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End-of-Life Medical Expenses

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End-of-Life Medical Expenses

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Abstract

In this review, we document end-of-life medical spending: its level, composition, funding, and contribution to aggregate medical spending. We discuss how end-of-life expenses affect household behavior and economic evidence on the efficacy of medical spending at the end of life. Finally, we document recent trends in health and chronic disease at older ages and discuss what they might imply for end-of-life spending and medical spending in the aggregate.

Section 1: Introduction

The high cost of end-of-life care has drawn scrutiny for some time. End-of-life care is often viewed as unusually wasteful and costly, and it is widely believed that its reform could significantly improve aggregate health care efficiency (e.g., Will, 1990; Gawande, 2014; Reid, 2017). At the household level, end-of-life expenses can impose a significant financial burden and are often viewed as an important motivation for saving at older ages (De Nardi, French, & Jones, 2016a).

In this review, we document end-of-life medical spending: its level, composition, funding, and contribution to aggregate medical spending. We discuss how end-of-life expenses affect household behavior. We then discuss economic evidence on the efficacy of medical spending at the end of life. Finally, we describe recent trends in health and chronic disease at older ages and discuss what they might imply for end-of-life spending and medical spending in the aggregate. We proceed as follows.

We begin in section 2 by documenting trends in mortality and the time and causes of death. As mortality rates have fallen, especially at infancy, death has become increasingly concentrated at very old ages. The causes of death have changed significantly as well; the fall in the death rates for respiratory infections and heart diseases are particularly pronounced. The trends in health at advanced ages are more mixed. On the one hand, the amount of time older individuals spend with disability appears to have fallen. On the other, while trends in chronic disease are difficult to measure and interpret, its prevalence has most likely risen.

In section 3, we discuss the international evidence on the cost of end-of-life care. We show that end-of-life care is expensive: in the U.S., average medical spending from all payers during the last 12 months of life was $80,000 (in 2011, measured in 2014 dollars) and spending during the last three calendar years of life was $155,000. Nonetheless, end-of-life spending comprises only a modest fraction of aggregate expenditures, because the fraction of the population that dies in any given year is small. The U.S. is in no way an outlier in terms of expenditures on end-of-life care. Cross-country data show that the fraction of medical spending incurred during the last 12 months of life ranges from 8.5% in the U.S. to 11.2% in Taiwan, while spending in the last three calendar years of life ranges from 16.7% to 24.5%. The high level of medical spending immediately before death is part of a pattern of elevated medical spending for several years prior to death; this suggests many end-of-life treatments are for chronic conditions.

In section 4, we discuss the financing of end-of-life care. In the U.S., most end-of-life expenses are financed by the government through Medicare, the (almost) universal program for the elderly and disabled. Medicare coverage for long-term care (LTC) expenses, however, is quite limited. Most LTC expenses are paid either out of pocket or through Medicaid, which is means-tested. Countries differ widely in how they fund end-of-life care, especially LTC.   We find that cross-country spending variation within individual categories, such as LTC or hospital care, is high. Interestingly, countries that devote a relatively high share of their GDP to LTC are also those where the government most generously funds that care. This may in part reflect substitution across providers, including informal caregivers.

In section 5, we present evidence that the risk of incurring high out-of-pocket medical expenses at very old ages is an important driver of savings. We discuss why privately provided LTC insurance is not utilized more heavily. Potential reasons include the desire to leave bequests, adverse selection, moral hazard (with respect to informal care), and means-tested social insurance programs such as Medicaid.

In section 6, we review evidence on whether end-of-life care is unusually wasteful. The economic evidence on the efficacy of medical spending at older ages is mixed. None of this implies, however, that medical resources are being wasted in obviously futile attempts to extend the lives of dying patients. The evidence instead suggests that most deaths were unexpected; a significant part of the high spending on those who die is spending on sick people who were unlucky. This, of course, does not imply that there is no room for improvement: most notably, there is evidence that continuing the shift from conventional to palliative care would improve patient satisfaction and potentially even health outcomes for those nearing the ends of their lives.

In section 7, we discuss the implications for medical spending on the ongoing demographic transition. The effects of increased longevity on aggregate medical spending reflects two offsetting forces: (i) at any point in time, older people have worse health, increasing medical spending; and (ii) health at any given age has generally improved over time, reducing medical spending. Some analysts have argued that end-of-life spending is central to this. Because time to death is a better predictor of medical spending than absolute age, it is proximity to death, not age itself, that drives medical spending in old age. This suggests that increased longevity is a "red herring," with little effect on aggregate expenditure. However, even if the proximity to death is the main determinant of medical spending, increased longevity may cause the relationship between time to death and medical spending to change. We review the evidence on this and find that the relationship between time to death and medical spending is in fact evolving, due in part to the rise of treatable but expensive chronic conditions in old age.

We conclude in section 8.

Section 2: Trends in Mortality, Causes of Death and Late-in-Life Medical Spending

The last century has seen changes in health, longevity, and medical care for developed countries that have had profound effects on death and the costs associated with death. These developments include large reductions in infant mortality and death from infectious disease. Due in large part to these declines, death increasingly occurs at old ages and is increasingly associated with chronic conditions. These conditions are often quite costly.

*Trends in Life Expectancy and Age of Death*

Figure 2.1 shows life expectancy at birth in the U.S. by year of birth, sex, and race. In 1900, life expectancy at birth varied by race but very little by sex. White women had the highest life expectancy at 48.7 years, followed closely by white men at 46.6 years. Life expectancy for African

American women and men lagged behind by more than a decade, at 33.5 and 32.5 years, respectively. Between 1900 and 1950, life expectancy increased rapidly for all groups, with blacks and women making the most rapid gains. Life expectancy continued to increase over the second half of the century, albeit at a much slower pace.
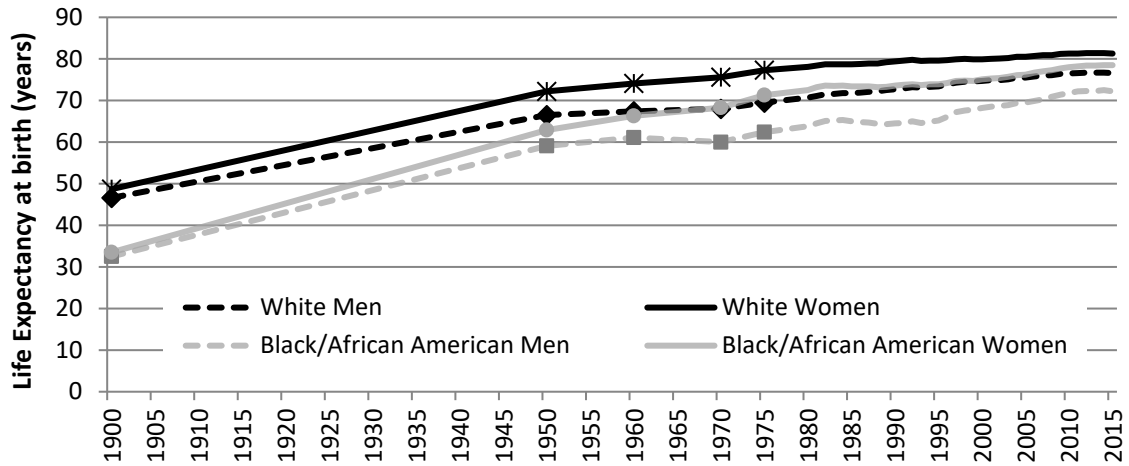
Figure 2.1: Life Expectancy at Birth by Race and Sex, U.S. 1900-2015

Source: Centers for Disease Control and Prevention (2018a, Table 015). Data available annually from 1980 onward. Earlier data points identified by markers.
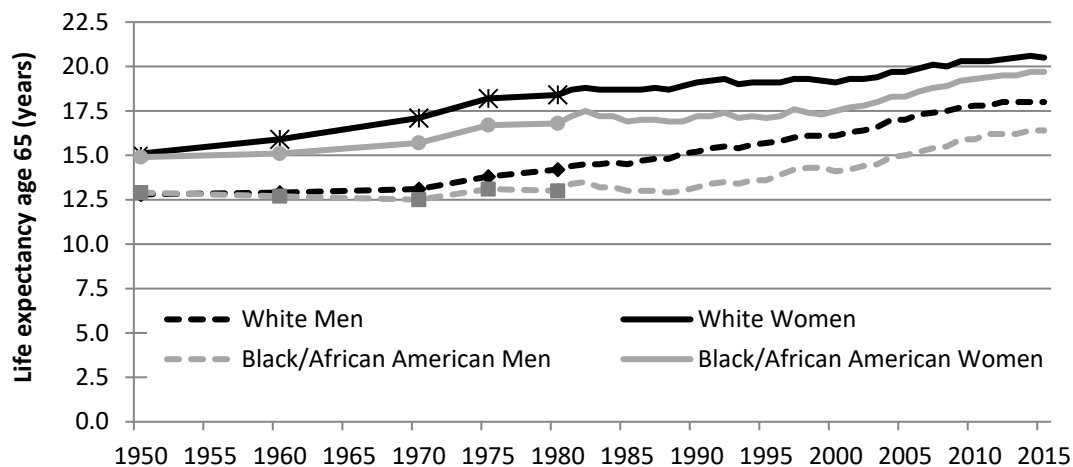
Figure 2.2: Remaining Life Expectancy at Age 65 by Race and Sex, U.S. 1950-2015

Source: CDC (2018a, Table 015). Data available annually from 1980 onward. Earlier data points identified by markers.

These longevity increases mask differential trends in age-specific mortality rates. In particular, most of the longevity gains in the first half of the 20th century were the result of declines in infant and childhood mortality. For example, the U.S. infant mortality rate fell from 10% in 1915 to 3% in 1950 (Meckel, 1990). It continued to fall in the second half of the 20th century, to under 1%, but most of the possible gains from reductions in childhood mortality had been realized by 1950. In contrast, most of the longevity gain post-1950 has been from reductions in mortality rates at older ages. Life expectancy at age 65, shown in Figure 2.2, increased about five years for most groups between 1950

and 2015. Life expectancy has grown more quickly for white Americans than for black Americans, although the gap has narrowed somewhat in recent years.

