DISCUSSION PAPER SERIES

DP13913

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PUBLIC ECONOMICS

ISSN 0265-8003

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Discussion Paper DP13913
Published 07 August 2019
Submitted 06 August 2019

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www.cepr.org

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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, both for the US and abroad. We discuss how end-of-life expenses affects household savings and other financial behaviour such as insurance choices. Lastly, we review economic evidence on the efficacy of medical spending at the end of life, assessing the value of palliative and other care for both longevity and patient satisfaction.

JEL Classification: I12, I13

Keywords: End of Life, medical spending, Savings, Insurance

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Acknowledgements
We thank Deborah Carr, Ellen Idler, Amy Kelley and Jon Skinner for helpful comments. Funding from the Social Security Administration through the Michigan Retirement Research Center (MRRC grant UM17-15) and the Economic and Social Research Council (Centre for Microeconomic Analysis of Public Policy at the Institute for Fiscal Studies (RES-544-28-50001) and Grant Inequality and the insurance value of transfers across the life cycle (ES/P001831/1)) for this work is gratefully acknowledged.

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, both for the US and abroad. We discuss how end-of-life expenses affects household savings and other financial behaviour such as insurance choices. Lastly, we review economic evidence on the efficacy of medical spending at the end of life, assessing the value of palliative and other care for both longevity and patient satisfaction.

Introduction

End-of-life care is costly to both governments and households. Its funding and delivery raise important economic and moral issues (e.g., Gawande, 2014), and it has been argued that the expense and delivery of end-of-life care are uniquely inefficient (e.g., Reid, 2017). This chapter reviews the current state of research on the topic.

Given that the cost of end-of-life care depends on the age of death and causes of death, we begin by documenting these trends over the past century. As mortality rates have fallen, death has become concentrated at older ages and more likely to result from chronic conditions.

Next, we document the level, composition, and funding of end-of-life medical spending. We review international evidence, placing emphasis on measurement issues. 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). Nonetheless, end-of-life spending comprises only 8.5% of aggregate U.S. health care expenditures, because the fraction of the population that dies in any given year is small. Cross-country data show that the U.S. is in no way an outlier in terms of expenditures on end-of-life care. We then focus on the financing of end-of-life care. Countries differ widely in how they fund end-of-life care, especially long-term care (LTC). In many countries, public assistance for LTC is available only to the financially constrained, with the expenses otherwise paid out of pocket.

We next consider how these expenses affect household behavior. We show that the risk of incurring high out-of-pocket medical expenses at very old ages is an important driver of savings. We discuss reasons why privately-provided LTC insurance, which would seemingly reduce spending risk, is not more heavily utilized.

We then review evidence on whether the high levels of end-of-life care spending are justified given their estimated effect on health and quality of life. The economic evidence on the efficacy of end-of-life medical spending is mixed. While some forms of late-in-life care, especially palliative care, appear to improve both longevity and quality of life, other medical treatments appear to be much less cost effective.

As in all aspects of health and healthcare, there are important disparities in end-of-life care by socioeconomic status and race or ethnicity. While such disparities are not our primary focus, throughout the chapter we highlight evidence on inequalities in end-of-life care.

We conclude with a discussion of useful avenues for future research.

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

In recent years, life expectancy gains in the U.S. have slowed or even reversed, driven largely by increases in death rates among those of working age (Kochanek, Arias, Bastian, & National Center for Health Statistics, 2016). However, over the course of the past century the pattern across all developed countries is of consistent and substantive improvements in health and longevity. Important contributing factors include large reductions in infant mortality and deaths from infectious disease across the early part of the twentieth century and rapid decreases in deaths from heart disease over the past fifty years. A much higher fraction of deaths now occur at older ages, and are attributable to chronic, rather than acute, conditions. This has had profound effects on the costs associated with death, as chronic conditions are typically associated with high medical expenditures over an extended period before death, compared to acute conditions/sudden deaths, which are not.

Trends in Life Expectancy and Age of Death

Figure 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.

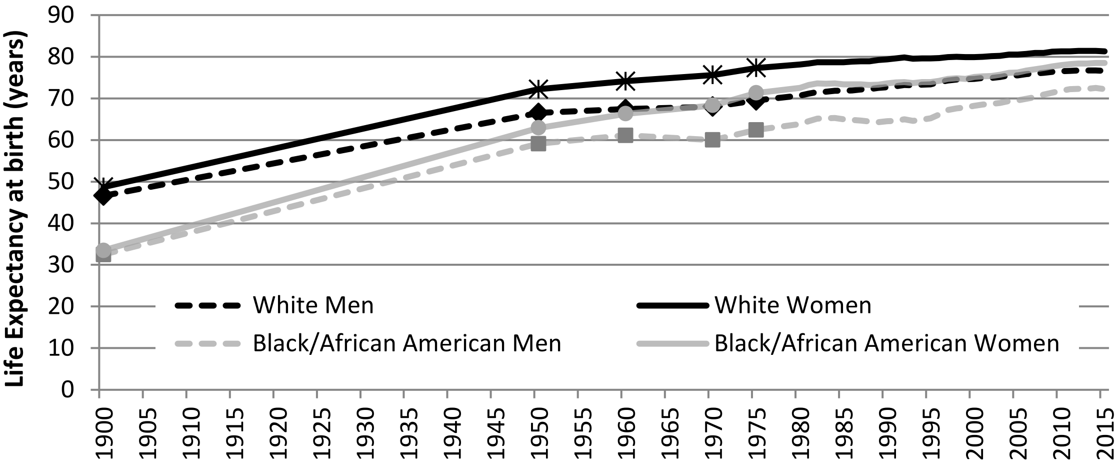

Figure 1: Life Expectancy at Birth by Race and Sex, U.S. 1900-2015

Source: Centers for Disease Control and Prevention (2018a, Table 015). Data available annually from 1980 onward. Earlier data points identified by markers.

