data on disability prevalence is evaluated.
- “LTC Intensity and Cost” evaluates the implications of the multistate life-table for the care requirements and costs of care for the disabled elderly population. The costs and intensity of care are stratified by severity of disability to assess the impact of restrictions introduced by HIPAA.
- “Discussion” comments on the limitations of the analysis and possible extensions.

2. Background

Under HIPAA, LTC was defined to mean the necessary diagnostic, preventive, therapeutic, curing, treating, mitigating and rehabilitative services, and maintenance or personal care services required by a chronically ill severely disabled person. More generally, the Actuarial Standards Board (1999) defined LTC to include a wide range of health and social services such as adult day care, assisted living care, continuing care, custodial care, home health care, hospice care, respite care and skilled/intermediate nursing care. LTC is generally necessitated by the development of chronic disability, which may result from a variety of medical conditions such as cancer, heart disease, chronic lung disease, arthritis, osteoporosis, stroke, Parkinson's disease, AIDS, Alzheimer’s disease and other diseases and medical conditions. LTC does not generally include short-stay hospital care.

In contrast, acute health care generally refers to skilled, medically necessary care provided by medical and nursing professionals for physiologically unstable conditions of relatively short duration, having a specific and foreseeable end, with the primary goal to restore the patient to a stable state. The limited duration and the relative instability of the associated medical conditions distinguish acute health care from LTC.

HIPAA was significant because it introduced for the first time in the United States precise legal definitions governing beneficiary eligibility for tax-favored treatment of LTC services provided under private LTC insurance contracts, and established rules governing tax-favored treatment of LTC insurance premiums and payments under qualified contracts. The net effect was that there came into existence a standard set of definitions of "chronically ill individuals" that had the force of law. This elevated HIPAA's definitions of chronic disability to a level comparable to other demographic events such as births, deaths, marriages and divorces typically recorded in national/state vital statistics registration systems.

HIPAA focused primarily on severely disabled persons with activity of daily living (ADL; Katz and Akpom, 1976) limitations, but it also introduced specific criteria for dealing with cognitive impairments (CIs) that are not associated with ADL limitations. Under HIPAA's definitions for tax-qualified LTC insurance, a policyholder is eligible for LTC insurance benefits only if a licensed health care practitioner certifies that the individual satisfies one of three criteria (triggers):

1. ADL Trigger—the individual is unable to perform without "substantial assistance" from another individual at least two out of six ADLs (bathing, dressing, toileting, transferring, continence and eating) for at least 90 days due to a loss of functional capacity; or
2. Similar Level Trigger—the individual has a level of disability similar to the level in the ADL Trigger; or
3. Cognitive Impairment (CI) Trigger—the individual requires "substantial supervision" to protect him/herself from threats to health and safety due to "severe cognitive impairment."

HIPAA permitted but did not require an LTC insurer to use any subset of the three benefit triggers in determining a given policyholder's eligibility for LTC benefits. Persons satisfying any one of the three triggers were defined as "chronically ill individuals" by HIPAA. Furthermore, HIPAA included references to the National Association of Insurance

Commissioners' Long-Term Care Insurance Model Act which defined "long-term care insurance" as any insurance policy or rider designed to provide coverage for at least 12 consecutive months for each covered person on an expense incurred, indemnity, prepaid or other basis. Chronicity was an integral part of the eligibility definition: HIPAA clearly excluded acute care needs from the benefit triggers of qualified LTC insurance policies.

HIPAA's ADL trigger did not count ADLs whose limitations can be appropriately resolved by the use of special equipment such as wheelchairs, walkers, canes, crutches, handrails, ramps, bed lifts, elevators, bed-pans, portable toilets, special underwear, catheters or similar devices.

HIPAA did not specifically mention instrumental activities of daily living (IADLs—i.e., housework, laundry, cooking, grocery shopping, outside mobility, travel, money management, taking medications and telephoning; Lawton and Brody, 1969) in defining LTC benefit triggers, but it is likely that persons who are so severely impaired that they satisfy the CI trigger would have difficulty with at least some IADLs. Certain combinations of ADLs and IADLs might also satisfy the Similar Level Trigger, and the IRS requested comments on the types of disability that should be included under the Similar Level Trigger (Internal Revenue Service 1997; Kassner and Jackson, 1998; Spector and Fleishman, 1998). To date, however, the Secretary of the Treasury has not issued regulations needed to operationalize the Similar Level Trigger.

As a consequence, it is reasonable to consider chronically ill individuals who satisfy HIPAA's ADL and/or CI triggers to be severely disabled, and to consider individuals with ADL and/or IADL limitations and CI below HIPAA's thresholds to be mild/moderately disabled. This raises the issue of how effectively HIPAA targeted the severely disabled subpopulation in terms of the intensity and cost of LTC.

3. Data

The National Long-Term Care Survey (NLTCS) was a series of related surveys conducted in 1982, 1984, 1989 and every five years thereafter. The NLTCS was designed to examine health problems, functional limitations, disability and use of LTC among the elderly (age 65+) at multiple points in time. The NLTCS collected information on IADL and ADL limitations, institutionalization and CI.