The cumulative effect of these mortality declines is that death has become an old-age phenomenon. Figure 2.3 shows that in 1936, 41% of those dying were 65 or older and only 5% were 85 or older. Over time, the distribution of death ages has shifted to the right. In 2016, 73% of those dying were at least 65 years old and 31% were at least 85.
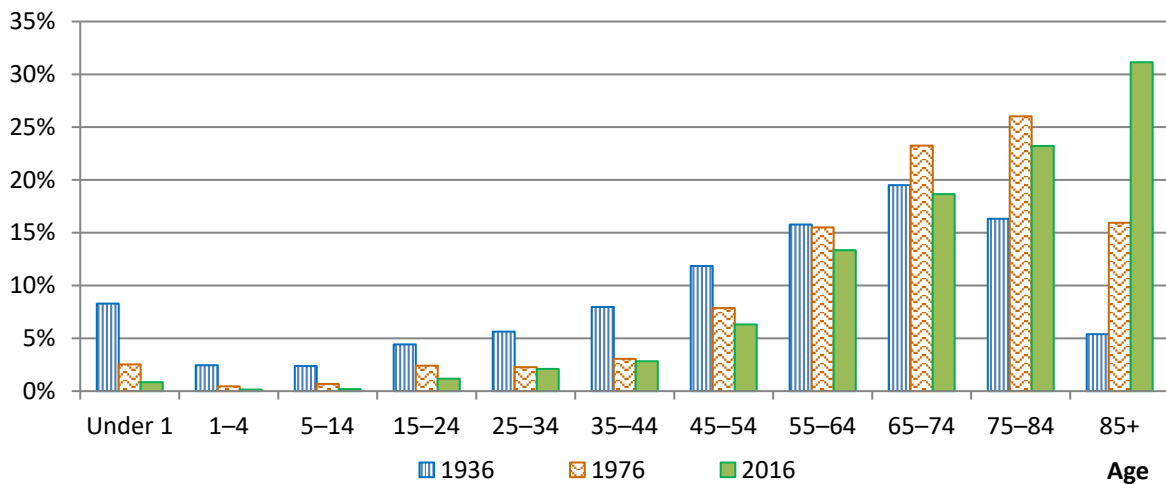
Figure 2.3: Cross-Sectional Distribution of the Age of Death: U.S., Selected Years
Source: CDC (2018b) and Xu, Murphy, Kochanek, Bastian & Arias (2018).

Causes of Death

Changes in the age at death are intimately related to changes in the causes of death. However, interpreting trends in the causes of death requires some care. The ability of medical science to treat patients has improved drastically over time but so has the accuracy with which conditions can be diagnosed. As a result, the number of deaths attributed to some diseases could rise, as deaths are ascribed to conditions that were previously undiagnosed, while the number of deaths attributed to other diseases could fall, as doctors reclassify from common to more specific causes of death.

Nonetheless, the primary causes of death appear to have changed in important ways. Table 2.1 lists the top five causes of death in the U.S. for the years 1900, 1950, and 2000. In 1900, three of the top five causes of death were related to infectious diseases. By 1950, the role of infectious diseases had greatly diminished, with only "certain diseases of infancy" making the list. By 2000, the top five causes of death were all chronic diseases or accidents. The trend toward death at later ages has thus been accompanied by a trend toward death from chronic conditions.

Table 2.1: Top Five Leading Causes of Death in the United States

| Rank	1900	1950	2000
1	Influenza/Pneumonia	Heart Disease	Heart Disease
2	Tuberculosis	Cancer	Cancer
3	Diarrhea/Enteritis/ Ulcerative Colitis	Vascular Lesions	Stroke
4	Heart Disease	Accidents	Chronic Respiratory Diseases
5	Stroke	Certain Diseases of Infancy	Accidents

Source: CDC (2018c).

Figure 2.4 shows age-adjusted death rates from five major causes for the U.S. over the period 1900-2015; as Figure 2.5 shows, since 1920 most of the age-adjusted death rate has been attributable to these causes. Age-adjusted death rates from heart disease increased rapidly from 1900 to 1950, before falling rapidly thereafter. While heart disease remained the leading cause of death throughout the second half of the 20th century, the death rate from heart disease in 2015 was approximately a third of that in 1950. In contrast to heart disease, the stroke death rate declined throughout almost the entire period. Death rates from influenza and pneumonia were similar to those from stroke (epidemic years excluded) until a sharp reduction in the 1940s. The rate of deaths attributed to cancer increased gradually until the 1990s, falling thereafter.
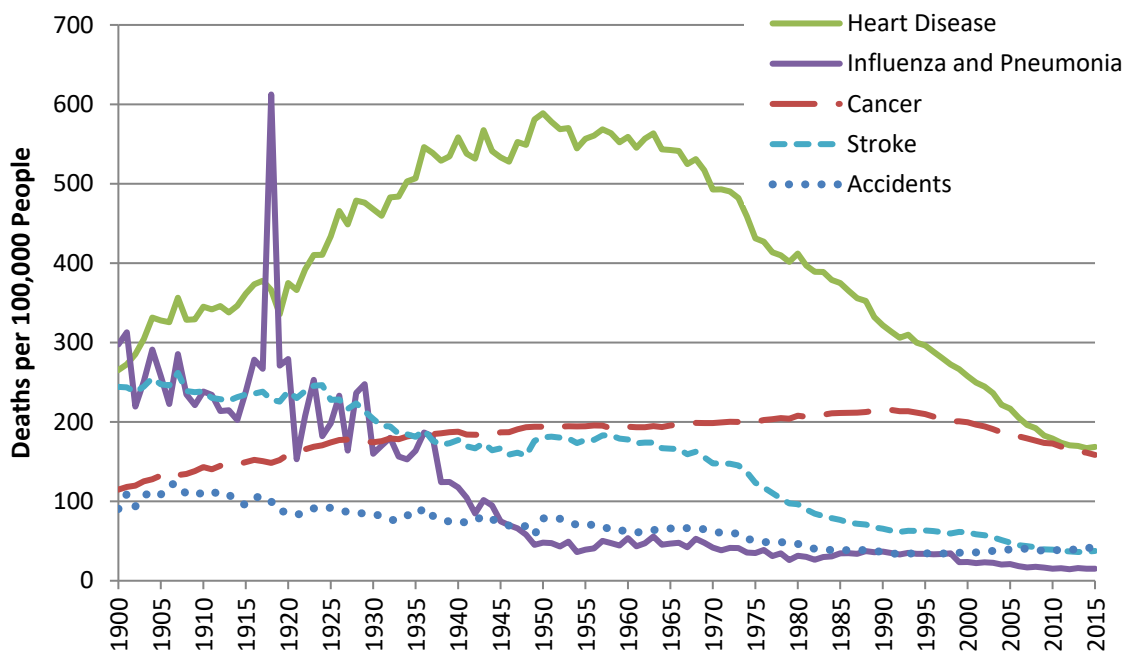
Figure 2.4: Age-adjusted Death Rates for Selected Causes of Death, U.S. 1900-2015
Source: CDC (2018a, Table 017).
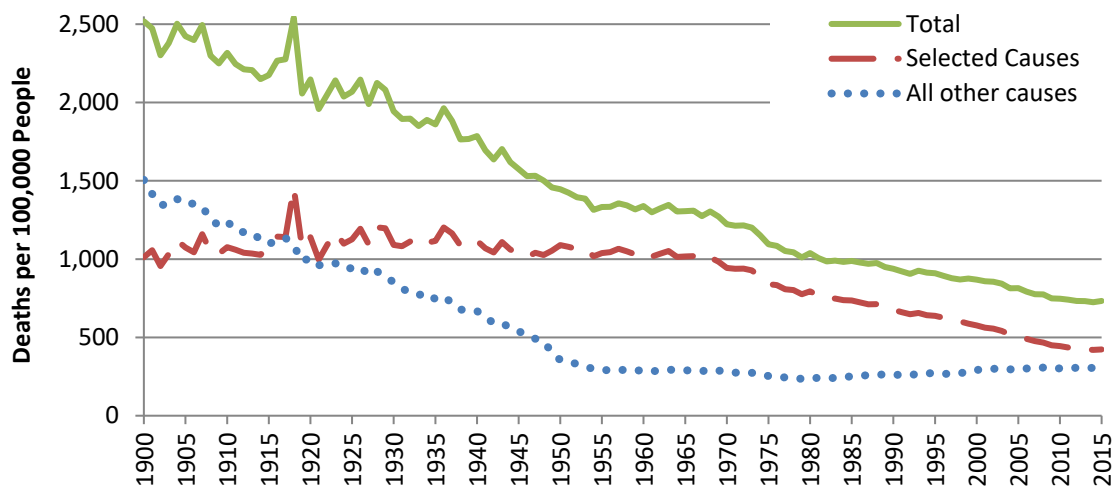
Figure 2.5: Age-adjusted Death Rates for All Causes and Selected Causes of Death, U.S. 1900-2015
Source: CDC (2018a, Tables 016 and 017).
Notes: The death rate for Selected Causes is the sum of the death rates for heart disease, influenza and pneumonia, cancer, stroke and accidents.

Trends in Chronic Disease and Poor Health

Death has become increasingly associated with chronic disease experienced in old age. This begs the question of whether the incidence of chronic disease, and poor health in general, have also increased.

Recent research has helped quantify the prevalence of chronic disease and its contribution to overall health care costs. For example, Buttorff, Ruder, & Bauman (2017) found that in 2014, 60% of the adult noninstitutionalised population in the U.S. had at least one chronic condition, with 42% having more than one. They also found that Americans with five or more chronic conditions accounted for 12% of the population but 41% of health care costs. By contrast, the 40% with no chronic conditions accounted for just 10% of the costs. Stafford et al. (2018), using U.K. administrative data from 2014 to 2016, reported that 46% of adults were living with one of 36 chronic conditions, with a total of 24% living with more than one. They found that approximately half of hospital admissions, outpatient visits, and primary care consultations were for people with two or more chronic conditions.

There is a general consensus that the incidence of chronic disease is increasing, but it is difficult to construct a long time series for multiple conditions. Buttorff et al. (2017) found no evidence of an increase in the prevalence of multiple chronic conditions between 2008 and 2014, but this is a relatively short interval.

Measuring chronic conditions is challenging because there is no single accepted definition of a chronic condition, and thus detection of chronic conditions has potentially changed over time. Furthermore, what is classified as chronic is likely to change over time as treatment improves. One example is cancer, many varieties of which have been transformed from acute to chronic diseases.

In the U.S, five-year survival rates for the most common types of cancer have increased from 50% in 1975 to 66% in 2012. There have been particularly large improvements in breast, prostate, and colon cancer (National Cancer Institute, 2017). In England, one-year survival rates for those diagnosed with cancer in 1971 were 50%, the same as the predicted 10-year survival rates for those diagnosed in 2011 (Quaresma, Coleman, & Rachet, 2015).

Improved health care does not necessarily reduce the prevalence of chronic conditions. If improved treatment allows individuals with a chronic disease (such as cancer) to survive longer, at any given time more people will be living with that chronic condition. Furthermore, individuals who would previously have died from other conditions are now more likely to survive to an age where they are more susceptible to chronic diseases. For example, the number of individuals diagnosed with dementia across the world is predicted to more than double by 2050. However, evidence suggests that the incidence of dementia at any given age is falling. The rise in rates is instead attributable to an aging population and people with dementia surviving longer (Derby, Katz, Lipton, & Hall, 2017).