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, whereas 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, increased about five years for most groups between 1950 and 2015. The cumulative effect of these mortality declines is that death has become an old-age phenomenon. Figure 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.

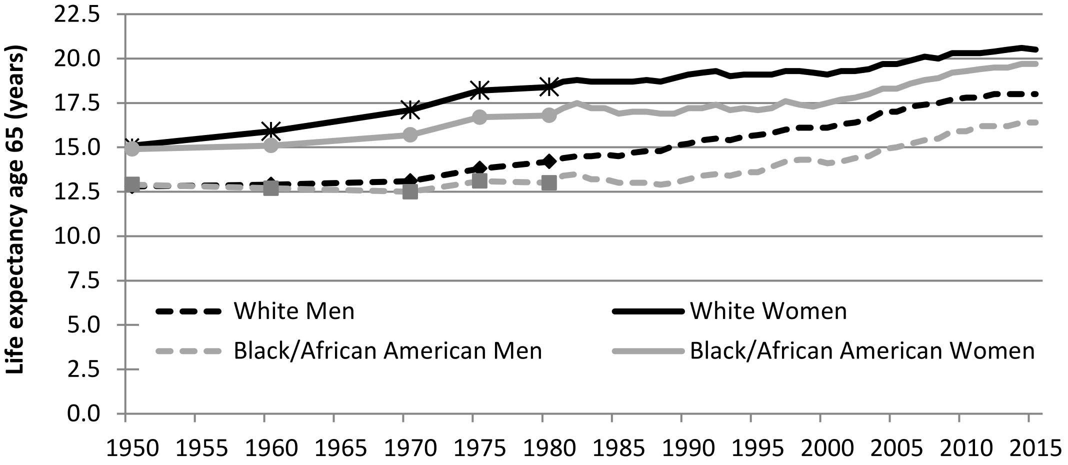

Figure 2: Remaining Life Expectancy at Age 65 by Race and Sex, U.S. 1950-2015

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

Life expectancy follows a strong socioeconomic gradient in both the U.S. and elsewhere, with more advantaged individuals living longer than their less advantaged compatriots. This is true across the socioeconomic distribution, with the most advantaged expected to live longer than those in the middle, and those in the middle expected to live longer than those at the bottom (see, for example, Banks, Marmot, Oldfield, & Smith, 2006; Chetty et al., 2016).

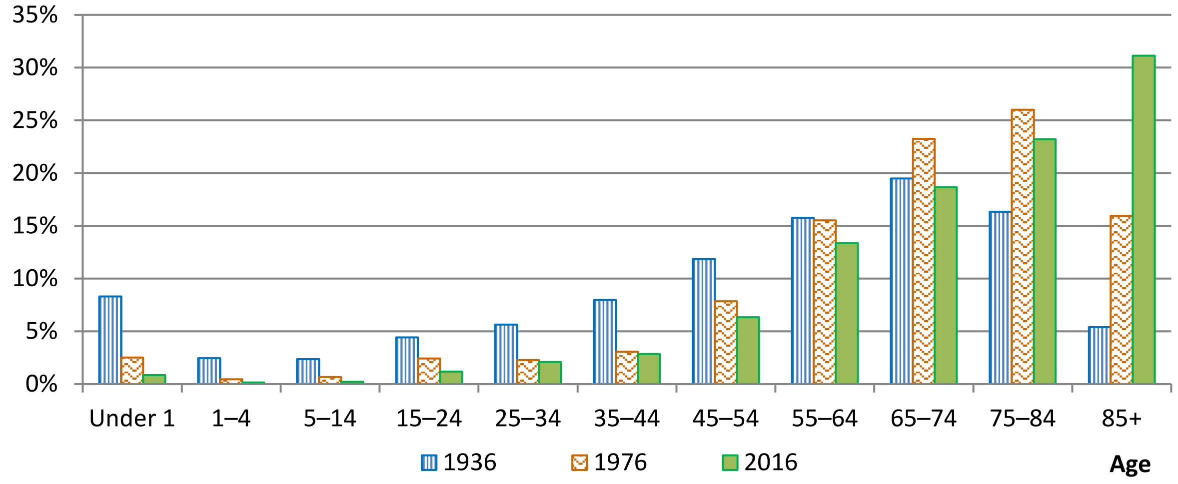

Figure 3: Cross-Sectional Distribution of the Age of Death: U.S., Selected Years

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. As the ability of medical science to treat patients improves over time, so does the accuracy with which medical conditions can be diagnosed. The number of deaths attributed to some diseases could therefore 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 have changed in important ways. Table 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 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 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).

International Evidence on the Cost of End-of-Life Care

Measurement Issues

Before reviewing the current evidence on the cost of end-of-life care, it is important to understand how it is measured. Measuring late-in-life medical expenditures is not straightforward. People who are dead or 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 and payors of medical care to mortality.

The U.S. has several surveys linked 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 2 summarizes important features of both datasets.

