



Distribution of lifetime nursing home use and of out-of-pocket spending

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Reliable estimates of the lifetime risk of using a nursing home and the associated out-of-pocket costs are important for the saving decisions by individuals and families, and for the purchase of long-term care insurance. We used data on up to 18 y of nursing home use and out-of-pocket costs drawn from the Health and Retirement Study, a longitudinal household survey representative of the older US population. We accumulated the use and spending by individuals over many years, and we developed and used an individual-level matching method to account for use before and after the observation period. In addition, for forecasting, we estimated a dynamic parametric model of nursing home use and spending. We found that 56% of persons aged 57–61 will stay at least one night in a nursing home during their lifetimes, but only 32% of the cohort will pay anything out of pocket. Averaged over all persons, total out-of-pocket expenditures looking forward from age 57 were approximately \$7,300, discounted at 3% per year. However, the 95th percentile of spending was almost \$47,000. We conclude that the percentage of people ever staying in nursing homes is substantially higher than previous estimates, at least partly due to an increase in nursing home episodes of short duration. Average lifetime out-of-pocket costs may be affordable, but some people will incur much higher costs.

lifetime nursing home | lifetime spending for nursing homes | long-term care insurance

Reliable estimates of the lifetime risk of nursing home use and of the associated out-of-pocket costs are important to individuals and households in deciding whether to purchase long-term care insurance and how much to save. They are also important to firms that sell such insurance, and to policymakers who may take action should risks not be amenable to private-market amelioration. The website longtermcare.acl.gov states that the risk of 65-y-olds entering a nursing facility sometime in their life is 35%, and the risk of entering any care facility is 37% (2). This figure is consistent with many others in the literature (3–6), but lower than the projections of Spillman and Lubitz (7) (45% projected for people reaching age 65 in 2010). Because of data limitations, prior estimates have been based on cross-section data or on short panel datasets that necessitate modeling transitions into and out of nursing homes. The models require numerous assumptions and often combine data from several sources with the attendant risks of variation in both data quality and populations covered. Furthermore, many published studies have used data from the 1980s or earlier, but there have been substantial changes in nursing home use over the last several decades, most notably an increase in short stays associated with posthospitalization rehabilitation (6). These changes have likely led to an increase in lifetime use and out-of-pocket spending.

The ideal study design follows a cohort as it passes through the ages of meaningful nursing home use until the death of the last cohort member, recording use and out-of-pocket spending of each individual. We use a study design that approaches that ideal: the Health and Retirement Study (HRS), which follows older individuals for up to 18 y. It is a single data source that consistently

records nursing home use and out-of-pocket spending, which we accumulate at the individual level over the observation period, thus substituting data for model assumptions that have, of necessity, been used in prior studies. We find that the lifetime frequency of any nursing home use by the cohorts we study is substantially larger than previous estimates. More importantly, the distribution of use was highly skewed: Approximately 5% of the population spent more than 4 y in a nursing home, while the median person spent just a week or so. Similarly, out-of-pocket spending on average was not particularly large relative to assets in late middle age, but it was highly skewed, implying a substantial risk of large spending. Assuming the experience of past cohorts is a good guide to the experience of future cohorts, our results suggest that the lifetime use of nursing homes by individuals in their late 50s will be substantially higher than current literature predicts.

Methods

The HRS is a biennial longitudinal survey. Appropriately weighted, the sample represents the US population over age 50. The first wave of the HRS was conducted in 1992 from cohorts born in 1931–1941 and, thus, the respondents were approximately age 51–61 at initial interview. We use 10 waves covering 18 y of data on this cohort. In 1993, the HRS interviewed individuals born in 1923 or earlier. These so-called “AHEAD” cohorts were incorporated into the HRS proper in 1998. We use 12 y of data on them. See *SI Appendix* for additional information about the HRS and for details of the analyses presented in this paper.