More frequently tracked are lifestyle risk factors that contribute to chronic disease, such as smoking, alcohol consumption, and obesity. These behaviors are usually easier to measure and are more easily obtainable for long periods. Smoking has been on the decline across the developed world for the past 50 years. In 1965, 42% of U.S. adults smoked. By 2016, this had fallen to 16% (CDC, 2018d). Unfortunately, while smoking has fallen, rates of another leading cause of chronic disease, obesity, have been on the rise. Recent results for the U.S. suggest that obesity continues to increase among adults, although it may have plateaued among children (Hales, Fryar, Carroll, Freedman, & Ogden, 2018). U.K. evidence (Public Health England, 2017a) also suggests obesity is plateauing in children, with lower rates when they enter school at age 4. Rates of obesity at the time children leave primary school (age 11) have increased, but this is largely confined to the two most deprived quintiles of the population.

A measure related to but broader than the incidence of chronic disease is healthy life expectancy, or the number of years that an individual can expect to be in good health. In practice, trends in healthy life expectancy are difficult to assess, in part because there is no universally accepted definition of good health. Chernew, Cutler, Ghosh, & Landrum (2017) defined health on the basis of disability, with disability itself defined as impairments in Activities of Daily Living or Instrumental Activities of Daily Living. They estimated that life expectancy at age 65 increased by 1.3 years between 1992 and 2008, but nondisabled life expectancy (the number of years that an individual can expect to be nondisabled) increased even more, by 1.8 years. The time spent living in disability by those 65 and over thus fell by 0.5 years.[1] By contrast, there is evidence that when health is measured as the presence of disease, the length of life spent in bad health has increased (Crimmins & Beltrán-Sánchez, 2011). This is consistent with findings that although the incidence of disease has increased, disability conditional on disease has fallen (Cutler, 2005). Crimmins & Beltrán-Sánchez (2011) also reported, however, that the portion of life spent with mobility functioning losses has increased.

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[1] Such a finding is consistent with the well-known "compression of morbidity" hypothesis (Fries, 1980): if medical progress increases the expected lifespan but has relatively little effect on the maximum possible lifespan, as longevity increases so will the fraction of life spent in good health. Perhaps not surprisingly, there is also a counterhypothesis that morbidity should expand (Gruenberg, 1977).

They conjectured that improvements in technology may be reducing the rate at which these losses translate into disability.

Yet another measure of health, more subjective but more holistic, is the individual's self-assessment. In the U.K., between 2000-2002 and 2012-2014 expected years in self-rated good health for men increased from 60.6 to 63.4 years, while expected years in poor health increased from 15.4 to 16.1 (Public Health England, 2017b). The results for women were similar.

Section 3: International Evidence on the Cost of End-of-Life Care

Measurement Issues

Measurement of late-in-life medical expenditures is not straightforward. People who have died or are seriously ill cannot respond to surveys. Even if "exit interviews" of survivors or caregivers are used to complete the survey, households are usually aware only of the expenses they pay out of pocket. However, there can be many different types of medical services and many different payers for them. Aggregating across expenditures and payers often requires bringing together data from multiple sources, and relatively few countries have high-quality administrative data linking all sources of medical care to mortality. Most countries lack any administrative data on end-of-life care that are accessible to researchers, and those that do usually only cover limited information, such as hospital care. Furthermore, in most countries there are both public and private payers for health care. Merging administrative data from both types of insurers is difficult. Moreover, in some countries, private insurers may cover only certain sectors of the population. For example, there are special insurers in Germany for high earners and special insurers in Japan for particular occupations. A sample from such an insurance company is not likely to be representative.

In the U.S., these issues have been circumvented by linking survey information to administrative data in an effort to account for all payers in a representative sample. For end-of-life expenditures, the Medicare Current Beneficiary Survey (MCBS) and the Health and Retirement Study (HRS) are the key datasets. However, both datasets have their own specific problems. Table 3.1 summarizes important features of both datasets.

The MCBS captures all payers of medical expenditure at a high frequency. Administrative data on Medicare expenditures and Medicaid recipiency are linked to individual survey data. Individual responses and Medicare reports of care often differ: the medical spending data are constructed using a sophisticated reconciliation process. Nonetheless, the MCBS understates medical spending relative to the national aggregates found in the National Health Expenditure Accounts (NHEA). This is partly because the NHEA includes expenditures on research and development, administration and public health, whereas the MCBS attempts only to measure personal health care expenditures. However, the MCBS also appears to understate personal health care expenditures. De Nardi et al. (2016b) found that the MCBS overall captured 86% of all Medicare payments and 79% of all Medicaid payments, while French, Jones, & McCauley (2017a) found that in 2011 the MCBS captured 78% of personal health care payments, inclusive of all types of care and all payment sources. Under-reports of medical spending do not seem to be specific to the MCBS. Using data from nine counties,

French et al. (2017a) found that the micro data from almost every country understates spending relative to the national aggregates.

Table 3.1: Comparison of the HRS and MCBS Datasets

	HRS	MCBS
Data Source	Survey, employer, and administrative data from Medicare, Medicaid, and other sources available for merging	Survey data reconciled with Medicare and Medicaid administrative data
Longitudinal Design	Full panel, new cohorts added as they (roughly) reach age 50	Rotating panels, each panel lasting four years
Sample Population	Nationally representative of those aged 50+	Nationally representative of the Medicare population (captures 98% of those aged 65+)
Interview Frequency	Every two years	Every four months
Measurement Unit	Household, spouses included	Individual
Interview Methodology	Mix of in-person and other	In-person
Institutional Population	Not included in initial samples, but households followed into institutions	Included (by proxy)

Source: French et al. (2017b).

Relative to the MCBS, the HRS interviews respondents much less frequently but over a much longer period of time; once a household enters the survey it is tracked until all its members die. Members are followed into nursing homes, and upon the death of a member, his or her survivors are interviewed. The HRS has long contained information on out-of-pocket expenditures, and recently it has been linked to both Medicare and Medicaid data. However, other payers, such as private insurance, are excluded. A strength of the HRS is its very comprehensive set of survey questions, including information on care provided by other family members. In combination with asset information, these data provide a broad measure of the cost of end-of-life care, including informal care, and how such costs impact wealth and overall well-being.

Given the differences in survey design, there are multiple dimensions along which the MCBS might be better or worse than the HRS for measurement of medical spending. However, French et al. (2017b) showed that for out-of-pocket expenses and Medicaid recipiency, the two surveys line up well. One limitation of the MCBS is that it is representative only of Medicare beneficiaries, who include Disability Insurance beneficiaries and virtually all of the age 65+ population and is thus representative of deaths only within that population. Fortunately, 73% of all deaths are among those 65+. The HRS covers a somewhat broader age range, with younger cohorts entering the survey around age 50.

Estimating End-of-Life Medical Spending

How researchers measure medical spending in the last 12 months of life depends on the data available. When data are available at an extremely high frequency, the most common approach is to measure spending starting from the date of death and sum backward for 12 months (e.g., Hogan et al., 2001). Einav, Finkelstein, Mullainathan, & Obermeyer (2018) have referred to this method as "backfilling."

However, in many large datasets, medical spending is available only at an annual frequency. For decedents, this means that total medical spending in the last calendar year of life, which is spending between January 1 and the date of death, is all that can be observed. Any comparison of the medical spending of decedents with that of survivors will suffer from the problem that while all survivors had 12 months of spending, spending data for decedents mixes together those who died in January (and so had only one month of spending in the "year of death") and those who died in December (and so had 12 months of spending), along with those dying in other months.

A commonly used way to work around this problem is that of Hoover, Crystal, Jumar, Sambamoorthi, & Cantor (2002), who estimated the following regression using MCBS data:

(1) $$E_i = \beta_0 + \beta_1\sqrt{m_i} + \beta_2 m_i + \beta_3 m_i^2 + \epsilon_i$$

where E_i is total medical spending in the last calendar year of life for individual *i*, m_i is individual *i*'s exact month of death (e.g., $m_i = 1$ if the month of death is January, and so on), and ϵ_i is a zero-mean residual. Average medical spending for the last 12 months of life can then be predicted by estimating the coefficients for equation (1) and evaluating the estimated equation at $m_i = 12$.

Estimates across Countries

Table 3.2 displays average medical spending at the end of life across nine countries. The estimates in this table are taken from French et al. (2017a), who utilized a collection of micro datasets.[2] (For the U.S. they used the MCBS.) Table 3.2 contains two measures of end-of-life spending: spending in the last 12 months of life, estimated using the Hoover et al. (2002) method; and spending over the last three calendar years of life. In the table, odd columns display average medical spending levels, expressed in 2014 dollars, and even columns display the percentage of aggregate spending in that medical spending category accounted for by decedents.

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[2] French et al. (2017a) sought to make the spending data as comparable across countries as possible by focusing on data from the same years, using common estimation methods, and restricting spending to the same service categories. They also adjusted their estimates so that mean medical spending per capita in each of the micro datasets matched the national aggregates for its source country. Methodological details can be found in French et al. (2017a) and its associated appendix.

Table 3.2: Average Spending on End-of-Life Care across Countries

	All medical care, including long-term care		All medical care, excluding long-term care		Long-term care		Hospital care	
	Spending (1)	% of Aggregate (2)	Spending (3)	% of Aggregate (4)	Spending (5)	% of Aggregate (6)	Spending (7)	% of Aggregate (8)
Final 12 months of life								
Denmark	62,672	10.95	52,286	9.97	9,059	21.74	36,554	10.01
England	--	--	--	--	--	--	18,633	14.59
France	--	--	36,350	8.50	--	--	24,458	15.00
Germany	52,742	10.96	46,480	10.59	4,686	14.89	29,428	21.17
Japan	--	--	38,942	5.93	--	--	37,869	8.21
Netherlands	63,473	10.01	36,592	7.32	14,982	22.12	20,586	8.85
Quebec	--	--	--	--	--	--	22,868	22.73
Taiwan	20,892	11.20	18,787	10.10	1,986	23.08	12,122	15.53
United States	80,094	8.45	59,180	7.11	14,034	18.12	35,376	9.91
Last 3 calendar years of life								
Denmark	128,612	22.16	102,333	19.23	26,279	54.24	68,900	18.65
England	--	--	--	--	--	--	39,620	29.78
France	--	--	59,534	14.10	--	--	34,804	22.08
Germany	95,844	21.40	80,633	19.85	15,211	36.59	40,834	29.87
Japan	--	--	66,256	10.36	--	--	61,027	13.50
Netherlands	123,019	19.40	68,332	14.28	54,687	44.86	35,159	15.12
Quebec	--	--	--	--	--	--	24,074	25.65
Taiwan	41,716	24.48	37,542	22.07	4,174	54.92	23,910	34.88
United States	155,398	16.70	104,222	12.77	51,176	44.92	56,351	16.27

Source: French et al. (2017a).