The NLTCS employed a nationally representative longitudinal design with cross-sectional replenishment at age 65–69. This design permits both longitudinal and cross-sectional analyses. This paper uses pooled cross-sectional analysis of the 1984, 1989 and 1994 NLTCS to develop estimates of the frequency and intensity of LTC service use among the U.S. elderly population and pooled longitudinal analysis of the 1984–1989 and 1989–1994 NLTCS survey pairs to evaluate health state transitions between adjacent rounds of the NLTCS, based on a Markov chain multistate life-table model.

Detailed descriptions of the 1984 and 1989 NLTCS data and the life table methods used in their analysis were provided in Stallard and Yee (2000). The data in that report were extended in the present paper to include the 1994 NLTCS, which had the effect of doubling the sample sizes for the transition rate estimates. In addition, the 1994 NLTCS provided additional information on costs of LTC services that was not collected in the earlier rounds but which was required for the cost analysis in the current paper. The rest of this section provides a brief summary of the NLTCS sampling methods and sample sizes.

The NLTCS began as a cross-sectional survey in 1982 with approximately 36,000 elderly Medicare enrollees aged 65 and over selected for initial assessment and future follow-up. Approximately 6,000 were disabled in the community and 2,000 were institutionalized. All participants were screened to assess their ability to perform nine IADLs and seven ADLs without help. Those disabled and living in the community were given detailed interviews to assess their functional state and the nature of care received. Those disabled and living in institutions (nursing homes or similar facilities with three or more beds that provided nursing care and personal care) were identified but not interviewed in 1982. Such persons were interviewed in all subsequent surveys.

The 1984 NLTCS was the first round to employ a longitudinal design with cross-sectional replenishment. The 1984 NLTCS was a longitudinal follow-up survey of the population sampled in 1982. However, because a pure longitudinal design would not sample persons who had turned age 65 in the interim, and, hence, would not provide a complete nationally representative cross-sectional sample of all U.S. elderly aged 65 years and older, the design was modified to include such persons in an additional sample component—the “cross-sectional replenishment.” Approximately 5,000 people aged 63–64 in 1982 were added to the 1984 sample group. This group, together with a 45 percent subsample of the non-disabled sample in 1982, was screened to assess their ability to perform the nine IADLs and seven ADLs without help. Those found to be disabled or institutionalized in 1984 and those disabled or institutionalized in 1982 were given detailed interviews to assess their functional state and the nature of care received. The sampling and interviewing techniques used in 1984 were similarly employed in 1989 and 1994.

Table 1 displays the resulting sample sizes available for use in the current analysis by survey year, sex and attained age within the age range 65–99. Each round of the NLTCS included at least 2,525 persons aged 85–99 and 862 persons aged 90–99. The pooled analysis of the 1984 and 1989 rounds included 39,358 persons aged 65–99 and 5,053 persons aged 85–99. Information on 64 additional persons aged 100+ was suppressed from Table 1 due to cell size restrictions, but their data were used in the analysis. The 1994 NLTCS introduced a supplementary sample of about 500 persons aged 95+, enhancing its suitability for cross-sectional rate estimation at the oldest-old ages. Although these persons were not included in the pooled longitudinal analysis because they were not part of the 1984 or 1989 sample, they did contribute to the estimation of the cost and resource utilization parameters based on the 1994 NLTCS.

The NLTCS was linked to Medicare expenditure/reimbursement records maintained by the Centers for Medicare and Medicaid Services (CMS) which permitted verification of the fact of death for NLTCS respondents who died during the study period 1984–1994.

4. Disability Classification

The NLTCS classified respondents according to whether the person was a resident in an institution or in a community setting. The latter were further classified according to the number of basic ADLs for which help was required, or, if none, according to the number of more complex IADLs for which help was required. At least one of these activity-limitations must have lasted or have been expected to last 90 days or longer in order for the person to be classified as chronically disabled in the NLTCS screening interview. Once a community resident was classified as chronically disabled in a screening interview, that person received the NLTCS detailed interview during that survey and all future surveys. Institutional residents received a modified version of the NLTCS detailed interview that assessed basic ADL limitations and CI. Once a person was classified as an institutional resident, that person was scheduled for a detailed interview (community or institutional form, as appropriate) during all future surveys.

Seven basic ADLs were assessed in the NLTCS: bathing, dressing, toileting, transferring, eating, continence and inside mobility, the first six of which were components of the HIPAA ADL Trigger. Measured limitations in ADLs included the use of special equipment and the assistance of another person in performing designated activities.

Nine IADLs were assessed in the NLTCS: light housework, laundry, cooking, grocery shopping, outside mobility, travel, money management, taking medications and telephoning. Measured limitations in IADLs generally included only the assistance of another person in performing designated activities (exceptions: outside mobility and telephoning, which included the use of special equipment). In all cases, IADL limitations must have been due to “a disability or health problem” in order to be recognized by the NLTCS. The ADL questions in the NLTCS screening interview probed limitations in both inside and outside mobility, but the questions in the NLTCS detailed community interview treated outside mobility as an IADL, not as a basic ADL.