The HRS collects information on residence in a nursing home at interview, as well as move-in date and detailed, self-reported information about nursing home use between waves, including number of nursing home episodes and total nursing home nights. Respondents are asked whether the costs of the nursing home stay(s) were covered by insurance and about costs they paid out-of-pocket. The HRS conducts “exit interviews” with a knowledgeable informant in the wave following the death of an HRS interviewee. Because of the intensity of nursing home use in the months preceding death, the exit

Significance

Although it is important to know the annual costs and use of nursing homes, for individuals and households, it is also important to know expected lifetime costs and use of nursing homes; that is, how much they will use nursing homes and how much might spend over their lifetimes. They need this information in deciding how much to save and whether to purchase insurance that will pay for nursing home use. By following individuals over many years as they progress to advanced old age, we estimated how many days individuals will spend in nursing homes and how much they will spend out-of-pocket.

A partial early version of this study was published (1).

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interviews are critical for obtaining complete information on lifetime use of nursing homes and associated out-of-pocket expenditures.

Our main estimation method is nonparametric: We follow individuals in panel data, recording their nursing home use, spending, and survival. However, even the long panel of the HRS does not cover a single cohort from middle age to death. To construct a trajectory of nursing home use from age 57 to the end of life, we select a core cohort, individuals initially ages 75–79 in 1998 (born 1919–1923). The survivors reached ages 87–91 in 2010. To account for right censoring (nursing home use to be incurred by survivors after 2010), we match each surviving individual to a similar individual from an older cohort where the matching is on age, sex, and on position in the distribution of out-of-pocket spending on nursing home use. The objective of this matching is to impute use and spending following the observation period while preserving heterogeneity in the persistence of spending. For survivors to 2010 who did not provide a 2010 interview, we apply the same matching algorithm using information from the latest available HRS interview. To account for left censoring (nursing home use incurred before 1998 by individuals in our core cohort), we perform a similar match to individuals from younger cohorts. Following this matching, we have complete histories of nursing home use and associated out-of-pocket spending by the cohort born in 1919–1923 from ages 57 to 61 to the end of life, conditional on survival to ages 75–79. We augment these data with nursing home use and out-of-pocket spending of those who died before ages 75–79 to generate data on the nursing home use and spending of a complete cohort from age 57 until death.

For comparisons with existing literature, and for forecasting, we also estimate a parametric model of the probability of any nursing home use between waves, which lie 2 y apart on average. We distinguish four individual outcomes since the preceding wave: (i) alive, no nursing home use; (ii) alive, with nursing home use; (iii) died, no nursing home use; and (iv) died, with nursing home use. We estimate multinomial logit models for the probability of each outcome, and conditional on nursing home use, the amount of use and associated out-of-pocket spending. An important explanatory variable is nursing home use in two preceding waves, which captures persistence in use. Additional explanatory variables are age, sex, education, race, marital status at age 50, number of children, any daughters, and ever a smoker. After estimating these models using the same single data source as the nonparametric approach, we simulate lifetime nursing home use and out-of-pocket spending until death for a representative sample of 50- to 55-y-olds from the HRS, generating a distribution of predicted lifetime outcomes.

The research reported in this paper uses publicly available, deidentified data. The research was reviewed and approved by the RAND Human Subjects Protection Committee, which serves as RAND's Institutional Review Board.

Results

Accumulated Nursing Home Use Across Panel Waves. To illustrate the strength of the HRS data, we first present data on nursing home use directly accumulated from raw data, not adjusted for left or right censoring. Conditional on reaching 75–79, 48.3% of the core cohort (Table 1) had some nursing home use between 1998 and 2010. By 2010, 35% of the core cohort was alive and might experience further nursing home use. We accumulated out-of-pocket spending discounted to age 57 by using a 3% discount rate to permit a comparison with wealth at an early age

when there has been little nursing home use. Out-of-pocket spending averaged \$5,253 expressed in 2013 prices.

We performed similar calculations for the birth cohorts 1905–1911, 1912–1918, and 1931–1936. The first cohorts aged from 87–93 to 99–105 over the 12 y of the HRS that we used. Some 72% of that cohort had nursing home use; out-of-pocket spending averaged \$11,596, in 2013 prices discounted to age 57. The second set of cohorts aged from 80–86 to 92–88 over the 12-y period. Approximately 64% had any nursing home use, with average out-of-pocket spending amounting to \$8,305 in 2013 prices discounted to age 57. The 1931–1936 cohorts were age 56–61 at baseline in 1992 and were followed for up to 18 y. Fifteen percent of them had nursing home use; average out-of-pocket spending accumulated over the 18 y was approximately \$1,100. See *SI Appendix, Table S2*) for details.