Notes: "Spending" is per decedent in 2014 U.S. dollars. '% of Aggregate' displays the spending as a percentage of all spending in that medical spending category (both on decedents and survivors). 'Final 12 months of life' displays the average medical spending in 2011 that went to those who were in their last 12 months of life. 'Last 3 calendar years of life' displays the average medical spending in 2011 that went to those who were in their last three years of life. For all countries the year of death is 2011, apart from Denmark, which uses 2012 data, and France, which uses 2013 data. Medical spending in the last three calendar years of life is the sum of medical spending in calendar years 2009 through 2011. Hospital spending refers to both inpatient and outpatient care, apart from France, England, and Quebec, which only have data on inpatients. Japanese data only includes hospital, dentist, and pharmaceuticals. "Long-term care" for Taiwan also includes home help. Data from Germany exclude home help. '—' denotes data unavailable.

Column (1) of Table 3.2 shows that average medical spending in the last 12 months of life is high, reaching $80,000 for the U.S., $63,000 for the Netherlands and Denmark, and $53,000 for Germany. Medical spending is also high during the last three calendar years of life, reaching $155,000 for the U.S., $123,000 for the Netherlands, $129,000 for Denmark, and $96,000 for Germany. These totals are roughly double those incurred in the final 12 months. Thus, the spending of those who die is far from fully concentrated right at the time of death. This suggests that the high cost of dying is due less to last-ditch efforts to save lives than to spending on chronic conditions, which are associated with shorter life expectancies. In a similar vein, Davis, Nallamothu, Banerjee, & Bynum (2016), who studied spending trajectories near the end of life, found that while 49% of U.S. decedents experienced "high persistent spending," only 12% had "late rise spending."
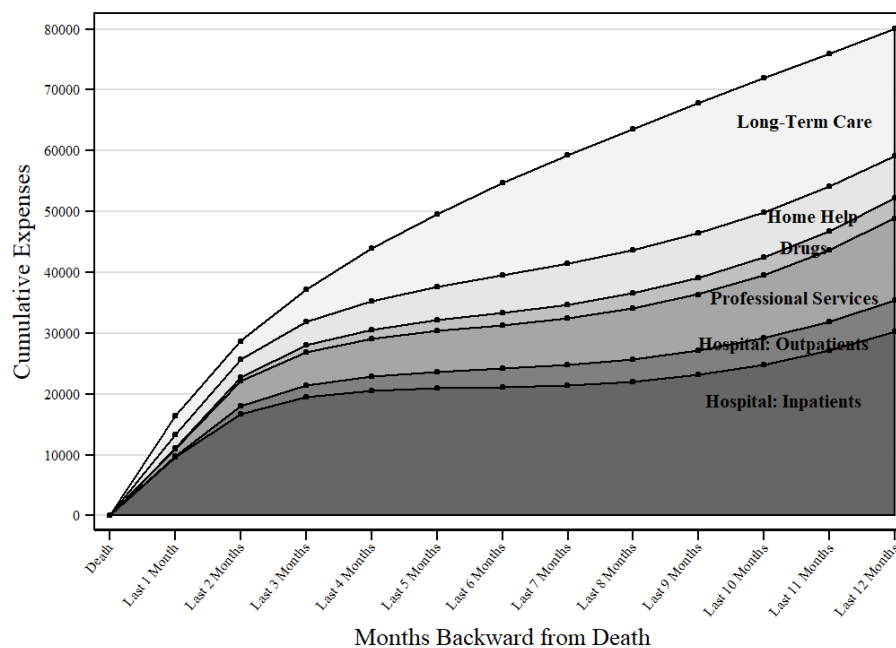
Figure 3.1: Average Medical Spending in the Last 12 Months of Life in the U.S., by Expenditure Type. Source: De Nardi et al. (2016c), adjusted to match aggregate spending.

Figure 3.1, taken from De Nardi et al. (2016c), contains a similar message. Figure 3.1 plots cumulative medical spending over the last 12 months of life for the U.S.[3] Although an average of almost $40,000 is spent in the three months preceding death, another $40,000 is spent in the nine months preceding that.

The even columns of Table 3.2 show for each country the fractions of national medical spending (in 2011) devoted to people in the last 12 months and last three calendar years of their lives. Although dying is expensive in all countries, in all countries the fraction of the population that dies in any given year is small. Medical expenses for those close to death therefore do not necessarily account for a large portion of aggregate medical expenditures. Each set of fractions is specific to the medical spending category listed in the headers. Column (2) displays the spending shares for all medical care

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[3] Figure 3.1 is based on data from the MCBS, adjusted for its undercount of medical spending relative to the national aggregates.

services. The top panel shows that medical spending in the last 12 months of life accounts for approximately 8-11% of aggregate medical spending in most countries, with the U.S. spending the least (8.5%) and Taiwan the most (11.2%) in percentage terms. There is no strong link between this percentage and the type of health care system.[4] The bottom panel shows that total medical spending in the last three calendar years of life is approximately twice as much as spending in the last 12 months, with the spending fractions ranging from 16.7% in the U.S. to 24.5% in Taiwan.

While the finding that end-of-life spending is a modest fraction of aggregate medical spending may be at odds with popular wisdom, it comports with earlier studies. Emanuel & Emanuel (1994) calculated that 10-12% of total U.S. medical spending was for end-of-life care. Aldridge & Kelley (2015) found a slightly higher value, 13%, but relied heavily on imputations. One possible source of misunderstanding for the U.S. is the well-known finding by Lubitz & Riley (1993), reaffirmed by Riley & Lubitz (2010), that about 25% of Medicare spending on the 65+ population is for care in the last year of life. However, this calculation overstates the share of aggregate medical spending that goes to those in the last year of life. Although most deaths are among those 65 and older, most medical spending goes to those 64 and younger. The share of 8.5% reported in Table 3.2 is based on end-of-life and aggregate spending for all ages.

What is the Money Spent On?

The remaining columns of Table 3.2 display spending and spending shares for different medical service categories. Column (6) shows that, relative to other medical services, a much greater proportion of LTC expenditures are incurred near the end of life. The share of LTC spending incurred in the last 12 months of life ranges from 14.9% in Germany to 23.1% in Taiwan. The share incurred in the last three calendar years of life ranges from 36.6% in Germany to 54.9% in Taiwan.

Columns (7) and (8) show spending and spending shares for hospital services, a spending category measured in all nine countries. In the countries where every medical spending category is accounted for, hospital care is the largest end-of-life expense. Hospital spending is not always more concentrated at the end of life than medical spending in general, and, Germany excepted, hospital spending is less concentrated than spending on LTC. The share of hospital spending accounted for by those in the last 12 months of life ranges from 8.2% in Japan to 22.7% in Quebec, and the share for those in the last three calendar years of life varies from 13.5% in Japan to 34.9% in Taiwan.[5] Comparing columns (2) and (8) shows that among countries with complete data, the variation in hospital spending shares is larger than that of the overall spending shares. For example, in the last three years of life, hospital shares for this group range from 15.2% to 34.9%, while the overall shares range between 16.7% and 24.9%. This suggests that some of the variation in the hospital shares is due to substitution between providers and/or services in the delivery of care.

Figure 3.1 sorts U.S. spending over the last 12 months of life into medical service categories. Inpatient hospital spending comprises the bulk of spending in the last two months of life. Other

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[4] French & Kelly (2016) briefly described each country's health care system.

[5] These results are in line with Bekelman et al. (2016), who compared patients older than 65 who died with cancer across seven developed countries. They found that end-of-life care was more hospital centric in Belgium, Canada, England, Germany, and Norway than in the Netherlands or the United States.

forms of care, such as LTC (which includes nursing home care) are more important in the months further from death.

Section 4: Funding for End-of-Life Care

Although end-of-life spending may comprise a relatively modest fraction of spending in the aggregate, at the household level it is hardly trivial. The averages reported in Table 3.2, high in their own right, mask the possibility of significantly higher expenditures. In this section, we describe how end-of-life care is funded, the first step in assessing the financial risk it poses to older households.

A country-by-country account of how end-of-life care is funded is beyond the scope of this review; French & Kelly (2016) provided summaries for the countries appearing in Table 3.2. Below, we provide a detailed description for the U.S., followed by a cross-country comparison of LTC, the service that seems to have the most cross-country variation in funding.

Funding in the U.S.

Figure 4.1 plots cumulative medical spending over the last year of life for the U.S., using the same data and methodology as Figure 3.1, but decomposing spending by payer rather than service. Of the $80,000 incurred over the final year of life, 66% is covered by Medicare, the public health insurance available to almost everyone 65 or older.[6] 9% is covered by Medicaid, public health insurance that is means-tested, and 2% by other government programmes. Many people have private coverage, and thus 8% of end-of-life costs are paid by private insurers. While end-of-life care is reasonably well-insured, there is still a nontrivial amount that must be paid out-of-pocket. Out-of-pocket expenses in the last year of life are $9,530, or 12% of the total.[7] Additionally, even after other payers have contributed, expenses can be so high that households are unable to cover them: uncollected liabilities are $2,060, or 3% of the total. Nonetheless, end-of-life expenses are on average better insured than medical spending for the elderly in general. The MCBS data behind Figure 4.1 shows that 19% of the medical spending by the over-65 population is paid out of pocket, relative to 12% for those in the last year of life.

Figure 3.1 shows that most end-of-life spending is for either hospital care or LTC. The largest expenditure item is hospital care. Hospital care is well-insured for those 65 and older, as Medicare covers most of their hospital costs, and many have private Medigap policies that pay for the remainder. Only 1% of hospital care is paid for out of pocket (De Nardi et al., 2016c).

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[6] In addition to being 65 or older, an individual or their spouse must have paid Medicare taxes for at least 10 years. Individuals not meeting this requirement may be able to buy Medicare coverage. (U.S. Centers for Medicare & Medicaid Services, 2018). 98% of the 65+ population receives Medicare (see Table 2.1).