There were several differences between the NLTCS definitions for ADL triggers and the definitions used in HIPAA. Tabulations from the NLTCS typically deleted continence from the basic ADL list because continence was queried as part of the toileting items (e.g., Manton, Corder and Stallard, 1997). Thus, there was no specific continence trigger among the NLTCS triggers. HIPAA retained continence, but deleted inside mobility, in defining its ADL list. The NLTCS ADL triggers counted ADLs whose limitations can be resolved by the use of special equipment without the use of personal assistance; HIPAA excluded such cases. The NLTCS ADL triggers were based on self-reported limitations whereas the HIPAA ADL Trigger was based on certification by a licensed health care practitioner. Moreover, the HIPAA ADL Trigger includes contemporaneous certification that the limitation will last at least 90 days whereas the NLTCS ADL triggers explicitly evaluated this expectation only once for each respondent at the time of the screener interview in which he or she originally met the screener disability criteria.

This paper used the implementation of the HIPAA criteria for ADL triggers described in Stallard and Yee (2000). For each ADL, the possible sets of limitations were ordered according to the following hierarchy:

0. Performs the ADL independently
1. Needs help, but does not get help, with the ADL
2. Performs the ADL with special equipment
3. Gets standby help, uses no special equipment
4 Gets standby help, also uses special equipment
5. Gets active help, uses no special equipment
6. Gets active help, also uses special equipment
7. Unable to perform the ADL.

This hierarchy was applied to each of the six HIPAA ADLs and inside mobility, generating a classification of ADL limitations ranging from no deficiency to complete inability to perform the ADL. Levels 3 and higher most closely match the criteria in the HIPAA ADL Trigger. Levels 2 and higher match the criteria in the standard NLTCS ADL trigger. Levels 1 and 2 identify ADL limitations below the HIPAA threshold.

HIPAA did not specify how the assessment of CI was to be conducted. Subsequent regulations indicated that the assessment should be based on “clinical evidence and standardized tests” (Internal Revenue Service 1997; p. 6). Following the implementation in Stallard and Yee (2000), the definition of CI in this paper was based on the error-score on the Short Portable Mental Status Questionnaire (SPMSQ; Pfeiffer 1975). For those who took the 10-item test, scores of three or four errors were classified as “mild/moderate CI,” and five or more errors as “severe CI,” with only the latter assumed to meet the HIPAA CI Trigger.

In addition, if the interviewer was unable to talk directly to the sampled person because the person had Alzheimer’s disease or any other form of dementia, then that person was classified as having severe CI (equivalent to the classification of persons with 5–10 errors on the SPMSQ). For certain institutional persons who did not receive the SPMSQ, the classification of severe CI was based on classifications established in prior NLTCS interviews and in searches of the linked Medicare records for Alzheimer's disease and other dementias. Such non-SPMSQ data accounted for approximately 30 percent of persons classified as having any level of CI in this sample; and approximately 45 percent of persons classified as having severe CI.

The classification procedure for persons who did not receive the SPMSQ closely followed the “inclusion criteria” of the algorithm for identifying suspected Alzheimer’s disease described in Kinosian et al. (2000, Table 1). Some modification was necessary to broaden the scope to identify all types of severe CI, not just Alzheimer’s disease. The “exclusion criteria” of Kinosian et al.’s (2000) algorithm were modified to retain non-Alzheimer’s dementias. Specifically, three conditions (arteriosclerotic dementia, alcoholic dementia and dementia in conditions classified elsewhere) were moved from the exclusion criteria to the inclusion criteria, and the exclusions for Parkinson’s disease, stroke and arteriosclerosis/atherosclerosis were deleted; the exclusion for mental retardation was retained.

Each NLTCS respondent was uniquely assigned to one of five groups, which were indexed by Roman numerals I–V:

I. Non-disabled
II. Disabled, satisfies neither HIPAA’s ADL nor CI trigger
III. Disabled, satisfies HIPAA’s ADL trigger, but not HIPAA’s CI trigger
IV. Disabled, satisfies HIPAA’s CI trigger, but not HIPAA’s ADL trigger
V. Disabled, satisfies both HIPAA’s ADL and CI triggers.

Groups II–V collectively formed the disabled subpopulation. Initial assignment to Group II was based on the respondent’s satisfying any of the following criteria:

1. Institutionalization in an LTC facility
2. Any ADL limitation classified in the range 1–7 on the ADL hierarchy (i.e., needs help, uses special equipment, gets help from another person or unable to perform the activity), applied to the six HIPAA ADLs and inside mobility
3. Any IADL limitation satisfying the NLTCS IADL trigger
4. Any CI (scored as three or more errors on the SPMSQ or other evidence of impairment or dementia used to impute an SPMSQ score of 5–10 errors).

Persons who were not classified as disabled were assigned to Group I (i.e., non-disabled).