The MCBS measures medical expenditures by all payers at a high frequency. Administrative data on Medicare expenditures and Medicaid use are linked to individual survey data. Individual responses and Medicare reports of care often differ: the 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). De Nardi, French, and Jones (2016b) found that the MCBS overall captures 86% of all Medicare payments and 79% of all Medicaid payments, while French, Jones, and McCauley (2017a) found that the MCBS captures 78% of all personal health care payments. Under-reports of medical spending do not seem to be specific to the MCBS. Using data from nine countries, French et al. (2017a) found that the micro data from almost every country understates spending relative to the national aggregates. This problem was especially severe for LTC, which is used intensively by those near death. Unless the bias is addressed, the cost of end-of-life care will be understated.

Relative to the MCBS, the HRS interviews respondents much less frequently – every other year – but over a much longer period: once a household enters the survey it is tracked until the respondent and spouse die. Members are followed into nursing homes, and upon the death of a member, a surviving household member or other proxy is 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.

Table 2: Comparison of the Health and Retirement Study (HRS) and Medicare Current Beneficiary Survey (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).

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 and is thus representative of deaths only within that population. However, Medicare covers virtually all of the age 65+ population (in addition to Disability Insurance beneficiaries), and roughly 73% of all deaths are among those 65+. The HRS covers a somewhat broader age range, with new cohorts added as they turn 51.

Estimating End-of-Life Medical Spending

End-of-life spending is usually measured as spending over the last 12 months of life. 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.

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, the decedents had expenditures for only the part of the year they were alive. A common way to correct for this problem is that of Hoover, Crystal, Jumar, Sambamoorthi, and Cantor (2002), who estimated the following regression:

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

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 zeromean 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 displays average medical spending at the end-of-life across nine countries. The estimates are taken from French et al. (2017a), who examined a collection of micro datasets for those who died in 2011, using common estimation methods and sample restrictions. (For the U.S. they used the MCBS.) They also adjusted their estimates so that mean medical spending per capita in each micro dataset matched the national aggregates for its source country. Table 3 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 a particular medical spending category incurred by decedents.

Column (1) of Table 3 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. Similarly, analyses of 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” (Davis, Nallamothu, Banerjee, & Bynum, 2016).

Table 3: 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 pharmaceutical spending. "Long-term care" for Taiwan also includes home help. Data from Germany exclude home help. '--' denotes data unavailable.

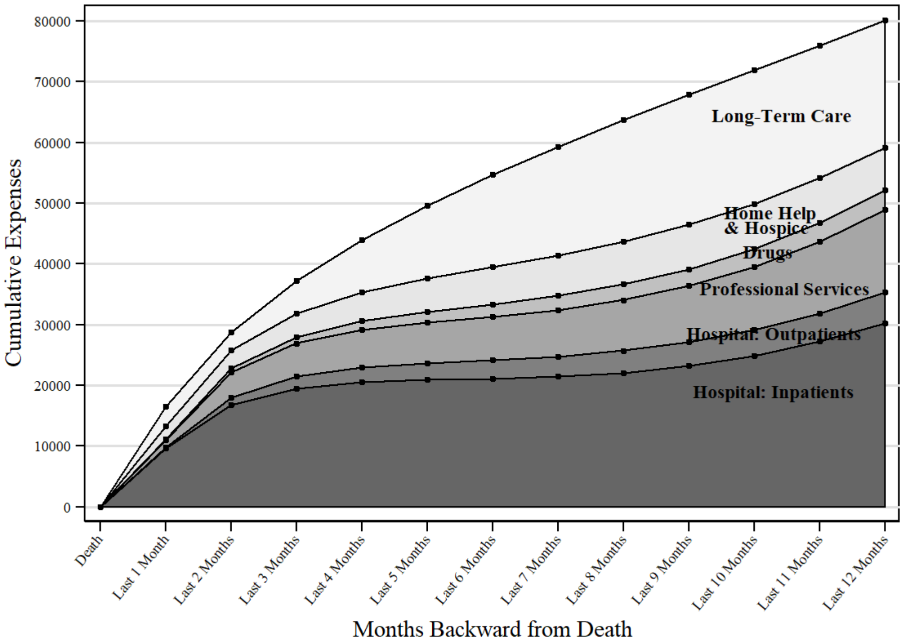

Figure 4: Average Medical Spending in the Last 12 Months of Life in the U.S., by Expenditure Type.

Source: De Nardi et al. (2016c), updated to 2011 MCBS data, adjusted to match national aggregate spending.

Figure 4, adapted from De Nardi, French, Jones and McCauley (2016c), contains a similar message. Figure 4 plots cumulative medical spending over the last 12 months of life for the U.S. 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. Thus, while medical spending in the final few months is very high, it is often preceded by a much longer period of elevated medical spending.

The even columns of Table 3 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 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 are no strong links between a country's percentage and the structure of its health care system. (For descriptions of the health care systems in Table 3, see French and Kelly (2016).) 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. Analyses using slightly different methods also find that 10-13% of total U.S. medical spending is for end-of-life care (Aldridge & Kelley, 2015; Emanuel & Emanuel, 1994). These figures are in stark contrast with the widely reported statistic of 25% for age 65+ Medicare recipients (Riley & Lubitz, 2010). This discrepancy comes from differences in the samples used. Although most deaths are among those 65 and older, the majority of the population is under 65 and thus a majority of aggregate medical spending is on those under 65. The share of 8.5% reported in Table 3 is based on end-of-life and aggregate spending for all ages.