Lifetime Nursing Home Use. To account for left and right censoring, we linked surviving individuals from our central cohort (Table 1) to individuals from the younger and older cohorts. We added data on individuals who died before the initial ages of our core cohort (before ages 75–79) to form a complete dataset on individuals from their late 50s to their deaths. Table 2 shows the estimated lifetime nursing home use and discounted out-of-pocket spending. Fifty-six percent of persons from the cohorts of 1919–1923 who survived to ages 57–61 had or will have at least one night in a nursing home over the course of their lifetimes. The average is 272 nights, but the distribution is highly skewed: The median is just 10 nights, but the 90th percentile is 1,001 nights and the 95th percentile is 1,495 nights. Thus, someone age 57–61 has a 10% chance of spending 3 y or more in a nursing home and a 5% chance of spending more than 4 y.

Although 56% of the population had a nursing home stay, just 32% paid anything out-of-pocket, implying that approximately 43% of those with a nursing home stay were completely covered by insurance, private or more likely, public. Accumulated lifetime out-of-pocket spending was \$7,344 in 2013 dollars discounted to age 57. As with nursing home nights, out-of-pocket spending is highly skewed: 5% of persons in that cohort spent an amount approaching \$50,000 or more.

These results do not distinguish the length of a nursing home episode, which is of interest for at least two reasons. First, a long stay may impact the well-being of individuals and their families differently from multiple short stays. Second, in some cases, the financial liability differs by length of stay: Medicare fully pays for 20 d of rehabilitative nursing home use following hospitalization and partially for the following days up to 100 d. Therefore, we define a long stay to be an episode greater than 100 d. We estimate that 27.0% of individuals age 57 will have a long nursing home stay. Of those with a long stay, approximately one-half (48.7%) will have just one long episode, but approximately one-fourth (27.1%) will have three or more long episodes.

Table 1. Cumulative nursing home use and out-of-pocket costs 1998–2010, birth cohorts 1919–1923

Age in 1998	<i>n</i>	Percent died 1998–2010	Percent with any NH use	Mean no. of NH nights	Percent nights covered completely	Discounted OOP spending	Undiscounted OOP spending
75	460	56.0	43.7	169.9	50.1	5,965	13,019
76	451	61.9	42.1	160.6	50.5	4,054	9,068
77	469	64.4	47.9	194.1	53.5	4,930	11,325
78	421	68.7	51.6	187.8	51.2	4,921	11,308
79	383	75.4	58.3	223.6	53.7	6,555	15,838
All	2,184	64.8	48.3	185.9	51.9	5,253	12,006

"Percent died" is the percent that died between 1998 and 2010. "Percent with any NH" is the percent that had at least one nursing home stay. "Mean no. of NH nights" is the average number of nights in nursing home, averaged over all, not just those with a stay. "Percent nights completely covered" is the percent of nursing home nights completely paid by insurance. "Discounted OOP spending" is the average of accumulated out-of-pocket spending for nursing home stays, discounted at 3% to age 57, and expressed in 2013 dollars. "Undiscounted OOP spending" is the average of accumulated out-of-pocket spending for nursing home stays, not discounted and expressed in 2013 dollars. NH, nursing home; OOP, out-of-pocket.

Table 2. Nonparametric estimates of nursing home use and out-of-pocket costs from age 57 to end of life, $n = 3,336$

Nursing home use and OOP spending	Mean	95% confidence interval	
		Lower	Upper
Lifetime NH use			
Percent with any lifetime use	55.7	54.1	57.4
Mean no. of nights	272	253	292
Percentiles			
10	0	0	0
25	0	0	0
50	10	5	15
75	240	208	272
90	1,001	913	1,089
95	1,495	1,391	1,599
Lifetime OOP spending			
Percent with any OOP spending	31.6	30.0	33.2
Mean dollars	7,344	6,519	8,168
Percentiles			
10	0	0	0
25	0	0	0
50	0	0	0
75	1,072	598	1,545
90	19,647	16,294	22,999
95	46,660	40,611	52,709

"95% confidence interval" gives the lower and upper bounds for the 95% confidence intervals. "Mean no. of nights" gives average lifetime number of nights in nursing home, averaged over all individuals, not just those with nursing home use. "OOP spending" means out-of-pocket spending on nursing home use. Spending is expressed in 2013 dollars as a present value at age 57 with a real discount rate of 3%. NH, nursing home; OOP, out-of-pocket.