Following initial assignment to Group II, an assessment was made of the number of HIPAA ADLs with limitations classified in the range 3–7 (i.e., gets help from another person, or unable to perform the activity) on the ADL hierarchy. Disabled persons with two or more such ADLs were “promoted” from Group II to III. Following this, an assessment was made of the number of errors on the SPMSQ, and disabled persons with five or more actual or imputed errors were “promoted” from Group II to IV or from Group III to V.

5. Disability Prevalence

Table 2 contains the relative frequency distributions by year and age for the five disability groups. The age standardized frequency for Group I increased from 75.3 percent in 1984 to 78.5 percent in 1994. Alternatively, the aggregate age standardized frequency for Groups II–V decreased from 24.7 percent in 1984 to 21.5 percent in 1994. This corresponds to an overall average rate of disability decline of almost 1.4 percent per year, consistent with results reported in Manton et al. (1997) and Stallard (2000).

Figure 1 displays the relative frequencies by year and select ages for Groups II–V. The figure shows that the overall disability decline for 1984–1994 had different temporal patterns for different ages. Furthermore, an increase in CI (Groups IV and V combined) appeared from 1984 to 1989, followed by a decrease from 1989 to 1994, except for ages 95–99. This suggests that the CI imputation procedures for nursing-home non-respondents to the SPMSQ in 1984 may have underestimated the proportions in Group V due to the lack of information from prior rounds of the NLTCS, or Medicare diagnostic codes, for these cases. If so, there would be a corresponding overestimation of the proportion in Group III. Alternatively, given the substantial decline from 1989 to 1994 it is possible that the imputations for the 1989 NLTCS overestimated the prevalence of CI with 1984 and 1994 providing more consistent estimates. The pooling of the three data years in the cross-sectional analysis and the two inter-survey intervals in the longitudinal analysis was designed, in part, to minimize bias relating to potential errors in CI assessment/imputation in the 1984 or 1989 NLTCS.

6. Disability Incidence

Table 3 displays the unisex and sex-specific five-year disability transition matrices aggregated over all ages. Corresponding age-specific transition matrices were computed for five-year age groups ranging from 65–69 to 100–104. Two additional matrices were computed for ages 65 and 105–109 and were used to initialize the life tables at age 65 and to close them out at age 112. To capture mortality in the transition matrices, the five disability groups were extended to include a sixth group (VI. Dead) that formed the only absorbing state in the multistate life-table model. Several general patterns were identified. The persistency rates (diagonal terms) for the non-disabled Group I were substantially higher than for any of the disabled groups, and within the disabled groups the persistency rates were highest for Groups II and V (the extremes), and lowest for Group III and IV (the single trigger groups). The death rates generally increased over the five groups, an exception being Group IV whose death rates generally were between those of Groups II and III. For all five groups, the persistency rates declined and the death rates increased with increasing age. The low persistency rates of Group VI were in part due to the relatively high transition rates to Group V, consistent with a relatively lengthy progressive decline in cognitive abilities that ultimately leads to a loss of independence in ADLs. If the Group IV persistency and Group IV–V transition rates were combined, then the resulting CI persistency rates would be comparable to the non-disabled Group II persistency rates. Transitions from Groups III–V to Group I were relatively infrequent except for Group IV below age 75. When an improvement did occur, it was much more likely to be from Groups III–IV to Group II. Transitions from Group V to lower levels of disability were very rare.

Examination of the sex-specific transition rates showed that females generally had higher persistency and lower death rates. Males in Group IV had higher transition rates below age 75 to

Group I than females. However, below age 75, females in Group IV had equal or higher transition rates to Group II than males. These differences lead one to expect females to have greater total life expectancy and greater disabled life expectancy above age 65.

7. Disability Duration

7.1 Multistate Life-Table Methods

Estimates of the average lifetime duration of disability above age 65, 75, 85 and 95 were computed using multistate life-table procedures (see Willekens et al., 1982, for discussion and detailed mathematical development). Briefly, the standard form of the multistate life-table model is a time-non-homogeneous finite-state continuous-time Markov process. For observations made at discrete regularly spaced time intervals (such as in the NLTCS), this simplifies to a Markov chain model.

The Markov chain model employs a conditional (or local) independence assumption for the transition probabilities from each initial disability state (i.e., the "states" of the Markov chain) to the disability states observed at the follow-up assessment. For many observation plans, this may be unrealistic. Therefore, it is important to define the disability states so that the local independence assumption is reasonably plausible.

As shown in Table 3, six disability states were defined for the model in this paper:

I. Non-disabled
II. Mild/moderate disability
III. HIPAA ADL only
IV. HIPAA CI only
V. HIPAA ADL and CI jointly
VI. Dead.

The first five states correspond to the five groups defined in Section 4. These six states approximate a hierarchy from the lowest level of disability (i.e., active or non-disabled) up to the highest levels of disability (i.e., ADL and CI jointly, followed by death). The model assumes that the transitions from any one state to the next are independent both of prior states and of the duration in the current state. This assumption can be made more realistic by expanding the number of states in the model. The trade-off is that it becomes more difficult to reliably estimate the transition rates as the number of states is expanded. The six states in the current model represent a reasonable compromise.