It also bears noting that the above 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 and Emanuel (1994) over 25 years ago, despite the changes in mortality and morbidity that have occurred since then. Riley & Lubitz (2010) likewise concluded that the share of Medicare expenditures incurred in the last year of life changed very little over a 30-year period. Such findings highlight the difficulty of projecting future expenditure shares.

What is the Money Spent On?

The remaining columns of Table 3 display spending for different medical service categories. Column (6) shows that, relative to other medical services, a large 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 hospital spending is not always more concentrated at the end of life than medical spending overall. Hospital spending is usually less concentrated at the end of life than spending on LTC. 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%. These results are in line with Bekelman et al. (2016), who find that end-of-life care is more hospital-centric in Belgium, Canada, England, Germany, and Norway than in the Netherlands or the United States.

Figure 4 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 forms of care, such as LTC (which includes nursing home care) are more important in the months further from death. This is consistent with the view that medical spending in the final 3 months of life is associated with acute conditions, but at longer horizons most of the spending is for chronic conditions. Again, the data suggest that medical spending in the last year of life is intended less for those who are just about to die than for the chronically ill, who have high mortality rates.

Funding for End-of-Life Care

Although end-of-life spending may comprise a relatively modest fraction of national healthcare spending, at the household level it is hardly trivial. The averages reported in Table 3, high in their own right, mask the possibility of significantly higher expenditures for some households. In this section, we describe how end-of-life care is funded, an important step in assessing the financial risk it poses to older households.

Below, we provide a detailed description for funding in the U.S., followed by a cross-country comparison of LTC, the funding of which vary greatly across countries. French and Kelly (2016) describe how other forms of medical care are funded in a number of countries.

Funding in the U.S.

Figure 5 plots cumulative average medical spending over the last year of life for the U.S., using the same data and methodology as Figure 4, but decomposing spending by payer rather than service. Of the $80,000 incurred over the final year of life, 66% is paid by Medicare, the public health insurance received by 98% of those 65 or older (U.S. Centers for Medicare & Medicaid Services, 2018); 9% by Medicaid (a means tested public health program); 2% by other government programmes; and 8% by private insurers. End-of-life care is for the most part well-insured. Nevertheless, $9,530, or 12% of the total, is paid out of pocket. Moreover, out-of-pocket expenses can be so high that households are unable to cover them: uncollected liabilities are $2,060, or 3% of the total. Out-of-pocket spending in the last year of life can be significant. In fact, French, Baker, Doctor, De Nardi, and Jones (2006) and Marshall, McGarry and Skinner (2011) found out-of-pocket expenses in the last year of life to be even higher than the amount reported here.

Nonetheless, end-of-life expenses are on average better insured than medical spending for older adults in general. The MCBS data used in Figure 5 shows that 19% of the medical spending by the over-65 population is paid out of pocket, which is higher than the 12% for those in the last year of life.

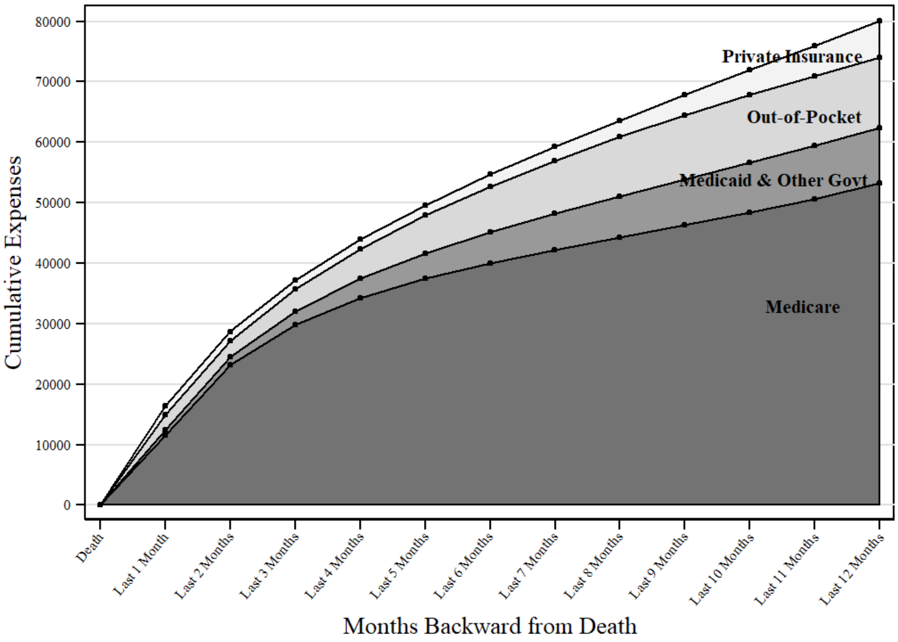

Figure 5: Average Medical Spending in the Last 12 Months of Life in the U.S., by Payer

Source: De Nardi et al. (2016c), updated to 2011 data, adjusted to match aggregate spending.

Figure 4 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).

Medicare also covers hospice care for patients who have a life expectancy of less than 6 months and opt for hospice care instead of other treatments. In 2014, approximately 1.2 million deaths in the U.S. occurred while receiving hospice care, out of a total of 2.6 million deaths (Centers for Disease Control and Prevention, 2016). Medicare paid out $19.0 billion for hospice care provided in 2017, or just over $12,700 per hospice patient (National Hospice and Palliative Care Organization, 2019).

