

*Demographic Variations in the Relationship
Between Long-Term Care Policies and Place of Death:
A Study of 20 OECD Countries*

*Maria Casanova, David Knapp, Jinkook Lee, Ana
Llena-Nozal, Paola Sillitti*

Paper No: 2024-002

**CESR-SCHAEFFER
WORKING PAPER SERIES**

The Working Papers in this series have not undergone peer review or been edited by USC. The series is intended to make results of CESR and Schaeffer Center research widely available, in preliminary form, to encourage discussion and input from the research community before publication in a formal, peer-reviewed journal. CESR-Schaeffer working papers can be cited without permission of the author so long as the source is clearly referred to as a CESR-Schaeffer working paper.

Demographic Variations in the Relationship Between Long-Term Care Policies and Place of Death: A Study of 20 OECD Countries

Maria Casanova, California State University, Fullerton

David Knapp, University of Southern California

Jinkook Lee, University of Southern California

Ana Llana-Nozal, Organisation for Economic Co-operation and Development

Paola Sillitti, Organisation for Economic Co-operation and Development

Abstract

As populations age across the world, countries are pursuing alternative policies to support care needs towards the end of life. Ensuring that individuals die where they wish is often a central goal. To understand the interrelationship between care policy, circumstances before death, and place of death, we examine deaths in harmonized, nationally representative panel studies that follow older households from 2006/8 until their death for 20 OECD countries, including the US, Korea, and 18 European countries. We find policy emphasis on supporting care needs at home or in an institutional setting is strongly associated with place of death. Policies that support living at home for longer or that provide access to palliative care outside of hospital settings shift deaths away from hospitals and toward homes. Alternatively, policies that support institutionalized care increase the share of individuals dying in institutions and generally decrease home deaths. The consequences of these policies are substantively modified based on individual characteristics, including living arrangements and proximity to potential caregivers up to 2 years before death, age, and disease leading to death. Governments aiming to support death in place must provide access to LTC services as an individual's health declines that enable them to stay where they live and reduce potential caregivers' costs that may lead them to forgo caregiving in favor of institutional care.

Introduction

As the population ages, the share of older individuals dying from advanced, progressive, and incurable illnesses is projected to rise (OECD, 2023). Consequently, the provision of long-term care (LTC), especially end-of-life care (EOLC) in the final year of life, has emerged as a crucial policy priority. Ensuring that individuals die where they wish is a central goal of EOLC policy.

Existing research indicates that most non-institutionalized individuals prefer to die at home (Billingham & Billingham, 2013; Gomes et al., 2013; Higginson et al., 2017). Once an individual becomes institutionalized in a long-term care facility, however, home is often no longer a feasible place of death. In fact, more than three-quarters of nursing home residents in Europe and the United States die in nursing homes, and most of the remaining 25% die in a hospital (Temkin-Greener et al., 2013). Research on the place-of-death preferences of institutionalized individuals is scant, but a few studies have suggested that they overwhelmingly prefer dying in the nursing home where they are receiving care (Ng et al., 2016; van Oorschot et al., 2019). Despite individual preferences, hospitals remain the most common place of death in many countries around the world (OECD, 2023).

A large body of research has identified factors that influence place of death, ranging from sociodemographic characteristics, clinical factors such as cause of death, characteristics of the healthcare system such as availability of hospital beds and LTC beds in the region, and availability of palliative care outside of hospital settings (Cohen et al., 2006, 2010; Costa et al., 2016; Gomes & Higginson, 2006; Pivodic et al., 2016; Reyniers et al., 2015). The role of public policy, in particular, how it interacts with other determinants of place of death, remains largely unexplored.

This study examines the link between public policies and place of death, a question that is key to better targeting LTC and EOLC spending. The contribution of the study is twofold: First, we consider three different policy variables that can have different impacts on place of death. Specifically, we focus on public expenditure in home-based LTC, public expenditure in non-home-based LTC, and home-based palliative care availability. We hypothesize that the increased expenditure in home-based LTC and home-based palliative care will shift deaths from hospitals