The general process governing the Markov chain model is defined by

$$\mathbf{l}_{t+1} = \mathbf{l}_t \cdot {}_1\mathbf{P}_t \,, \tag{1}$$

where $\mathbf{l}_t$ is a six-element row vector of initial state counts at the start of the unit time (one-year) interval indexed by t and ${}_1\mathbf{P}_t$ is the 6×6 transition probability matrix governing transitions over the interval (t, t + 1). Equation (1) can be parameterized to represent a survival process by setting row 6 of the transition probability matrix ${}_1\mathbf{P}_t$ to 0. In this case, l_{t6} records the deaths in the interval (t - 1, t). This process can be re-specified for five-year time intervals as

$$\mathbf{l}_{t+5} = \mathbf{l}_t \cdot {}_5\mathbf{P}_t \,, \tag{2}$$

where ${}_5\mathbf{P}_t$ is the transition probability matrix governing transitions over the five-year interval (t, t + 5)—see Table 3.

The group specific residual life expectancy at age t for group g was defined as

$$e_{tg} = \int_t^{\infty} l_{sg}\, ds \Big/ \sum_{g=1}^{5} l_{tg} \,, \tag{3}$$

which is additive over the five surviving groups.

Linear interpolation procedures were employed between adjacent values of $\mathbf{l}_t$ and $\mathbf{l}_{t+5}$ to obtain values of $\mathbf{l}_s$ for $t < s < t + 5$. This facilitated the integration calculations required for computing non-disabled and disabled life expectancy. An alternative approach involves solving for the transition hazard-rate matrix underlying equation (2) (Singer and Spilerman, 1976; Stallard and Yee, 2000).

7.2 Multistate Life-Table Results

Table 4 displays the age-specific residual life expectancy estimates by disability group and sex. The unisex results show that nearly three-quarters (74.2 percent) of the 17.6-year life expectancy at age 65 was spent non-disabled. The non-disabled share of residual life expectancy declined to almost 60 percent at age 75 and below 40 percent at age 85.

Sex differences were large. Less than 20 percent of the residual life expectancy at age 65 for males was spent chronically disabled, with less than 10 percent spent severely disabled in Groups III–V. Almost 30 percent of the residual life expectancy at age 65 for females was spent chronically disabled, with nearly 15 percent spent severely disabled in Groups III–V. For both sexes, about half of the disability time was spent severely disabled. Females had about a 1.3-year advantage in non-disabled life expectancy at age 65 that was mostly dissipated by age 75 and actually reversed by age 85. Females had about a 4.1-year advantage in total residual life expectancy at age 65, but 2.8 of these years (68.3 percent) were spent disabled. These results were consistent with the sex differences in persistency and death rates observed in Table 3.

Because the NLTCS sample was designed to be representative of the entire U.S. elderly population, it was reasonable to expect the total residual life expectancies calculated from the Markov chain model to closely match similar estimates for the total population. The last three columns of Table 4 showed that the model most closely matched the estimates for the 1925 birth cohort (which reached age 65 in 1990) produced by the Social Security Administration (Bell, Wade and Goss, 1992). Indeed, the differences between the estimates from the model and the 1925 birth cohort were generally smaller than the differences between the life expectancies based on the period life tables for 1989–1991 and 1998. These comparisons served to validate the overall behavior of the model and provided confidence in the accuracy of the results.

Figure 2 compares the unisex survival curves from the Markov chain model with the corresponding curves from the 1925 cohort and 1989–1991 period life-tables. The three survival curves were very close until the mid-80s at which point the 1989–1991 curve dropped more rapidly than the other two curves. The largest absolute discrepancy occurred at about age 95. The model curve and the 1925 cohort curve were almost indistinguishable. Where differences were detectable, the model was midway between the 1925 cohort and the 1989–1991 period curves.

Given that it takes 20 years for the model-based cohort to reach age 85, and 30 years to reached age 95, the patterns in Figure 2 were reasonably consistent with a projected gradual improvement in mortality over the decades of the 1990s, 2000s and 2010s.

The detailed behavior of the model was more difficult to validate because of the absence of comparable published estimates. One way to deal with this was to examine how well the model matched the cross-sectional disability prevalence rates exhibited in Table 2. Figures 3–7 compare the unisex model-based results for Groups I–V with corresponding prevalence rates for 1994 and pooled prevalence rates for 1984, 1989 and 1994.

Given the overall behavior of the model evaluated via comparisons of life expectancies and survival probabilities, the expectation was that the model-based detailed prevalence rates would initially (at younger ages) be close to the cross-sectional rates with small gradual divergences toward reduced disability at older ages. This pattern was observed in Figure 3 where the model-based prevalence rates for Group I initially matched those of the pooled data. By age 85–89, the model-based prevalence rates diverged upwards from the pooled data.

Also included in Figure 3 were the Group I prevalence rates based on the 1994 data. These are complementary to the Group II–V rates in Figure 1. As expected from Figure 1, the 1994 Group I rates were higher than the pooled rates. However, Figure 3 showed that they were also higher than the model-based rates, providing evidence that the model captured the pooled experience from the three rounds of the NLTCS, but not the secular declines in disability rates across the three rounds.