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). As a result, Medicare covers less than 25% of the nursing home costs of those 70 and older. Furthermore, few individuals purchase LTC insurance; private insurance covers less than 8% of nursing home costs.

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, French, Gooptu, & Jones, 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 rely on Medicaid. The data show that wealthier people are much less likely to receive Medicaid (Borella, De Nardi, & French, 2018) and take longer to spend down their wealth (Wiener, Anderson, Khatutsky, Kaganova, & O'Keeffe, 2013). There is also evidence, discussed below, that Medicaid-funded LTC is considered inferior to privately-funded care. On the other hand, the data also show that rich people are more likely to live to very old ages, and at these older ages a significant fraction of high-income individuals are on Medicaid (De Nardi et al., 2016b).

In short, a significant portion of LTC spending is uninsured or insured only upon means testing. Wealthy households cover most costs out of pocket – De Nardi et al. (2016c) show around 28% of LTC expenditures are out of pocket – and poorer households rely heavily on Medicaid.

Because Medicare and Medicaid cover different types of care and operate very differently, people with different health conditions may be insured to very different degrees. Health conditions requiring LTC are insured relatively poorly. Kelley, McGarry, Gorges, and Skinner (2015) use the HRS to estimate medical costs over the last five years of decedents' lives. As shown in Table 4, they find that total average expenditures per decedent for dementia ($218,000) are significantly greater than for those who die of heart disease ($153,000), cancer ($144,000), or other causes ($164,000). While Medicare expenditures are similar across illnesses, the average out-of-pocket spending of dementia patients ($66,000) is 81% higher than that of non-dementia patients, consistent with Medicare's limited coverage of LTC services. Not only is absolute out-of-pocket spending significantly higher for those with dementia, but Kelley et al. (2015) report that out-of-pocket spending as a proportion of total household wealth five years prior to death is 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 is especially pronounced among 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 (as what households would have paid on the private market for a similar level of care), Kelley et al. (2015) find that the average value of the informal care provided to dementia decedents is more than double that of non-dementia decedents.

Table 4: Expenditures over the Last Five Years of Life, by Disease and Payer

	Average Medical Expenditures* (1)	Medicare & Medicaid (2)	Medicare (3)	Out of Pocket (4)	Imputed Informal Care (5)	Social Cost (1 + 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.

Differences in Long-Term Care Systems

LTC is arguably the most significant financial burden that older households bear for medical services, in the U.S. as well as other nations. Although most OECD countries other than the U.S. provide universal insurance for acute care, many fail to provide similar insurance for LTC (Brown & Finkelstein, 2011). Descriptions of LTC systems can be found in Dobrescu (2015) and Nakajima and Telyukova (2016).

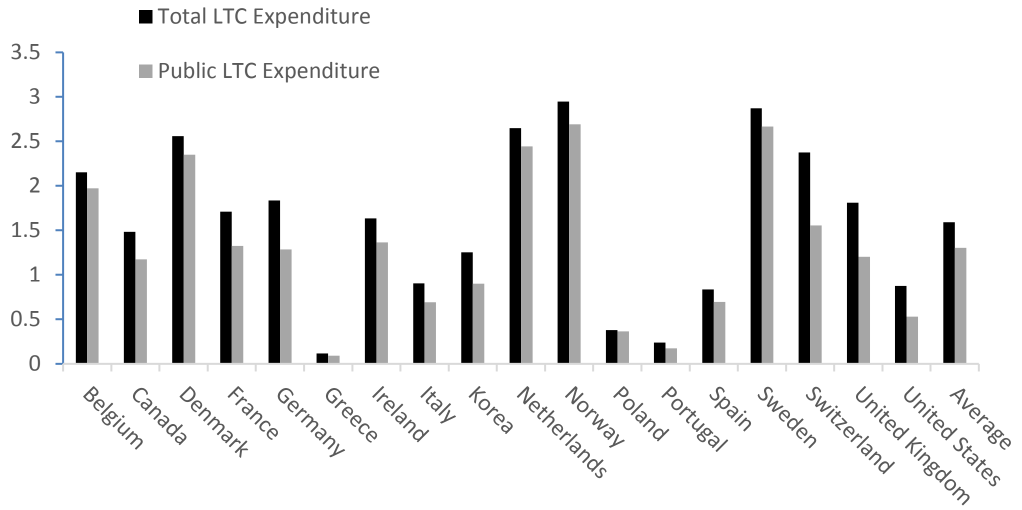

Figure 6: Long-Term Care Expenditures in the OECD, as Percentages of GDP, 2016

Source: OECD (2018). 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.

LTC expenditures vary widely across countries. Figure 6 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. Public financing of LTC likely influences the use of end-of-life care (Orlovic, Marti, & Mossialos, 2017). For example, Scandinavian countries and the Netherlands, which provide universal publicly funded 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. Some of the differences in spending likely reflect substitution across providers, such as the replacement of institutional care with informal care in countries with low public LTC funding. Rodrigues, Huber, and Lamura (2012, Figure 7.4) used cross-country variation to show a negative correlation between formal care provision and the informal care provided 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 and Kredler (2018) showed that as one moves from Northern to Southern Europe, public funding of LTC falls and the use of informal care rises, with the U.S. being close to the average for both public and informal provision of LTC. In short, in many countries, end-of-life care, especially LTC, can impose significant financial burdens on households.