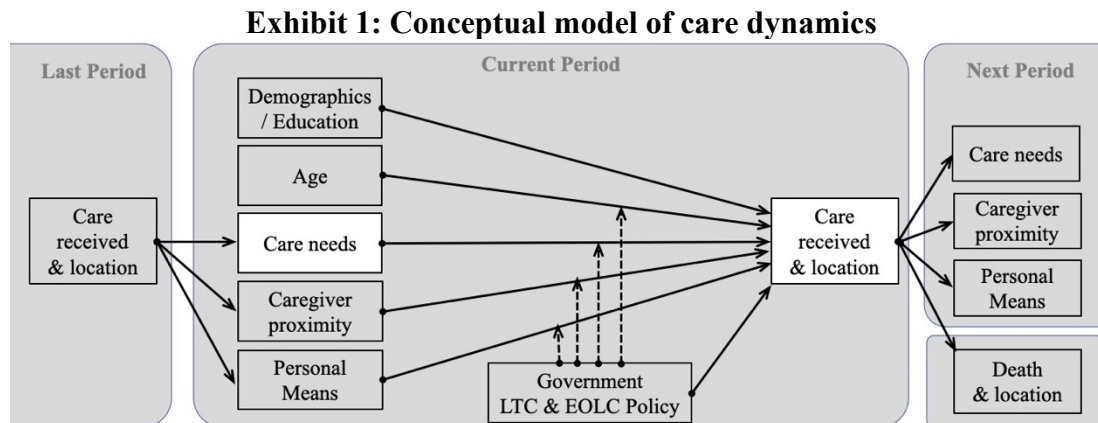
toward homes, while public increased expenditure in non-home-based LTC will shift deaths from hospitals toward nursing homes. Second, we analyze how the three policy variables interact with other determinants of place death. This is key to identifying populations who stand to benefit from policy interventions. Our hypothesis is that policy is unlikely to shift the place of death in cases where it is largely driven by non-modifiable factors (for example, those dying in a hospital from acute myocardial infarction) but will shift deaths that are driven by modifiable factors (for example, making palliative care available in non-hospital settings will shift deaths from hospitals to homes and nursing homes).

To answer these questions, our approach innovatively combines person-level panel survey data over 15 years, internationally harmonized survey instruments, more than 23,400 end-of-life surveys, and country long-term care (LTC) and end-of-life care (EOLC) policies. Person-level panel data linked to end-of-life surveys identifies a deceased person's circumstance before death, including personal characteristics, urbanicity, access to caregivers, functional limitations, and income. Internationally comparable person-level data enables comparing determinants of place of death across countries, including 20 countries and three alternative places of death (hospital, home, and institutions, e.g., residential care homes or hospice). To understand the role of policy, we combine these individual circumstances with spending on long-term care systems at the time of death and cross-country differences in the availability of EOLC services.

Conceptual model

Place of death is closely linked to care dynamics at the end of life. Exhibit 1 summarizes this relationship with a conceptual model that characterizes care received in a given period as a function of individual characteristics, such as care needs, caregiver proximity, personal means, age, and other demographic factors, and structural characteristics, such as government policies.¹

A person's characteristics determining care today are themselves partly determined by care received in past periods, and the outcome of care received today influences care needs, the likelihood of survival in future periods, and place of death.



SOURCE: Authors

For some people, death is sudden, with few current, observable events or symptoms that indicate the end of life (as in the case of death by accident or heart attack). For most people, death is a process, often characterized by the onset of physical, health, or cognitive limitations (care needs) that lead to an individual's decline, eventually resulting in death at some uncertain future point in time. In Exhibit 1, an individual's gradual decline is characterized by ever-increasing levels of care received based on their care needs, which influence their needs in future periods, their means and family proximity, and the location where care is provided (e.g., home versus long-term care institution).

LTC and EOLC policies can influence the speed of a person's decline and the location where care is received. In some countries, access to care services differs by age, need, and means. Furthermore, the location where care is received influences the place of death. Increased government spending on both LTC and EOLC may have competing influences on place of death, depending on the type of spending that is prioritized. EOLC policies supporting home death aim to shift the place of death from hospitals and other institutions to a person's home. On the other

hand, LTC policies supporting care in institutional settings are likely to decrease home deaths and increase institutional deaths.

To quantify the importance of public policy in determining the place of death and, in particular, how public policy spending interacts with the care dynamics preceding death highlighted in Exhibit 1, we use panel survey data following individuals at regular time intervals until death. We will merge these with data from end-of-life interviews with a next-of-kin to understand the circumstances surrounding a survey respondent's death.

Study data and methods

Survey data and sample

This study uses data pooled from waves 8 to 14 (2006 to 2018) of the Health and Retirement Study (HRS) in the US, waves 2 to 8 (2008 to 2020) of the Korean Longitudinal Study of Aging (KLoSA) in South Korea, and waves 2 to 8 (2006 to 2020) of the Survey of Health, Ageing and Retirement in Europe and Israel (SHARE) (Bergmann et al., 2019; Börsch-Supan et al., 2013; Health and Retirement Study, 2023; Park et al., 2023; RAND Corporation, 2023). These three studies are representative of the population aged 50 and older and collect information on care needs, family proximity, and demographic, social, and economic measures of survey participants and their spouses. Following a respondent's death, end-of-life interviews were conducted with their next-of-kin, if available, or another proxy respondent to elicit information about their last year of life and the circumstances of their death.