Figures 4–7 showed that the model captured the major features of the level and age-trends of the prevalence rates for the four disability groups. In general, the model-based rates were close to or between the pooled rates and the 1994 rates, the main exceptions being ages 70–79 in Figure 4 and ages 90–99 in Figure 7.

8. LTC Intensity and Cost

This section provides estimates of the overall cost burden of disability on the elderly population and assesses how effectively HIPAA targets the severely disabled subpopulation. Table 4 shows that the disabled life expectancy at age 65 was evenly divided between the mild/moderately disabled Group II and the HIPAA-defined severely disabled Groups III–V, implying that approximately half of the disabled population was ineligible for benefits under tax-qualified LTC insurance policies and could not claim medical expense deductions on their federal income tax returns for their out-of-pocket LTC costs. In practice, this means that LTC services for these individuals generally would not be covered by insurance and, when paid out-of-pocket, the costs would be paid with after-tax dollars.

The NLTCS collected extensive information on LTC intensity and cost. Table 5 displays the LTC intensity parameters by disability group and sex obtained from the pooled 1984, 1989 and 1994 NLTCS, aggregated over all ages. Corresponding costs were derived from the 1994 NLTCS and were expressed in constant 2000 dollars in Table 5. All parameters were expressed on a per capita basis and were grouped according to whether the services were provided in a nursing home or in the community (which included the respondent's home and other non-institutional settings). Expressing the parameters on a per capita basis means that the parameters applied to the general population of persons in each disability group, independent of location of residence. The per capita costs were expressed on an annual basis (i.e., they were computed by multiplying the corresponding daily cost rates by 365.25) and they represented a mixture of zero dollar costs for those who did not use the indicated services and non-zero dollar costs for the those who did use the indicated services. For example, the $980 annual nursing-home cost for unisex Group II (second line) reflects non-zero costs for the 3.8 percent of that group in a nursing home (on any given day) and zero costs for the remaining 96.2 percent. Similarly, the $29,904 cost for unisex Group V reflects non-zero costs for the 64.0 percent of that group in a nursing home (on any given day) and zero costs for the remaining 36.0 percent. The highest nursing-home cost and utilization rates were experienced by Group V, with Group III a distant second. In contrast, Group III had the highest annual cost and utilization rates for paid care among community residents ($3,803), with Group V a close second on cost ($3,338) but a distant fourth on utilization rates (15.2 percent vs. 26.1 percent). The lower utilization rate for Group V reflected the fact that only 36.0 percent of this group resided in the community compared with 60.7 percent for Group III.

Given the observation in Table 3 that the overall five-year transition rate from Group IV to V is more than double the Group IV persistence rate, it is informative to contrast the intensity and cost parameters for these two groups in Table 5. The nursing-home proportion increased from 13.4 percent to 64.0 percent, with corresponding annual cost increases from $3,200 to $29,904. The annual cost of paid care in the community increased from $873 to $3,338, implying that the total annual cost increased from $4,073 to $33,242—a factor of 8.2.

The multistate life-table model facilitates calculation of a variety of summary measures of the cost burden of disability. The general expression for the summarized costs is given by

$$C_{tg} = \int_t^{\infty} c_{sg} v^s l_{sg} ds / \sum_{g=1}^{5} l_{tg} \, , \tag{4}$$

where c_{sg} is the age-specific cost component and l_{sg} is the life-table survival function at age s for group g; and v is an appropriate discount factor.

To implement equation (4), the intensity and cost components in Table 5 were tabulated by five-year age groups (65–69, 70–74, ..., 90+) and linearly interpolated to single years within the age range 67–90. The use of age-specific intensity and cost components provided a first-order approximation to changes in family structure, living arrangements and informal/formal care due to the loss of a spouse and the aging of the children of very old disabled persons. The discount factor v was set to 1.0 for all calculations involving cumulative time of care. For cost summarization, the discount rate is typically set equal to the ratio of a cost inflation factor and an investment accumulation factor.

During the period 2001–2007 the inflation factor for the nursing home and adult daycare component of the CPI was 4.5 percent per year, a value that matches the LTC insurance valuation interest rate for policies issued during 1995–2005. It can be argued that the LTC insurance valuation interest rate is an appropriately conservative rate for discounting future LTC costs faced by the elderly given that only a small fraction of these costs will be prefunded through insurance or other mechanisms that could yield higher rates of investment income on the accumulated funds. Both rates were assumed to be equal in the future, which allowed the factor *v* to be set to 1.0 in equation (4).

Unisex and sex-specific results are presented separately in Tables 6–8 for person-years of nursing home (NH) care, home and community-based (HCB) care, hours of HCB care and costs of NH and HCB care, calculated for ages 65+, 75+, 85+, and 95+.