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 financial burdens, 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, French, & Jones, 2016a). That is, older 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

Death is associated with significant declines in household wealth, 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, and Wise (2011) also found that wealth declines around the time of death.

De Nardi, French, Jones, and McGee (2019) update the results in French et al. (2006) and develop a model of lifetime decision-making to shed light on the results. Figure 7, taken from this study, shows the medical spending of couples and unmarried persons, respectively, around the time of death (the HRS interview where the death is reported). 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.

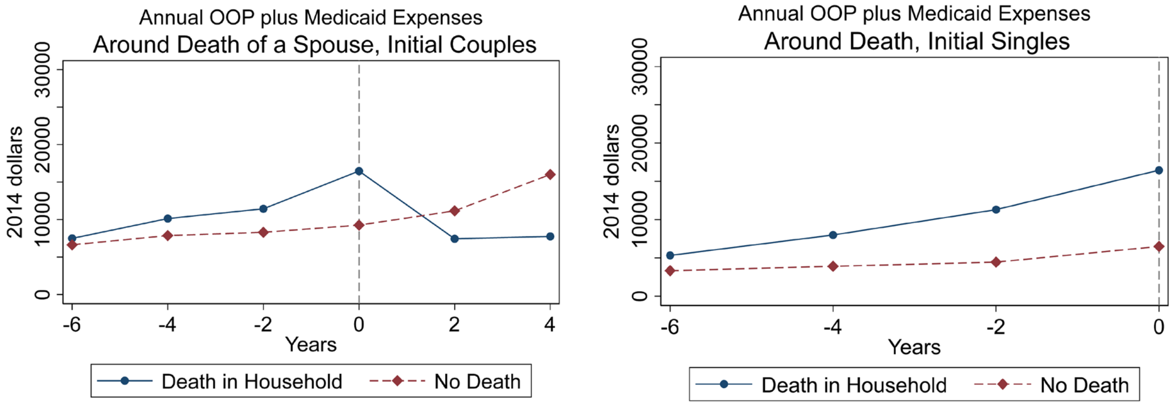

Figure 7: Mean Annual Out-of-pocket, Medicaid and Death Expenses around the Time of Death

Source: Reproduced from De Nardi et al. (2019).

The left panel of Figure 7 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 per year in the two-year period when the death occurs. After the period of death, medical spending returns to its original level. The right panel of Figure 7 shows that for singles, medical spending rises from $6,000 six years prior to death to $16,000 in the period of death.

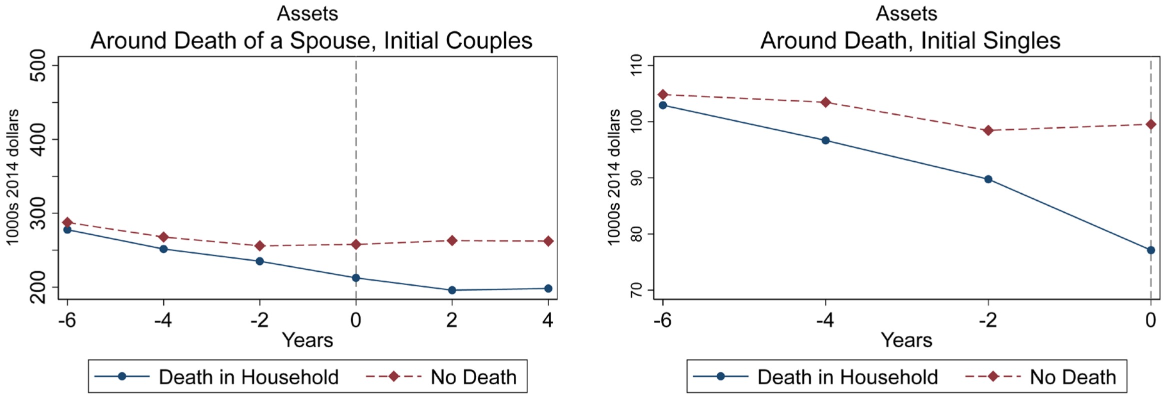

Figure 8: Mean Wealth around the Time of Death

Source: Reproduced from De Nardi et al. (2019).

Figure 8 tracks mean assets around the time of death. As with the graphs for medical spending in Figure 7, 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 8 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 death of the first member of a couple, mean assets fall by approximately $75,000, whereas couples who do not experience a death experience a decline of about $25,000.

A perhaps surprising result in Figures 7 and 8 is that the drops in assets around the time of death are too large to be fully 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 (e.g., parent to child cash) transfers, perhaps in exchange for informal care. Kvaerner (2018) studies Norwegian households where a member is diagnosed with cancer. He finds that after a cancer diagnosis, single households make significant inter-vivos transfers but married households do not.

Saving Behavior

Many older 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, French, and Jones (2010) and Kopecky and Koreshkova (2014) show that life-cycle models calibrated to observed patterns of mortality and medical spending can explain a significant portion of U.S. saving during retirement.

Other social and family factors may also encourage thrifty behavior. Older households may be saving to leave bequests or to ensure continued residence in their own homes. Distinguishing these motives in the data is difficult, in part because the same assets can serve multiple purposes (Dynan, Skinner, & Zeldes, 2002; De Nardi et al., 2016a).

One strategy for assessing medical spending motives is to exploit cross-country variation. If medical spending risk is an important determinant of savings, then late life savings should be lower in countries with lower medical spending risk. Nakajima and Telyukova (2016, 2018) found evidence in favour of this hypothesis; however, Blundell, Crawford, French, and Tetlow (2016) found the reverse.