Forecasts of Nursing Home Use and Associated Out-of-Pocket Spending.

Based on the estimated parametric model, we simulated the lifetime experience of a representative sample drawn from HRS, and we accumulated nursing home use and out-of-pocket spending from ages 57 to 61 to the end of life. The predicted probability of any nursing home use (Table 3) is very close to the predicted probability from the nonparametric approach (Table 2), and the distributions are similar with overlapping confidence intervals in the lower part of the distribution (up to and including the 75th percentile). However, the nonparametric estimation of the average number of nights is some 47 d greater than the parametric estimation due to a fatter upper tail of the distribution: The 95th percentile is approximately 350 d greater. Thus, the risk (the chances of an extreme outcome) as estimated nonparametrically is substantially greater than the risk as estimated by the model, although the model uses up to 6 y of longitudinal data to capture persistence in use. This difference is likely due to the model being a simplification of the more complex actual process.

The parametric estimates of out-of-pocket spending are similar to the nonparametric, but with a lower mean due to smaller values at the highest percentiles.

Using individual simulated lifetime nursing home use and spending based on the models, we analyzed variation in use and spending by individual characteristics (Table 4). The lifetime risk of nursing home use (starting from ages 57 to 61) by females is 64%, considerably higher than for males. The number of nursing home nights and out-of-pocket spending are approximately double those of males. These differences result from greater survival on the part of women, so they are exposed to more years of risk, and, at advanced ages, often lack spouses to provide care. Whites and nonwhites have similar nursing home use, but whites

spend considerably more out-of-pocket because they have more economic resources and are less likely to qualify for Medicaid. The better educated have modestly greater use, but spend much more out-of-pocket because they also have greater economic resources. Having children, especially daughters, provides a resource that could keep an older person in the community. There is little association between the number of children and the lifetime risk of using a nursing home, but the association with lifetime nursing home nights and out-of-pocket is substantial: For example, those with four or more children will spend approximately 38% less than those with no children. Having daughters reduces spending further, but it is not associated with the lifetime risk of nursing home use. Thus, children reduce lifetime use by slowing the transition into a nursing home or hastening the transition out, but they have little, if any, effect on whether someone uses a nursing home over the lifespan. Because of shorter lifetimes, smokers, whether active or previous at age 50, have less nursing home use than those who never smoked.

Discussion

Lifetime Risk of Nursing Home Use. Our estimate of lifetime nursing home use by the birth cohorts 1919–1923 is 56%, considerably larger than previous estimates, which use data on a variety of cohorts. To find an estimate for a similar birth cohort, we look to Kemper and Murtaugh (3), who project the lifetime nursing home risk of those turning age 65 in 1990 (the birth cohort of 1925) to be 43%.

Because of substantial differences in methods and data, it is difficult to locate the causes of the differences from prior estimates. Some studies used recall data from the deceased's next-of-kin, others used surveys of older populations with differing degrees of follow-up. Three features of our data are likely

Table 3. Model-based predictions of nursing home use and out-of-pocket costs from age 57 to end of life

Nursing home use and OOP spending	Mean	95% confidence interval	
		Lower	Upper
Lifetime NH use			
Percent with any lifetime use	57.7	56.0	59.8
Mean no. of nights	225	210	243
Percentiles			
10	0	0	0
25	0	0	0
50	14	10	19
75	224	195	252
90	776	743	828
95	1,139	1,069	1,256
Lifetime OOP spending			
Percent with any OOP spending	31.0	29.7	32.6
Mean dollars	6,201	5,654	6,872
Percentiles			
10	0	0	0
25	0	0	0
50	0	0	0
75	2,106	1,676	2,734
90	18,039	16,042	21,116
95	43,421	37,588	47,684