[7] French, Baker, Doctor, De Nardi, & Jones (2006) and Marshall, McGarry & Skinner (2011) found even higher out-of-pocket expenses in the last year of life.
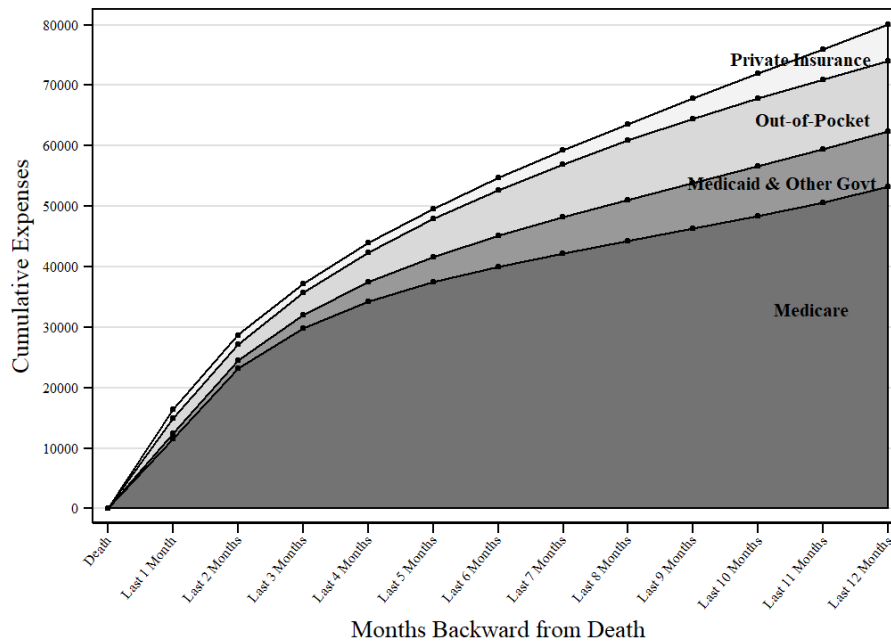
Figure 4.1: Average Medical Spending in the Last 12 Months of Life in the U.S., by Payer

Source: De Nardi et al. (2016c), adjusted to match aggregate spending.

Medicare coverage of LTC and home help costs is far less comprehensive. Medicare pays only for skilled nursing care such as rehabilitative services, but most LTC is unskilled custodial care. Furthermore, Medicare pays for at most 100 days in a nursing home (U.S. Centers for Medicare & Medicaid Services, 2018). While Medicare covers nearly 70% of the hospital costs of those 70 and older, it covers less than 25% of their nursing home costs. Furthermore, few individuals purchase LTC insurance; private insurance covers less than 8% of nursing home costs. As a result, a significant portion of LTC spending is uninsured: around 28% of LTC expenditures are paid for out of pocket (De Nardi et al., 2016c).[8] Given its high cost, its concentration near the end of life (see Table 3.2), and its high out-of-pocket share, LTC is an important driver of out-of-pocket spending near the end of life.

The largest LTC payer, covering almost 30%, is Medicaid. While the Medicaid rules are complicated and vary from state to state, people in nursing homes typically qualify through one of two channels (De Nardi et al., 2012). They are either "categorically needy," because their income and wealth are low in an absolute sense; or they are "medically needy," because their medical expenses have exhausted their financial resources. The latter provision extends Medicaid beyond the lifetime poor but requires households to spend down their wealth before receiving benefits. An open question is the extent to which wealthier households avoid spend-down through trusts, transfers, or other financial devices. While the data show that people with higher wealth are much less likely to receive Medicaid (Borella et al., 2018) and take longer to spend down their wealth (Wiener, Anderson, Khatutsky, Kaganova, & O'Keeffe, 2013), they also show that at very old ages a significant fraction of high-income individuals are on Medicaid (De Nardi et al., 2016b).[9]

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[8] See Table 1. Values are based on the 2010 National Health Expenditure Accounts.

[9] There are also a number of direct analyses of spend-down evasion. While the ability of Medicaid to recover its costs from its beneficiaries' estates appears quite limited (see the discussion in De Nardi et al., 2012), the

Differences in funding of the types of health care lead to differences in the amount of insurance provided to those with different health conditions. Health conditions requiring LTC are relatively poorly insured. Kelley, McGarry, Gorges, & Skinner (2015) used the HRS to estimate medical costs over the last five years of decedents' lives. As shown in Table 4.1, they found that the total average expenditures per decedent for dementia ($218,000) were significantly greater than for those who died of heart disease ($153,000), cancer ($144,000), or other causes ($164,000).

Table 4.1: Expenditures over the Last Five Years of Life, by Disease and Payer

	Average Medical Expenditures*	Medicare & Medicaid	Medicare	Out-of-Pocket	Imputed Informal Care	Social Cost (1 + 5)
	(1)	(2)	(3)	(4)	(5)	(6)
Dementia	$218,288	$130,295	$92,476	$65,826	$88,830	307,117
Cancer	143,537	109,636	108,330	30,834	41,974	185,512
Heart Disease	152,877	103,266	97,769	37,763	34,510	187,387
Other	164,022	117,495	111,046	38,596	47,065	211,087

Source: Kelley et al. (2015, Table 1).
Notes: Values in Kelley et al. (2015) converted from 2010 to 2014 dollars using the PCE. The sample includes 1,702 subjects over age 70 in the HRS who died between 2005 and 2010. *Average medical expenditures include Medicare, Medicaid, out-of-pocket expenses, and imputed third party payments for nursing home expenditures. Average medical expenditures exclude imputed informal care costs.

While Medicare expenditures were similar across illnesses, average out-of-pocket spending for dementia patients ($66,000) was 81% higher than that of non-dementia patients, consistent with Medicare's limited coverage of LTC services. Not only was absolute out-of-pocket spending significantly higher within the dementia group, but Kelley et al. (2015) reported that out-of-pocket spending as a proportion of total household wealth five years prior to death was also substantially higher, as those who die from dementia tend to have less wealth than those who die of other diseases. The gap in the out-of-pocket burden between dementia and non-dementia decedents was especially pronounced in lower education and minority groups.

In addition to out-of-pocket expenditures, informal care provided near the end of life can impose great strains. Informal care is often ignored in end-of-life expenditure analyses. Imputing the implicit cost of informal caregiving,[10] Kelley et al. (2015) found that the average informal care burden for dementia decedents was more than double that of non-dementia decedents.

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use of trusts to qualify for Medicaid appears limited as well (Taylor, Sloan, & Norton, 1999). The degree to which households transfer assets to qualify for Medicaid, discussed below, also appears to be modest.

[10] HRS respondents report the total hours of informal care provided in the month prior to each interview. Kelley et al. (2015) converted these reports into five-year totals, which they then multiplied by the state-specific average cost of home help services.

Differences in Long-Term Care Systems

While many medical services impose significant financial burdens on U.S. households, LTC is arguably the most significant. It turns out that LTC is a significant financial risk for households in many other countries as well. As Brown & Finkelstein (2011) noted, although most OECD countries other than the U.S. provide universal insurance for acute care, many fail to provide similar insurance for LTC.[11]

There is also considerable cross-country variation in LTC expenditures. Figure 4.2 shows that total spending on LTC equals almost 3% of GDP in some countries, such as the Netherlands and Sweden. Other countries, such as Greece, Portugal, and Poland, devote less than .4% of GDP to LTC. The LTC share for the U.S. is toward the bottom of the range at .9% in 2016, in contrast to the overall U.S. health expenditure share, which is much higher than in other countries. Variation in funding arrangements may be driving the dispersion in LTC shares.[12] For example, Scandinavian countries and the Netherlands, which provide universal LTC, spend a very high share of GDP on LTC. In contrast, the U.K., Canada, and the U.S., who have means-tested public programs for LTC, spend a more modest share of their GDP on LTC.
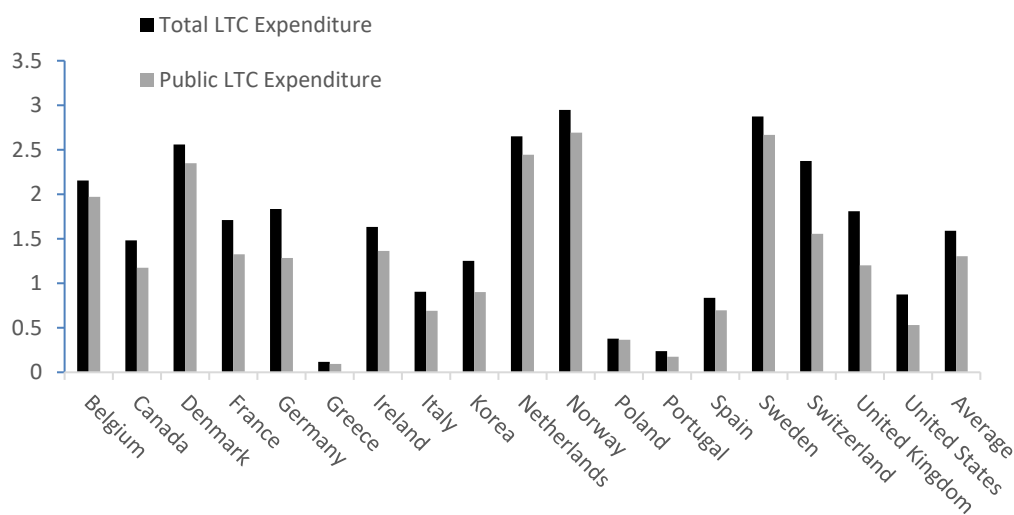
Figure 4.2: Long-Term Care Expenditures in the OECD, as Percentages of GDP, 2016

Source: OECD (2018). This figure is an updated version of Figure 1 in Brown & Finkelstein (2011).
Notes: Figure shows total expenditures and public LTC expenditures as percentages of GDP for various OECD countries. Public LTC expenditure data for the U.S. are not available for 2016; this spending is inferred by assuming that the public share of total LTC expenditures in 2016 was the same as in 2013.

Some of the differences in spending likely reflect substitution across providers, particularly to or away from informal care. Rodrigues, Huber, & Lamura (2012, Figure 7.4) used cross-country variation to show a negative correlation between formal care provision and informal care provided

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[11] Descriptions of LTC systems can be found in Dobrescu (2015) and Nakajima & Telyukova (2016).

[12] Public financing of LTC has been shown to have an impact on use of care at end-of-life. Orlovic, Marti, & Mossialos (2017) found that in countries where public financing of LTC is particularly strong, patients at the end-of-life were more likely to have reduced hospitalizations and a higher share of out-of-hospital deaths.

by families: for example, individuals in both Sweden and the Netherlands receive relatively little informal family care and a relatively large amount of formal care. Barczyk & Kredler (2018) showed that as one moves from north to south across Western Europe, public funding of LTC falls and the use of informal care rises; the U.S.'s location on this gradient is somewhere between the central and southern European countries. Accounting for informal care only reinforces the conclusion that LTC spending risk is not unique to the U.S. Indeed, in countries such as the U.K., there have been policy proposals to provide greater state support for LTC (Commission on Funding of Care and Support, 2011).

It is natural to think that because LTC spending tends to be concentrated toward the end of the life cycle, countries with relatively high LTC spending would also incur more of their medical spending late in life. However, comparing Figure 4.2 to Table 3.2 (column 2) provides little if any support for this conjecture. For example, the Netherlands devotes relatively little of its medical spending to end-of-life care, despite spending a large share of its GDP on LTC. Conversely, Taiwan devotes a relatively large share of its medical spending to end-of-life care, despite spending little on LTC.