Households run down their financial assets much more quickly than their housing wealth. Nakajima and Telyukova (2017) concluded that older households place a high value on residing in their own homes. Because individuals no longer need their home once they enter a nursing facility, they can sell the home to pay for nursing home care; thus, home equity may be a particularly effective asset for guarding against nursing home expenses (Davidoff, 2010). A potential alternative explanation for households running down their financial assets quicker than their housing wealth is that, in the

U.S. at least, 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

While many individuals run down their assets paying for LTC, there is concern that others may intentionally run down their assets prior to entering a LTC facility in order to qualify for Medicaid. Most of the evidence suggests that intentional asset rundown is modest. As noted above, older Americans appear reluctant to run down their assets in general.

A related concern is that wealthier households may avoid spend-down through trusts, transfers, or other financial devices. Moses (2017) discusses methods for evading the Medicaid spend-down provisions. The literature suggests at best modest transfers from parents to children to qualify for Medicaid (Waidmann & Liu, 2006; Bassett, 2007; Baird, Hurd, & Rohwedder, 2014). In fact, there is some evidence older individuals are more likely to receive transfers in an attempt to *avoid* Medicaid than to give transfers in order to receive Medicaid (Norton, 1995). The use of trusts (Taylor, Sloan, & Norton, 1999) to qualify for Medicaid also appears to be modest.

One reason why households may seek to avoid Medicaid is that Medicaid pays nursing homes less than what nursing homes typically charge, leading to lower quality care in nursing homes that accept Medicaid patients (Hackmann, 2017). Surveys show that the desire to avoid Medicaid-funded care is a powerful saving motivation (Ameriks, Caplin, Laufer, & Van Nieuwerburgh, 2011; Ameriks, Briggs, Caplin, Shapiro, & Tonetti, 2017).

These results should not be taken to imply that Medicaid has little value to wealthier households. De Nardi et al. (2016b) and Braun, Kopecky, and Koreshkova (2017) found that means-tested social insurance programs like Medicaid are an effective way of insuring older adults against late-in-life risks, because they provide LTC funding to households when they have no other means to pay for that care.

Long-Term Care Insurance

Individuals also have the option to purchase medical spending insurance, particularly against LTC needs such as nursing home stays. Individual LTC insurance contracts specify the annual premium, the conditions under which an individual can be reimbursed for care (such as inability to engage in multiple activities of daily living), and the rate of reimbursement. 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 U.S. households hold private LTC insurance (Lockwood, 2018). The private LTC insurance market is also very small in Europe, and households in European countries with more limited public LTC insurance rely more heavily on informal care (Barczyk & Kredler (2018)).

The low rate of LTC insurance purchases potentially implies that LTC spending risk is not a major concern for older households (Lockwood, 2018). An alternative explanation is that owner-occupied housing may be a good substitute for formal LTC insurance, as it is a store of wealth that can be liquidated when the individual enters a nursing home (Davidoff, 2010; but see Achou, 2018). Furthermore, many households receive LTC assistance from Medicaid: Kaiser (2017) reports that Medicaid covers over 60% of nursing home residents. Medicaid acts as the "payer of last resort," covering only the expenses not covered by other insurers. Brown & Finkelstein (2008) calculate that for most households, purchasing private LTC would just displace Medicaid payments, rather than provide additional insurance.

Even if consumers would like to insure against LTC risk, it is possible that they view LTC insurance as expensive and low quality. Premia for LTC insurance policies are often marked up substantially above the expected claims, with loads on typical policies from 13 to 66 cents on the dollar (Brown &

Finkelstein, 2011). These loads are much higher than the loads estimated for 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, which is often fixed in nominal terms (Fang, 2016). Even the policies that index the daily maximum payment are typically linked to aggregate price indexes rather than 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. Finally, people holding LTC insurance face the risk of unilateral price increases or insurer default (Ameriks, Briggs, Caplin, Shapiro, & Tonetti, 2018).

Suppliers of LTC insurance face several significant hurdles. One is that households holding private LTC insurance may encourage families to switch from informal to formal LTC, even in cases when formal care is of little value to the family, driving up the cost to the insurer (Pauly, 1990). This is a case of “moral hazard”. Mommaerts (2016) and Ko (2018) find empirical support for this hypothesis in the HRS. A second hurdle for suppliers is the difficulty of assessing applicants’ risks. If insurers cannot identify the applicants that are most likely to end up in a nursing home, those high-risk applicants will be the ones most likely to purchase LTC insurance. This is a textbook case of “adverse selection”, and its consequences range from higher costs to market collapse. Hendren (2013) estimates that 17 percent of 65-year-olds are precluded from purchasing LTC insurance because their risks are too difficult to assess. Braun, Kopecky, and Koreshkova (2018), who used a detailed model of the LTC insurance market to evaluate several potential explanations, concluded that the most important reason for the low take-up of LTC insurance is adverse selection.

Evidence on the Efficacy of End-of-Life Care

The high cost of dying is sometimes 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 near future (Scitovsky, 1984); (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, Einav, Finkelstein, Mullainathan, and Obermeyer (2018) showed that is extremely difficult to predict who is likely to die in a given year. Using machine learning techniques and detailed Medicare records, they find 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. Furthermore, most of those who die are sick, and sick people – including those who recover – use more health care than the healthy. They estimate that between 30% and 50% of the additional spending on the dead can be attributed to the higher cost of treating the sick.