"95% confidence interval" gives the lower and upper bounds for the 95% confidence intervals. "Mean no. of nights" gives average lifetime number of nights in nursing home, averaged over all individuals, not just those with nursing home use. "OOP spending" means out-of-pocket spending on nursing home use. Spending is expressed in 2013 dollars as a present value at age 57 with a real discount rate of 3%. NH, nursing home; OOP, out-of-pocket.

prices in excess of general price inflation makes a considerable difference: It is equivalent to reducing the real discount factor by 1.3 percentage points, that is, from 3 to 1.7%. When we discount by 1.7%, our estimated lifetime out-of-pocket spending becomes \$10,695, which is 94% of the adjusted figure in Kemper et al. (6).

Limitations. The HRS data on nursing home stays and spending are based on self-reports, which might potentially be biased. We compared estimates from the HRS of the average number of nursing home nights and average out-of-pocket spending with estimates derived from external data. We found that average nights reported in HRS were approximately 5% lower, and that HRS out-of-pocket spending was, at most, 12% lower than our calculations based on CMS National Health Expenditure data and MetLife data (8, 9). See *SI Appendix* for details. Our findings would not be materially changed by such errors.

A second possible limitation is that in the nonparametric analysis in some cases, we combined individual-level data from two or three different respondents based on our matching method. Because nursing home use is particularly intense at the end of life, the matching method could lead to incorrect estimates of the probabilities of extremely long stays. We investigated the effects of matching by artificially discarding data on a subpopulation where we had completed, lifetime nursing home use, and reassigning data based on our matching algorithm. We found that the matching method produced data that were similar to the actual data. See *SI Appendix* for details. We are also reassured by the similarity between the nonparametric results and the model results, which do not require matching.

A third limitation concerns extrapolation from older to prospective cohorts, requiring an assumption of stationary in underlying processes. Looking at trends across cohorts, Spillman and Lubitz (7) conclude that the main driver of differences between cohorts in lifetime nursing home use is greater longevity, while changes in patterns of use of nursing homes appear quantitatively less important. They project for people reaching age 65 in 2000, 2010, and 2020 a lifetime risk of nursing home entry of 44%, 45%, and 46%, showing the slow pace at which increases in longevity translate into increases in risk of nursing home use. Indeed, in the HRS, the rate of nursing home residence at interview shows little consistent change from 1998 to 2012: Among those 75 or older, 7.4% resided in a nursing home

in 1998; the rate declined until 2008 reaching 6.6%; but increased to 7.7% in 2012. However, as discussed above, there has been a trend toward more nursing home use and especially short stays which would not appear in the HRS as residence in a nursing home: In the event of a short stay, HRS would postpone the interview until the respondent returned to the community, so that the respondent would not be recorded as a nursing home resident. Should the trend toward greater nursing home use continue, our estimates of lifetime use will be too low. Demographic trends are also underway that may affect future nursing home use. Our central cohort were the parents of the leading edge of the baby-boom generation, and so they had several children available for informal care. Indeed, we found a systematic negative relationship between the number of children and lifetime nursing home nights and out-of-pocket spending. Future cohorts will have fewer children, and, to the extent that nursing home use is a choice (rather than constrained by medical necessity), they will have more nursing home use. Similarly, the rise in female labor force participation will reduce the availability of informal caregivers, also increasing nursing home use.

Conclusion

We conclude that the lifetime risk of any nursing home use is approximately 56%, substantially higher than prior estimates; however, a substantial portion of the higher rate is likely due to an increase in short stays, which have a different impact on families than long stays. We estimate that 5% of older individuals will experience lengthy stays costing them \$47,000 or more (discounted), and that the lifetime chances of an episode longer than 100 d are approximately 27%. The risk of high spending juxtaposed with a moderate mean would seem to call for insurance. However, take-up of long-term care insurance is low, just 10.5% among those age 60 or older (10). One important reason for this low take-up is that Medicaid provides insurance of last resort.

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