The top panels of Tables 6–8 display the distribution of person-years of LTC by disability group and type of care. For each combination of disability and age, the sum of person-years NH and HCB has as its upper limit the residual life expectancy in Table 4, with differences occurring because not all disabled persons receive personal care. Of the 2.24 years spent in HIPAA Groups III–V at ages 65+ in the unisex life-table (Table 4), 1.53 years (68.3 percent; Table 6) were spent with paid HCB/NH LTC. This contrasts with the 2.31 years spent in Group II, where 0.66 years (28.6 percent) were spent with paid HCB/NH LTC. For females, 72.1 percent of the years in HIPAA Groups III–V were spent with paid HCB/NH LTC, compared with 59.3 percent for males.

The middle panels of Tables 6–8 display the distribution of HCB hours of LTC by disability group and payment status. Total hours of care were the most direct measures of intensity in the NLTCS. The unisex total at ages 65+ was 4,686 hours, with males requiring 3,771 hours and females 5,451 hours. For males, 14.7 percent were paid hours; for females, 26.0 percent were paid hours. On average, males consumed 3,216 and females 4,034 hours of unpaid care. This care was generally provided by the disabled person's spouse or children and the volume of care indicated that this was a major component of LTC in the United States. Because no actual payments were made, it is difficult to determine the economic value of this care. One can approximate the value by using the overall average hourly cost for paid care in Table 6 ($9.12 per hour, unisex age 65+). This is similar to the approach used by Arno, Levine and Memmott (1999) and implies a value of $29,330 for males and $36,790 for females.

The bottom panels of Tables 6–8 display the distribution of LTC costs by disability group and type of care. The overall unisex cost of HCB/NH LTC at age 65+ was $58,855; $29,150 for males and $81,826 for females. Overall, 92.2 percent (males 91.4 percent; females 92.6 percent) of HCB/NH costs were incurred during disability episodes included in HIPAA Groups III–V. This contrasts with unpaid hours of care where, overall, 65.5 percent (males 65.0 percent; females 66.0 percent) of such hours were incurred during HIPAA disability episodes. The fact that the vast majority of HCB/NH costs were incurred during HIPAA disability episodes indicates that HIPAA successfully targeted the elderly subpopulation most seriously impacted financially by severe disability. Only about 8 percent of LTC costs occurred outside of HIPAA disability episodes.

The cost estimates in Tables 6 can be roughly compared with nursing home and home health care costs reported for ages 65+ by Spillman and Lubitz (2000, Table 1), by (1) inflating their estimates from 1996 to 2000 dollars (+19.0% CPI-NH), (2) restoring to their estimates the 10 percent of nursing home care and 42 percent of home health care costs covered by Medicare (Spillman and Lubitz, 2000, p. 1410); and (3) removing 54 percent of the home health care costs to reflect the use of these services among non-severely disabled persons (Stallard 2000, Table 3). With these adjustments, the Spillman and Lubitz (2000) analysis yields a total cost of $56,010, with $45,225 for nursing home care and $10,785 for home health care. Their adjusted total estimate was 4.8 percent lower than the $58,855 estimate in the current analysis; their adjusted nursing home estimate was 8.6 percent lower than the current $49,497 estimate; and their adjusted home health care estimate was 15.2 percent higher than the current $9,358 estimate. These comparisons provide evidence that the estimates in Tables 6–8 are reasonable, although they are not sufficient to confirm the specific dollar values.

The multistate life-table model allows a variety of supplementary calculations to be conducted. For example, the state vector $\mathbf{l}_t$ can be reset at any age t to obtain estimates for any of the five disability states represented in the model. Using this method, one can calculate the group-specific average costs of HCB/NH LTC at ages 65+ as: I, $56,827; II, $73,002; III, $99,922; IV, $82,630; and V, $130,611. The $56,827 estimate for Group I was the average net cost of future HCB/NH LTC expenditures for a group that approximated an insurable subpopulation (Stallard and Yee, 2000). For comparison, the American Academy of Actuaries Committee on Long-Term Care (1997) estimated that the single-premium cost at age 65 for a typical LTC insurance policy at the end of 1996 with 5 percent compounded inflation protection, lifetime benefits, a 90-day elimination period (deductible) at the start of each benefit period and benefit caps of $100 per NH day and $50 per HCB day, would be in the range $57,000–67,000. Adjusting this range for NH inflation through mid-2000 (+17.0% CPI-NH) yields a revised range of $66,700–78,400. Assuming that the 0.25-year benefit elimination period reduced Group I's 2.07 person-years of paid HCB/NH LTC to 1.82 person-years, and that the same relative reduction (87.9 percent) applied to the $56,827 Group I cost estimate, one would obtain a net cost of $49,962 before application of the daily benefit caps. This net cost represents 64–75 percent of the LTC insurance single-premium cost, close to the 60–70 percent loss ratios used by LTC insurers. Again, these comparisons provide evidence that the current estimates are reasonable.

