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

		95% confidence interval	
	Mean	Lower	Upper
Nursing home use and OOP spending			
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

		95% confidence interval	
	Mean	Lower	Upper
Nursing home use and OOP spending			
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.

Table 4. Lifetime nursing home use and associated out-of-pocket spending by individual characteristics based on parametric models, from ages 57–61

Characteristics	Any lifetime use			No. of nights in nursing home			Out-of-pocket spending (2013 dollars)		
	Percent	Lower	Upper	Mean	Lower	Upper	Mean	Lower	Upper
Female	64.1	61.9	66.8	301	277	328	8,126	7,260	8,940
Male	50.6	47.8	52.6	141	127	165	4,080	3,662	5,174
White	58.5	56.6	60.5	222	206	242	6,642	6,016	7,342
Nonwhite	52.0	49.7	57.0	243	205	285	3,072	2,350	4,541
<HS	50.2	49.0	55.2	205	193	246	3,497	3,271	4,824
HS	59.9	57.6	63.7	236	211	268	6,752	5,920	7,806
College	60.5	56.0	61.6	228	180	243	7,518	6,314	8,418
No children	59.0	52.6	67.7	279	211	368	8,943	4,751	9,604
1–3 children	59.3	57.8	61.6	233	210	256	6,422	5,879	7,445
4+ children	55.2	51.7	57.9	206	189	245	5,532	4,898	6,439
Never smoker	64.7	61.4	67.6	277	245	315	8,003	6,795	8,707
Smoker	53.7	51.7	56.2	196	182	214	5,180	4,849	6,141
Not married at 50	59.4	57.3	64.2	276	245	314	5,848	4,859	7,028
Married at 50	57.4	55.2	59.2	216	197	234	6,265	5,687	7,119
No daughters	56.2	54.3	63.4	236	221	303	6,710	5,834	8,828
Has daughters	58.0	55.7	59.5	223	202	238	6,094	5,473	6,699

"No. of nights in nursing home" means average nights spent in a nursing home over the lifetime beginning at ages 57–61. "Spending" means lifetime out-of-pocket spending on nursing homes discounted to age 57 at a 3% real interest rate, expressed in 2013 dollars. "Lower" and "Upper" mean the lower and upper bounds of the 95% confidence intervals. "Characteristics" are recorded at age 50, e.g., "smoker" means an individual was or had been a smoker at age 50.

important. First, we use seven waves of biennial longitudinal data on our core cohort as they pass through years of high nursing home use and mortality. Thus, the data permit direct calculations of the bulk of nursing home use and out-of-pocket spending. Studies based on cross-sections or short panels require modeling and assumptions about data processes that we can mostly avoid in the nonparametric approach. Further, these studies combine data from various sources, which increases concern about reliability and whether each source pertains to the same population. In contrast, the HRS data are from one source with a longitudinally consistent survey design and elicitation methods. Second, the HRS data have relatively short recall periods for nursing home use—averaging two years—reducing recall error. Third, the exit interview data account for a considerable fraction of nursing home use: Ignoring them reduces the estimated lifetime risk of any nursing home use to 36%—similar to literature estimates.

The type of nursing home use included may account for differences. Kemper et al. (6) found that 35% of those turning 65 in 2005 would use a nursing home at some time in their remaining lifetimes. However, their study excluded posthospitalization rehabilitative care, which is fully or partially paid for by Medicare up to 100 d. We include such care because if an episode lasts beyond 20 d, an individual is responsible for substantial and possibly consequential copays: out-of-pocket costs for days 21–100 would accumulate to \$13,160 per episode. To ascertain whether our inclusion of short stays can account for the difference, we analyzed a subsample (88.8% of cases) where we could confidently measure the duration of episode length, namely when there were zero or one episode in any HRS wave. Over 14 y of HRS data, the percentage of this sample with any nursing home use was 44.1%; excluding episodes of less than 22 d reduced this to 29.9%. While we cannot repeat this analysis for the entire sample because we do not know episode length when there was more than one episode, the results for the subsample strongly suggest that our higher lifetime risk is at least partially due to short stays. Furthermore, the incidence of episodes of less than 22 d (short stays) appears to be increasing over time:

Comparing HRS 1998 with HRS 2010, we find that among those with one episode, 28.1% had a short stay in 1998 and 33.9% had a short stay in 2010. Compared with earlier studies, our use of more recent data is partially responsible for estimating a higher level of nursing home use.

Lifetime Out-of-Pocket Spending on Nursing Homes. From the perspective of a 57-y-old, average rest-of-lifetime out-of-pocket spending (\$7,344) is a small fraction (less than 10%) of mean financial wealth, as observed in multiple waves of HRS data. A forward-looking household could set aside this amount of money at age 57, and at the assumed real rate of return of 3%, would be able to pay for average out-of-pocket spending on nursing home use. However, this comparison does not account for a number of difficulties. First, these figures relate to mean wealth and mean out-of-pocket spending, but due to the skewed distribution of wealth, median financial wealth at age 57 would be depleted by setting aside this amount. Second, there is substantial risk: the 95th percentile of lifetime out-of-pocket spending is approximately \$47,000. Third, the dollar amounts assume discounting of 3% real, but some households may not be able to achieve that (high) real rate of return. Discounting at a zero real rate of return, which may be more realistic, yields higher present values: Average expected cost would be \$18,000; the 95th percentile would be \$115,000. Fourth, the figures are all on a per-person basis: The average expected costs for a couple would be approximately twice as great.

Our estimate of average out-of-pocket spending is considerably less than that of Kemper et al. (6): \$12,100 (in 2005 prices) among those surviving to age 65 in 2005, discounted to age 65 at 3% real. Putting their figure in 2013 prices and discounting to age 57 brings it to \$11,400 compared with our \$7,344 (nonparametric) or \$6,201 (parametric). In our most comparable model-based estimate, we assume stationary in processes, and convert to 2013 prices by the actual historical consumer price index. Kemper et al. assume 3% general price inflation and an additional 1.3% inflation in the long-term care sector. Over a 40-y time horizon, the assumption of inflation in nursing home

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 stationarity 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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