Section 5: End-of-Life Care as a Driver of Saving and Other Financial Behavior

Having established that uninsured end-of-life spending, particularly for LTC, often imposes a significant financial burden, we turn to the evidence on how households respond to this risk. In addition to its direct effects, end-of-life medical spending may provide an important motive for retirement saving (De Nardi et al., 2016a). That is, elderly households may be holding onto their assets to cover expensive medical conditions at extremely old ages. While late-in-life medical expenses mechanically reduce wealth, the risk of catastrophic late-in-life medical spending may lead to saving that increases wealth.

Wealth at the End of Life

Several papers have shown that death is associated with significant declines in household wealth and that these declines are driven at least in part by high medical spending around the time of death. French et al. (2006) used HRS data to document changes in health care use, medical spending, and assets around the time of death. Poterba, Venti, & Wise (2011) also showed that wealth declines around the time of death.

De Nardi et al. (2018b) updated the results in French et al. (2006) and developed a model of lifetime decision-making to help understand them. Figure 5.1, taken from this study, shows the medical spending of couples and singles, respectively, around the time of death. Each panel of this figure compares the spending of households that experience a death with the spending of households with similar initial household composition (i.e., single man, single woman, couple), health, age, income, and wealth that do not experience a death. Medicaid as well as out-of-pocket spending is included, as Medicaid is not available unconditionally but is subject to means-testing.

The left panel of Figure 5.1 shows average annual medical spending for married households that lose a spouse from six years prior to death to four years after death. The right panel shows average

annual spending for singles (including those widowed, divorced, and never married) in the six years prior to their deaths. Six years prior to a household death, average out-of-pocket plus Medicaid spending is $8,000 per year for couples. This spending rises in the years leading up to death, reaching $19,000 in the period the death is recorded. [13] After the period of death, medical spending returns to its original level. The right panel of Figure 5.1 shows that for singles, medical spending rises from $6,000 six years prior to death to $16,000 in the year the death is recorded.
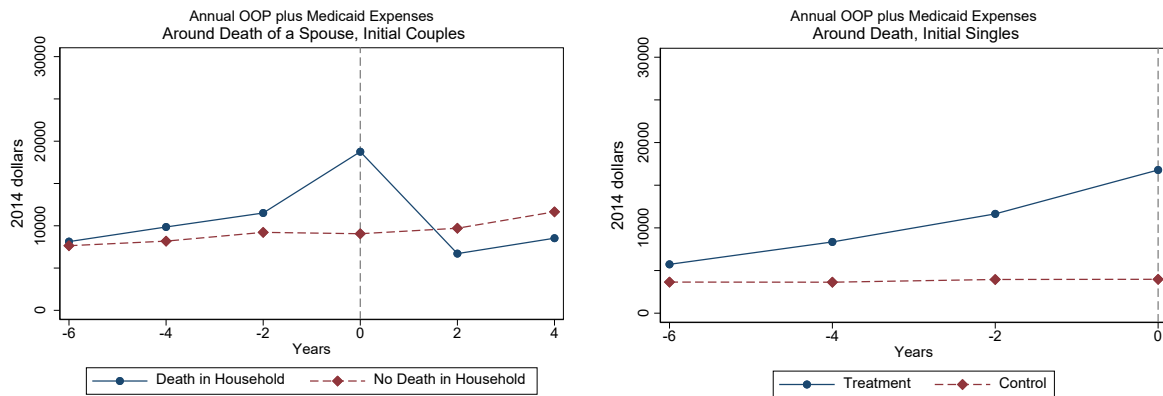
Figure 5.1: Average Annual Out-of-pocket, Medicaid and Death Expenses around the Time of Death
Source: Reproduced from De Nardi et al. (2018b).
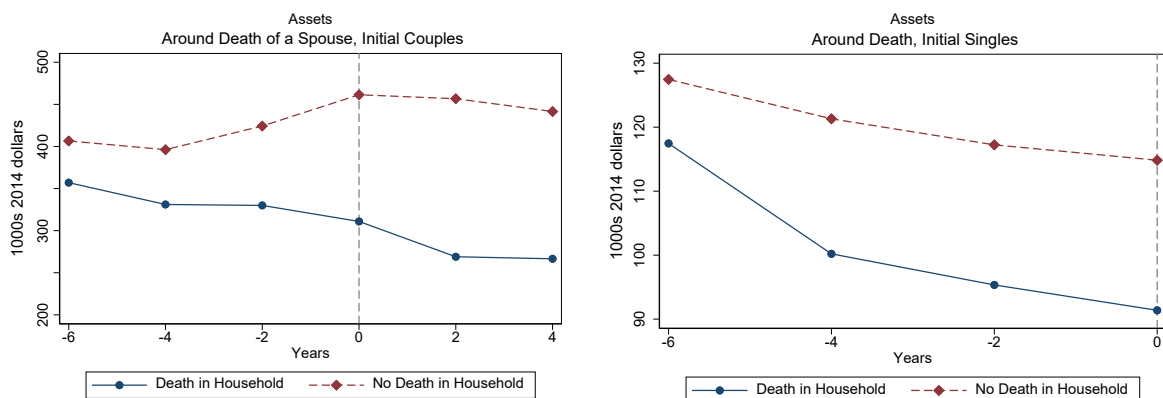
Figure 5.2: Median Wealth around the Time of Death
Source: Reproduced from De Nardi et al. (2018b).

Figure 5.2 shows median assets around the time of death. As with the graphs for medical spending in Figure 5.1, the left panel is for households who begin as couples and transition to singles, and the right panel is for households who begin as singles and then die. Similarly, Figure 5.2 shows asset profiles both for households who experience a death, as well as for otherwise similar households who do not. Households that experience a death have more rapid wealth declines in the years prior to the death. These wealth declines are significant. For example, in the 10 years surrounding the

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[13] The HRS medical spending measure is backward-looking: respondents are asked about the medical expenses they (or the decedent) recorded in the two years preceding the interview.

death of the first member of a couple, median assets fall by approximately $100,000, whereas couples who do not experience a death experience no wealth declines.

A perhaps surprising result in Figures 5.1 and 5.2 is that the drop in assets around the time of death is too large to be explained by measured medical expenditures, especially for couples. Possible explanations include the misclassification of health-related expenditures as regular consumption (e.g., home remodeling) or inter-vivos transfers, perhaps in exchange for informal care.[14]

Saving Behavior

Many elderly households draw down their wealth at a relatively slow rate. A commonly offered explanation for this behavior is that older households are saving against the possibility of high medical expenses near the ends of their lives (De Nardi et al., 2016a). De Nardi et al. (2009, 2010) and Kopecky & Koreshkova (2014) showed that life-cycle models calibrated to observed patterns of mortality and medical spending can explain a significant portion of U.S. saving during retirement.

Medical spending is not the only potential explanation of the elderly's thrifty behavior. Households may be saving to leave bequests or to ensure continued residence in their own homes. Distinguishing these motives in the data is difficult. For example, even if the elderly save solely to cover their medical expenses, many of them will leave bequests because they die earlier or face lower medical expenses than expected. It is also likely that the motives operate concurrently (Dynan, Skinner, & Zeldes, 2002), so that the question is one of relative strength. As De Nardi et al. (2016a) noted, differentiating the competing explanations requires examining features of the data beyond wealth and consumption, such as insurance take-up.

One strategy for assessing medical spending motives is to exploit cross-country variation. Nakajima & Telyukova (2016, 2018) compared the saving behavior of older households in countries that provide universal public LTC insurance with the behavior of households in countries that do not. They found that saving is in fact lower in countries with universal public LTC insurance, but that most of the effect was on financial assets, not housing.[15]

The distinction between housing and nonhousing assets is an important one. Households appear to run down their financial assets much more quickly than they run down their housing wealth. Nakajima & Telyukova (2017) concluded that older households place a high value on residing in their own homes. Because this utility flow ceases once individuals enter a nursing facility, home equity is

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[14] Kvaerner (2018) studied Norwegian households where a member has been diagnosed with cancer. He found that after a cancer diagnosis, single households make significant inter-vivos transfers but married households do not. (In interpreting these results, note that Norway provides universal LTC insurance.)

[15] Blundell, Crawford, French, & Tetlow (2016) compared savings patterns of older household in the U.S.to those in England, which has a similar system of funding for LTC but fully insures other health care. They found faster asset growth in England than the U.S. The differences appeared to be largely driven by increases in English house prices. Focusing only on financial assets, they found that Americans run down their financial assets more slowly than the English.

a particularly effective asset for guarding against nursing home expenses (Davidoff, 2010).[16] A potential alternative explanation is that, in the U.S., older households can often qualify for Medicaid even if they own their own home, so long as they have little in the way of financial assets.

Medicaid and Insurance

In countries that fail to provide universal public LTC insurance, households may be able to insure themselves in other ways. One way is to run down assets and qualify for means-tested public insurance programs such as Medicaid. Medicaid is available to those with low assets (with exemptions such as housing) and either low income or catastrophic medical expenses.   (See De Nardi et al. [2012] for more on the asset limits and other aspects of Medicaid eligibility for the elderly.) While many individuals run down their assets paying for their nursing home care, there is concern that others may intentionally run down their assets prior to entering a nursing home in order to qualify for Medicaid. Most of the evidence suggests that intentional asset rundown is modest. As noted above, elderly Americans appear reluctant to run down their assets in general. Furthermore, the literature suggests at best modest transfers from parents to children to qualify for Medicaid. For example, Norton (1995) concluded that elderly individuals are more likely to receive transfers in an attempt to *avoid* Medicaid than to give transfers in order to receive Medicaid. While Bassett (2007) and Baird, Hurd, & Rohwedder (2014) found that the self-assessed probability of entering a nursing home helped to predict asset transfers, Waidmann & Liu (2006) and Bassett (2007) found that the amounts involved were small.

Medicaid pays nursing homes less than what nursing homes typically charge, which potentially results in lower quality. Several papers have assessed whether the LTC that is affordable with means-tested insurance is of adequate quality. LTC, especially at nursing homes, is a combination of medical and nonmedical goods, and the latter can differ greatly in quality, the choice between a single and a shared room being just one dimension. Studying the nursing home industry in Pennsylvania, Hackmann (2017) concluded that low Medicaid reimbursement rates led to lower-quality care. Ameriks et al. (2011, 2017) surveyed customers of the Vanguard financial services company, a set of middle- to high-income individuals, about their willingness to purchase hypothetical financial products. They concluded that the desire to avoid Medicaid-funded care is a powerful saving motivation.

These results should not be taken to imply that Medicaid has little value. Braun, Kopecky, & Koreshkova (2017) found that means-tested social insurance programs like Medicaid are an effective way of insuring the elderly against late-in-life risks. De Nardi et al. (2016b) found that most elderly singles, including wealthier ones, valued Medicaid above its actuarial cost.