9. Discussion

The multistate life-table is a powerful tool for the analysis of disability transitions in the elderly population. Demographic applications of this model to the joint analysis of mortality and morbidity data have evolved from Sullivan’s (1971) static component or prevalence rate method for single-decrement life tables to Katz et al.’s (1983) double-decrement life-table method, to the more general increment-decrement or multistate life-table method employed in this paper (Rogers, Rogers and Branch, 1989). Branch et al. (1991) argued for the superiority of the multistate life-table method in computing active (non-disabled) life expectancy. Land, Guralnik, and Blazer (1994) introduced Markov panel-data regression procedures to the active life expectancy model and Laditka and Wolf (1998) extended their approach to allow unequal follow-up intervals. Latent state-space alternatives to these regression procedures were introduced by Manton and Stallard (1991) for static component applications to multistate single-decrement life tables, by Manton, Stallard and Woodbury (1991) for continuous-state multistate life tables, and by Kinosian et al. (2000) for modeling the natural history of Alzheimer's disease.

Markov chain transition rates based on the NLTCS were first provided by Manton (1988), and later updated by Manton, Corder and Stallard (1993). Stallard and Yee (2000) estimated Markov chain transition rates for home and community-based (HCB) LTC using the

HIPAA disability criteria. This paper extended that analysis to include nursing home (NH) disability episodes satisfying the HIPAA disability criteria.

Given the complexity of the model and the large number of parameters that must be estimated, it was essential to validate the outputs of the model against available external and internal data. The marginal survival function compared favorably with the Social Security Administration's cohort life-table survival for the 1925 birth cohort, a cohort that reached age 65 in 1990, just one year from the midpoint of the NLTCS observation interval 1984–1994 for the data used to calibrate the multistate life-table model. Further tests showed that the implied age-specific disability prevalence rates from the multistate life-table model deviated only slightly from the cross-sectional NLTCS prevalence rates and that the patterns of deviation were consistent with gradually improving secular trends in disability. These comparisons support the position that the reported results from the multistate life-table model are reasonably accurate.

Stallard and Yee (2000) conducted detailed analyses of the assumption that the continuance functions governing the persistence (survival) of episodes in each disability state following transition into that state were exponential in form. The exponential survival function was predicted by the constant hazard assumption typically used in the Markov chain model when converting from discrete to continuous time. This assumption was implicit in the single-month time interval method proposed by Laditka and Wolf (1998).

Stallard and Yee (2000) found the constant hazard assumption to be satisfactory for HCB LTC episodes but seriously in error for NH LTC episodes. NH LTC episodes were appropriately modeled using continuance functions that were stochastic mixtures of pairs of exponential survival functions, with each NH admission cohort split roughly 50-50 between short-stay and long-stay residents. Validation tests of the multistate life-table model showed that the model accurately predicted the NH prevalence rates, implying that the model produced compensating errors in the incidence and continuance rates: the incidence rates were underestimated while the average durations were overestimated.

Figure 8 illustrates this phenomenon using data from the Society of Actuaries 1984–1991 LTC Intercompany Study (SOA 1996). The horizontal axis represents length of stay (LOS) in months following the start of an insured HCB/NH LTC disability episode. The vertical axis represents the density of claims at the indicated LOS-values (note the unequal LOS class-intervals). Model 1 was the best fitting exponential distribution; Model 2 was the best fitting mixture of two exponential distributions. Compared with Model 1, Model 2 provided a significant improvement in fit to the observed data. The implied incidence under Model 2 was about 1.8 times higher than that implied under Model 1. This signaled that one should be cautious when attempting to use the Markov chain model to estimate incidence and continuance parameters that require a constant hazard assumption.

The current estimates of active and disabled life expectancy were based on pooled analyses of the 1984–1989 and 1989–1994 observation intervals of the NLTCS. Pooling increased the stability of the estimated parameters and centered the analysis on the cross-sectional experience of the 1987–1992 calendar period. However, sequential cross-sectional analyses of the 1982, 1984, 1989 and 1994 NLTCS showed that there were secular declines in age-specific disability prevalence rates (Manton et al., 1997). Secular declines in functional limitations during this period were validated by Freedman and Martin (1998) using sequential cross-sectional analyses of the 1984 and 1993 Survey of Income and Program Participation; secular declines in severe cognitive impairment during at least the latter part of this period were validated by Freedman, Aykan and Martin (2001) using data from the 1993 Asset and Health Dynamics of the Oldest Old Study and the 1998 Health and Retirement Survey.

Secular declines in disability were not explicitly represented in the multistate life-table calculations. They were implicitly represented to the extent that the five-year transition probability matrices were chain-multiplied in equation (2), and to the extent that these matrices were impacted by secular changes during 1984–1994. Further research will be needed to evaluate additional adjustments and to develop optimal strategies for reflecting secular changes in disability and mortality in the multistate life-table model. Examples of how these analyses might be conducted were provided by Boult et al. (1991), Crimmins, Hayward and Saito (1994) and Cai and Lubitz (2007). What is needed is high-quality longitudinal data with repeated applications of the same measurement instruments over sufficiently long time periods to reliably measure secular changes in the age-specific transition parameters of the Markov chain multistate life-table model. This will be facilitated by the recent release of the 2004 NLTCS which will provide a 20-year observation interval over which period and cohort differences in the transition parameters can be analyzed with the goal of developing more accurate forecasts of chronic disability and related use of LTC.

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