The second presumption is that the additional health care given to those near death does not extend life. Although medical research has shown that many treatments have significant health benefits, it is less clear whether increasing (or modestly decreasing) medical care from its current level would significantly affect health – as opposed to quality of life – especially at older ages. A number of economic studies have suggested that at current levels of medical spending, additional medical services will fall mostly on the "flat of the curve" and produce little or no improvement in health (Brook et al., 1983; Finkelstein & McKnight, 2008; Black, Espín-Sánchez, French, & Litvak, 2017; and Fisher et al., 2003).

Regarding the third presumption, treatments with little direct mortality benefit may significantly improve the quality of patients' lives (Emanuel & Emanuel, 1994). Research suggests 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.

One area where end-of-life care may be mismanaged is in the mixture of conventional and palliative care. Palliative care packages may involve visits from palliative care specialists, residential stays, and drugs and equipment that relieve suffering. 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) find 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, Gruneir, Schwartz, Nanda, & Wetle, 2007; Teno et al., 2013; Krakauer, Spettell, Reisman, & Wade, 2009).

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.

The use of non-conventional care at the very end of life appears to be rising. Between 2001 and 2007, the fraction of Medicare decedents using hospice for three days or more rose from 19% to

30% (National Hospice and Palliative Care Organization, 2014). In 2017, 48% of all Medicare decedents had received at least one day of hospice care and were enrolled in hospice at the time of death, up from 44% in 2012 (National Hospice and Palliative Care Organization, 2019). CDC data (CDC, 2019) show that in 1999 nearly 51% of deaths in the U.S. occurred in hospitals; by 2017, this had fallen to 36%. Over the same period, the share of deaths that occurred at home increased from 22% to 31%. Although the prevalence of hospital deaths has fallen across all ethnic groups, white decedents remain significantly less likely to die in a hospital than their non-white counterparts (Orlovic, Smith, & Mossialos, 2019).

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. Despite these uncertainties, there is a strong argument for focusing on how to improve the quality of care for the growing population of older people, 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, Teno, Kabumoto, & Mor, 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. As part of the Affordable Care Act, Medicare has paid physicians to discuss end-of-life issues in order to help patients draw up their directives since 2016. 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).

While there is a trend toward the use of advanced care directives and end-of-life planning overall, there are substantial differences by ethnicity. Using HRS data from 2002 to 2014, Orlovic et al. (2019), found that non-white individuals were less likely to engage in end-of-life planning activities. They further found that when planning by black and Hispanic people did take place, instructions were written on average 19 months nearer to death than for white individuals, and the plans were less likely to involve the withdrawal of any treatment. Potential reasons for these disparities include ethnic differences in household structure and social networks (Iwashyna & Chang, 1993), differences in available information (Givens, Tjia, Zhou, Emanuel, & Ash, 2010), and geographic variation in availability of LTC (Chen & Miller, 2017). The role of cultural differences, particularly the apparent preference of minority groups for more intensive treatment at the end of life, remains under debate. While it is likely that these racial differences are partly caused by inequalities in the quality of healthcare throughout life (Orlovic et al., 2019), many cultural differences, such as religion, are also related to advance planning (Garrido, Idler, Leventhal, & Carr, 2012).

There are fewer studies that consider the variation in advanced care planning by socioeconomic status. The evidence that does exist points toward lower levels of planning for those with lower levels of education, income and wealth (Carr, 2012; 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). It is claimed that these financial incentives lead to the overtreatment of the dying in the U.S. (e.g., Gawande, 2014). 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).

Conclusion and Directions for Future Research

Many policy makers have identified end-of-life care as a large and easily-exploited opportunity for cutting wasteful spending. We find relatively little support for such a belief. The fraction of aggregate medical expenditures incurred during the last 12 months of life ranges from 8.5% to 11.2% across most wealthy Western and Asian nations, and the fraction for the last three calendar years of life ranges between 16.7% and 24.5%. This percentage is smaller for the U.S. than most high-income countries, suggesting that provider incentives in the U.S. do not lead to unusually large amounts of wasteful treatment at the ends of patients' lives. The empirical literature suggests that a significant portion of end-of-life treatment addresses chronic conditions and is not necessarily directed toward "hopeless" cases.

There is tremendous cross-country variation in how end-of-life care is provided and financed. For example, LTC is largely financed out of pocket in some countries, but is almost entirely state-provided in others. We urge more researchers to bring together cross-country insights in order to inform how any potential end-of-life financing reforms may affect both government costs and households' well-being.

We conclude by highlighting some areas we view as particularly productive for future research. First, the evidence suggests that a shift toward palliative care would significantly improve the quality, and possibly even the length, of life for those with terminal diseases. Thus, researchers should continue to study the efficacy and cost of end-of-life treatments. A second priority should be the financial implications of end-of-life spending risk, along with proposals to mitigate it. There is evidence that subsidizing informal care is an effective strategy (Barczyk & Kredler, 2017). A particularly pressing question is why the utilization of private LTC insurance is so low. Ameriks et al. (2018) concluded that LTC policies with benefits based on the insured's health (e.g., failures in Activities in Daily Living), rather than formal LTC services, would be more attractive to households. Such policies should help older households compensate informal caregivers. Given the high cost of LTC, work of this sort is of utmost importance.

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