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[16] The high value that elderly households appear to place on remaining in their own homes raises the question of why reverse mortgages are not more heavily utilized. Nakajima and Telyukova (2017) concluded that "[b]equest motives, uncertainty about health and expenses, and loan costs account for [the] low demand."

Households also have the option to purchase medical spending insurance, particularly against LTC. If LTC poses a significant financial risk, we might expect to see extensive use of LTC insurance products. In practice, only about 10% of older households hold private LTC insurance (Lockwood, 2018). Lockwood found that insurance use rose with wealth but was below 20% for all groups. Barczyk & Kredler (2018) found that in Europe very few people purchase LTC insurance unless they are compelled to do so. They found relatively little variation across countries: in countries with limited public LTC insurance, households relied more heavily on informal care.

Some explanations of why households do not purchase LTC insurance involve arguments that they can self-insure against LTC risk by saving. Savings at older ages not only provide insurance against the risk of living long and having high medical spending, but also allow individuals to leave bequests to their heirs. Lockwood (2018) argued that the low rate of insurance use implies that older households are more concerned with leaving bequests than with avoiding LTC spending risk. Another self-insurance mechanism is owner-occupied housing, which can be a good substitute for LTC, as it is a store of wealth that can be liquidated when the individual enters a nursing home. Davidoff (2010) described how illiquid owner-occupied housing might serve as a substitute for formal LTC insurance. Achou (2018) found, however, that the quantitative magnitude of this effect was small.

The reasons why households concerned with LTC risk might choose to not purchase private LTC insurance go beyond self-insurance. Many of these explanations are based on inefficiencies in the private market for LTC insurance.

First, there is the problem of adverse selection: if insurance prices do not fully reflect applicants' risks, then those most likely to need LTC are the ones most likely to apply for coverage. Hendren (2013) estimated that 23 percent of 65-year-olds have health conditions that preclude them from purchasing LTC insurance. Those not denied coverage will still face high prices. (See Finkelstein & McGarry, 2006, and Oster, Shoulson, Quaid, & Dorsey, 2010.)

Second, there is the problem of moral hazard: households holding private LTC insurance may switch from informal to formal LTC (Pauly, 1990), which drives up the cost of LTC insurance. Konetzka, He, Guo, & Nyman (2014), Mommaerts (2016), and Ko (2018) found empirical support for this hypothesis in the HRS. The low profitability of U.S. LTC insurance providers suggests that moral hazard problems could be severe. In spite of daily and lifetime benefit limits, LTC policies have performed poorly. Underwriting has slowed, and many firms have left the market. It seems likely that moral hazard is one reason why insurers underestimated their claims (Cohen, Kaur, & Darnell, 2013). It is perhaps not surprising that most new LTC insurance policies are hybrid products, especially those that combine life and LTC insurance (Bodnar, 2016). Under these policies, LTC benefits reduce death benefits, generating an incentive to utilize informal care. If elderly households prefer informal care by family members to formal care, they may be unwilling to purchase insurance products that encourage the use of formal care (Pauly, 1990). The incentives offered by hybrid policies may better align with their wishes. In addition, the risks covered by hybrid

products are often negatively correlated, making them easier to insure in combination (Bodnar, 2016).

The effect of adverse selection and moral hazard, along with other supply-side imperfections, is to make LTC insurance much less desirable. LTC insurance is expensive: Brown and Finkelstein (2011) found that premia for LTC insurance policies are marked up substantially above expected claims, with loads on typical policies from 13 to 66 cents on the dollar, depending on whether one accounts for lapsed policies. These loads are much higher than the loads estimated in other private insurance markets. Moreover, most LTC insurance policies provide only limited insurance against nursing home risk. The typical LTC insurance contract caps both the maximum number of days covered over the life of the policy and the maximum daily payment for a nursing home stay, a daily payment that is often fixed in nominal terms (Fang, 2014). Even the policies that index the daily maximum payment are typically linked to aggregate price indexes rather than actual nursing home costs, generating substantial purchasing power risk between the time a person purchases the policy and the time she enters a nursing home. Most available policies thus provide only modest insurance against the risk of catastrophic LTC expenses. Brown & Finkelstein (2009) reported that comprehensive insurance contracts exist but are not purchased. Finally, people holding LTC insurance face the risk of unilateral price increases or insurer default (Ameriks et al., 2018).

A third potential explanation for the low take-up is the demand-side explanation that Medicaid crowds out private LTC insurance. Medicaid is the "payer of last resort," covering only the expenses not covered by other insurers. This means that for many households, purchasing private LTC will serve mostly to displace Medicaid payments. Brown & Finkelstein (2008) calculated that Medicaid significantly reduced the return on LTC insurance for 75% of U.S. single households.

Some recent papers have considered multiple explanations simultaneously in order to determine the key drivers of the low take-up of insurance. Braun et al. (2018), who developed a quantitative model of the LTC insurance market, concluded that the most important reason for LTC insurance take was applicant rejection due to adverse selection. Medicaid and administrative costs also played important roles. Ameriks et al. (2018) focused on Medicaid and the fact that individuals receive little satisfaction from consumption when they are sick. They also considered policy design. Exploiting strategic survey responses, they concluded that demand would be significantly higher if LTC policies were better tailored to households' needs. In particular, benefits based on a person's health (typically measured as failures in Activities in Daily Living), rather than explicit LTC services, appeared to be much more desirable. By allowing beneficiaries to compensate informal caregivers, such policies would also help address issues of moral hazard.

Section 6: Evidence on the Efficacy of End-of-Life Care

In section 3, we documented that around one-tenth of all medical spending occurs in the last 12 months of life. In the U.S., one-quarter of spending by Medicare, the principal insurer of the elderly, occurs in the last 12 months of life (Lubitz & Riley, 1993; Riley and Lubitz, 2010). These fractions, and the high cost of dying in general, are commonly interpreted as evidence of waste. However, to take this as evidence of waste, we must presume three things: (i) we know ahead of time who will

die in the next 12 months; (ii) end-of-life care does not extend the length of life; and (iii) the care does not improve the quality of life.

Regarding the first presumption, Scitovsky (1984) was one of the first to point out that most analyses of the cost of dying are ex post; they assess spending on people who in fact have died. To properly uncover wasteful spending requires an ex-ante approach, that is, an assessment of spending on people who were expected to die. In the past, most people died of diseases that killed them quickly. Today, modern medicine can keep people alive long after being diagnosed with the diseases that eventually kill them. Given that the timing of death is far from certain, what determines whether an individual is "near death" (Gawande, 2014)?

Einav et al. (2018) estimated mortality risk by applying machine learning techniques to detailed Medicare records. They found that less than 5 percent of Medicare beneficiaries who died in 2008 had, on January 1, 2008, a predicted annual mortality risk above 50 percent. In short, from (at least) the perspective of the data available in the Medicare claims data, most deaths can be viewed as unexpected.

Einav et al. (2018) also pointed out that most of those who die are sick, and sick people – including those who recover – use more health care than the healthy. They estimated that between 30% and 50% of the additional spending on the dead can be attributed to the higher cost of treating the sick. It is therefore not at all obvious that spending on the ex-post dead is mostly spending on the ex-ante "hopeless." Making such an inference would require detailed knowledge about the impact of specific treatments on individual survival probabilities. Kelley & Bollens-Lund (2018) have discussed the development of a system to better predict the need for palliative care.

The second presumption, that additional health care does not extend life, is surprisingly debatable. Although it seems uncontroversial that having access to some health care is better for health than having no health care, it is less clear that increasing (or modestly decreasing) medical care from its current level would significantly affect health, especially at older ages.

Most economics studies that exploited plausibly exogenous variation in health care have found little or no health benefit from the additional health care provided by a more generous health insurance plan (Brook et al., 1983), access to Medicare health insurance (Finkelstein & McKnight, 2008; Black, Espín-Sánchez, French, & Litvak, 2017), higher local Medicare spending (Fisher et al., 2003), or access to Medicaid (Finkelstein et al., 2012). However, a few studies have found that medical expenditures have significant effects on health and/or survival: Card, Dobkin & Maestas (2009) and Doyle (2011) are examples.

Many studies have found that the privately insured are in better health and live longer. However, Black et al. (2017) showed that these associations are mostly driven by selection. Healthy people are more likely have strong employment histories and thus receive insurance from a current or past employer. They are also more likely to purchase private insurance.

To get around these problems, Khwaja (2010) estimated a structural model in which medical expenditures both improve health and provide utility. He found that medical utilization would

decline by less than 20 percent over the life cycle if medical care was purely mitigative and had no curative or preventive components. Blau & Gilleskie (2008) also estimated a structural model and reached similar conclusions.

Most of these results suggest that a nontrivial portion of medical spending on the elderly is for "flat-of-the curve" treatments. However, such evidence does not directly answer the question of whether medical spending at the end of life is particularly ineffective. One area where end-of-life care may be mismanaged is in the mixture of conventional and palliative care. For patients with an advanced or terminal illness, there is evidence that those who receive palliative care can live at least as long if not longer than those who receive conventional medical care alone (Temel et al., 2010; Connor, Oyenson, Fitch, Spence, & Iwasaki, 2005). Temel et al. (2010) found that among patients with stage IV lung cancer, the half randomized to be treated by a palliative care specialist while receiving conventional oncology treatment stopped chemotherapy earlier, experienced less suffering at the end of their lives, and lived 25% longer than those who received oncology treatment alone. The evidence on whether a switch toward palliative care at the end of life also reduces costs is more mixed (Teno et al., 1997; Teno, Gruneir, Schwartz, Nanda, & Wetle, 2007; Teno et al., 2013; Krakauer, Spettell, Reisman, & Wade, 2009; Spettell et al., 2009). Cost impacts will likely vary across both patients and the treatments considered.

The debate about whether high end-of-life spending is wasteful typically focuses on whether the spending would prolong life. However, treatments with little direct mortality benefit may significantly improve the quality of patients' lives (Emanuel & Emanuel, 1994). To conclude that end-of-life care is wasteful therefore requires a third presumption: that the treatment provided at the end of life fails at advancing the quality, as well as the quantity, of life.

There is evidence that intensive treatment at the end of life can lead to poor quality of life for both the patient and their caregivers (Wright et al., 2008). However, this must again be balanced against uncertainty over when the end of life is coming. Some patients are willing to trade off current discomfort for the hope of a cure or more time. The presumption that patients wish to extend their lives can nonetheless mean that too little attention is given to other priorities, such as avoiding suffering, remaining mentally aware, spending time with friends and family, and not imposing burdens on others (Singer, Martin, & Kelner, 1999; Steinhauser et al., 2000). Treatments that conflict with these broader priorities may be wasteful.

It bears reiterating that the alternative to prolonging life is often not the withdrawal of care altogether (Gawande, 2014). Palliative care aims to ensure that individuals can live their remaining lives to the fullest. This does not mean doing nothing. Palliative care packages may involve visits from palliative care specialists, residential stays, and drugs and equipment that relieve suffering. Patients who receive palliative care may in fact live longer than similar patients who stay within conventional medicine (Temel et al., 2010; Connor et al., 2006).

An increased knowledge of how intensive treatment at the end of life affects patients and their families has been accompanied by a decline in the share of patients who die in the hospital. CDC data (CDC, 2018e) show that in 2000 around half of deaths in the United States occurred in hospitals; by 2016, this had fallen to 36%. Over the same period, the share of deaths that occurred

at home increased from 23% to 30%. Deaths in hospice facilities were first recorded under a separate category in 2003, at which time they accounted for less than 1% of deaths; by 2016, hospice deaths accounted for almost 8% of all deaths. The growth in deaths at hospice facilities reflects a much broader growth in the use of hospice care, as two-thirds of hospice patients in 2013 died at home. Between 2001 and 2007, the fraction of Medicare decedents accessing hospice for three days or more rose from 19% to 30%. For decedents with a cancer diagnosis, the increase was from 27% to 43% (National Hospice and Palliative Care Organization, 2014). In 2016, 48% of all Medicare decedents had received at least one day of hospice care and were enrolled in hospice at the time of death (National Hospice and Palliative Care Organization, 2018).

Uncertainties in whether curative treatment will be successful, and the value of curative and palliative care when it is not, mean that is hard to determine whether medical spending at the end of life is too high or too low. This applies to both individual patients and whole populations. In spite of these uncertainties, there is a strong argument for focusing on how to improve the quality of care for the growing elderly population, for whom care provided at the end of life can be both costly and painful. A start would be to refrain from using therapies that do not improve quality of life, including the use of feeding tubes in patients with dementia (Gozalo et al., 2011; Mitchell, Mor, Gozalo, Servadio, & Teno, 2016; Mitchell et al. 2003) and "burdensome" transitions in the place of care immediately before death (Gozalo et al., 2011).

One way to increase the probability that patients die in a place and manner of their choosing is for them to specify their choices by drawing up an Advance Care Directive. Since the Patient Determination Act in 1990 (Abele & Morley, 2016), U.S. patients have been able to choose whether to have medical treatment or not, to make advance care directives, and to transfer their decision-making power to a friend or relative. Since 2016, Medicare has paid physicians to discuss end-of-life issues in order to help patients draw up their directives. Between 2000 and 2010, the share of those over 65 who died with an advance care directive in place increased from 47% to 72% (Silveira, Wiitala, & Piette, 2014). A systematic review of advance care planning has shown it can reduce hospitalization without increasing mortality, reduce the share of deaths that occur in hospitals, and reduce burdensome treatments (Martin, Hayes, Gregorevic, & Lim, 2016). Overall, "advance care planning [is] considered an essential step for achieving a 'good death' in which physical pain and emotional distress are minimized, and the patient's and family members' treatment preferences are respected" (Carr & Luth, 2017).

We finish this section by noting that much has been made of the incentives faced by physicians in the U.S. The interaction between the patient and the doctor is structured more like a retail transaction than in other countries, with more of a "the customer is always right attitude." This may lead physicians to err on the side of over-optimism (Baile, Lenzi, Parker, Buckman, & Cohen, 2002). Doctors are paid for chemotherapy given and surgeries performed but not for the time taken to talk to patients about whether further treatment is the right course of action (Gawande, 2014). Insurance companies have been successfully sued for restricting access to treatments for the terminally ill, even when those treatments are subsequently shown to be ineffective (Stadtmauer et al., 2000).

All of this, it is claimed, has led to overtreatment of the dying in the U.S. However, it is important to recall that the share of total medical expenditures devoted to those in the final year of life in the U.S. is very similar to the shares for a range of other developed countries, where financial incentives for "overtreatment" are not nearly as strong. The U.S. spends more than other countries on both the living and those close to death. The causes of high spending at the end of life are therefore unlikely to be specific to the U.S. and more likely to reflect universal factors, such as the range of available treatments or the unpredictability of how patients will respond to them (Gawande, 2014).

Section 7: Demographic Transitions and Late-in-Life Medical Spending

To what extent does increased longevity lead to increased medical spending, aggregate or per capita? Two factors come into play. The first is that older people have worse health and higher medical expenses. Using the same MCBS sample as Figures 3.1 and 4.1, Figure 7.1 shows that between ages 65 and 100 average annual medical spending rises by a factor of 5, from less than $10,000 to nearly $50,000. The second factor is that over time health at any given age has generally been improving – healthy life expectancy has generally been increasing as quickly as life expectancy in general. With the two factors working in opposite directions, the overall trajectory of medical spending is uncertain.
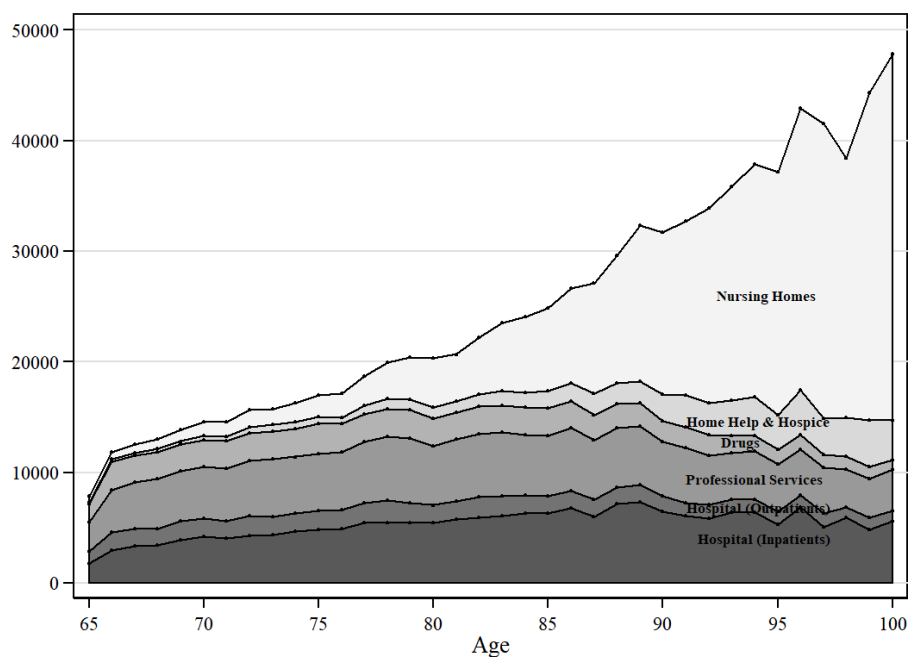
Figure 7.1: Average Medical Spending in the U.S., by Age and Expenditure Type
Source: De Nardi et al. (2016c), adjusted to match aggregate spending.

An illuminating extreme is the "red herring hypothesis" (Zweifel, Felder, & Meiers, 1999), which is that time to death rather than absolute age determines medical spending. If the relationship between time to death and medical spending is stable, increased longevity should have only modest effects on aggregate expenditures. In fact, if people live longer but face the same medical expense flows before and during their terminal illnesses, increased longevity should lead per capita medical spending to *fall*, as a greater fraction of the population will be in good health.

If true, the red herring hypothesis implies that medical expenses rise with age only because older individuals are more likely to die. But it is also possible that people require more expensive medical services at older ages regardless of their proximity to death. A robust finding in the literature is that time to death is a stronger predictor of expenditures than age; see Howden and Rice (2018) for a recent review. However, there is also evidence that time to death is in fact a proxy for morbidity (de Meijer, Koopmanschap, d'Uva, & van Doorslaer, 2011; Howdon & Rice, 2018) and that the cost of dying varies with age. Yang, Norton, & Stearns (2003) found that inpatient expenditures incurred near the end of life were higher at younger ages, while LTC expenditures rose with age. Braun et al. (2015) found that total end-of-life costs rose with age. Reviewing the literature, Payne, Laporte, Deber, & Coyte (2007) concluded: "On one hand, decedents' costs rise with age for some services and fall with age for others and, in some cases, rise to a certain age and then fall thereafter. On the other hand, survivors' costs generally rise with age for all services."

An equally important consideration is that increases in longevity may be accompanied by changes in the causes of death and thus changes in the cost of dying. Discerning these trends, however, requires extended longitudinal data with end-of-life related information. Such data are generally unavailable. One exception is Seshamani & Gray (2004), who estimated the rate at which hospital expenditures rose as people approached their deaths. Comparing estimates from cross-sectional samples from 1970, 1980 and 1990, they found that the run-up in costs became less pronounced over time, although the differences were not statistically significant.

Measures of healthy life expectancy present a mixed message. People appear to be spending more of their lives with chronic conditions but less with disability. Cutler (2005) argued that this reflects increasingly "intensive medical technology." If so, the observed reductions in disability time may not translate into significant cost savings.   On the other hand, it is suggestive, if only weakly, that our estimate of the fraction of U.S. medical spending devoted to care in the last year of life is slightly smaller than that estimated by Emanuel & Emanuel (1994) over 20 years ago. Riley & Lubitz (2010) likewise concluded that the share of Medicare expenditures incurred in the last year of life has changed very little over a 30-year period.

Section 8: Conclusion and Directions for Future Research

There is a widespread belief that end-of-life care represents large and low-hanging fruit for those interested in health care reform. We find relatively little support for such a belief. For the countries considered above, the fraction of aggregate medical expenditures incurred during the last 12 months of life ranges from 8.5% to 11.2%, and the fraction for the last three calendar years of life ranges between 16.7% and 24.5%. The empirical literature suggests that a significant portion of end-of-life treatment addresses chronic conditions and is unable to show that a large fraction of end-of-life spending is directed toward "hopeless" cases.

This in no way implies that there are no pressing issues. End-of-life care is expensive in absolute, if not relative, terms. The fact that wasteful spending is hard to document does not mean that it does not exist. The evidence suggests that a shift toward palliative care would significantly improve the

quality, and possibly even the quantity, of life for those with terminal diseases. Finally, in countries without universal public LTC insurance, end-of-life care imposes significant financial risks on older households and their informal caregivers.

We thus see a number of areas for productive future research. One is to continue to study the efficacy and cost of end-of-life treatments. A second is to continue to study the financial implications of end-of-life spending risk, along with proposals to mitigate it. Barczyk &Kredler (2017) concluded that subsidizing informal care is a particularly effective strategy. More analyses of this sort are essential. Also essential is continued research into why private LTC insurance is so lightly subscribed. Ameriks et al. (2018) argued that basing this insurance strictly on health outcomes, rather than the purchase of particular LTC services, would increase its demand. Finally, we have little knowledge of how end-of-life spending, and spending at older ages in general, will evolve in the future. Given the fiscal magnitude of public health insurance, guidance on this topic is of first-order importance.

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