The empirical sample includes data on 23,451 individuals whose deaths were recorded across 20 countries: Austria, Belgium, Croatia, Czech Republic, Denmark, Estonia, France, Germany, Greece, Hungary, Italy, Korea, The Netherlands, Poland, Portugal, Slovenia, Spain, Sweden,

Switzerland, and the USA. Ten countries from the SHARE survey were excluded because fewer than 200 deaths were observed or LTC spending data was not available.

Information on the respondent's marital status, proximity to potential informal caregivers (whether they lived with a spouse, children, or others), income, home ownership, educational attainment, and difficulties with activities of daily living (e.g., eating, getting in or out of bed) or instrumental activities of daily living (e.g., shopping for groceries, taking medications) was collected from the last survey completed prior to death. Additional data on the respondent's place of death, disease leading to death, and year of death was obtained from exit interviews.

Supplementary Appendix A provides additional details on these surveys and data, including variable definitions, country and sample restrictions, as well as summary statistics and a discussion of the substantial cross-country variation in the explanatory factors.

Policy data

Two LTC spending categories were considered due to their potentially different impacts on place of death. The first category, home-based LTC, reflects public funding intended to support individuals receiving LTC at home and their families. The second category, non-home-based LTC, captures funding aimed at replacing unpaid home care with care provided in institutional settings such as nursing homes and assisted living facilities. Both are measured as a percent of a country's gross domestic product (GDP).

LTC spending encompasses policies aimed to support people who have significant health or personal care needs who are not necessarily near death, as well as policies specifically targeted to individuals nearing the end of their lives (EOLC). Because data on the proportion of home-based and non-home-based LTC spending allocated to EOLC were not available, in the analysis we considered an alternative EOLC policy variable, namely the ratio of specialized community-based

palliative care teams per 100,000 inhabitants. This variable serves as a proxy for the availability of palliative care outside the hospital setting and has been found to be an important determinant of place of death (Costa et al., 2016).

Data on annual public spending on home-based and non-home-based LTC policies were obtained from the OECD Data Explorer (OECD, 2024) and linked to survey respondents according to their country of residence and year of death. Data on the ratio of specialized, non-hospital-based, palliative care teams per 10,000 inhabitants for the year 2019 were obtained from Arias-Casais et al. (2020). In what follows, we refer to these as home care teams (HCT) to be consistent with the European Association for Palliative Care terminology (Radbruch & Payne, 2009).

Additional details on these data, including data collection methods and descriptions of the policies covered within the home-based and non-home-based categories, are available in Supplementary Appendix A.

Analytical approach and methods

We produced descriptive statistics of home-based and non-home LTC spending and HCT by country. Next, we analyzed the association between place of death, the policy variables, and individual characteristics prior to death using multinomial logit models where the dependent variable was categorized into three possible outcomes: dying at home, dying in an institution, and dying in the hospital. Institutions were defined to include both nursing homes and palliative care facilities such as hospices, mirroring how questions were asked in the end-of-life surveys.

The primary focus of the empirical analysis is the interaction of the policy variables with the following factors: age at death (50-64, 65-79, and 80+), disease leading to death (memory-related condition, cardiovascular with no memory-related condition, cancer with no memory-related condition, or other disease with no memory-related condition), caregiver proximity (co-reside

with the partner, co-reside with kids only, co-reside with others, live alone but near kids, live alone but not near kids, live alone and no kids), and income indicators capturing whether the individual had no income or belonged to each of the country-specific income quartiles for the subsample with positive income. Income was measured as all household income (respondent and spouse), including pension benefits and net of government transfers.

Additional independent variables included indicators for educational attainment (less than upper secondary, upper secondary and vocational training, and tertiary education), whether the respondent lived in an urban area, and whether they owned a home, as well as the number of limitations in activities of daily living (ADLs) and the number of limitations in instrumental activities of daily living (IADLs).

Finally, to proxy for between and within-country differences over time in the potential supply of unpaid care, measures of adult women's employment rates and women's statutory retirement ages from the public pension system were added to the models.

As illustrated in Exhibit 1, several factors considered in the analysis may depend on the care received prior to death. To better guarantee independence of these measures from the place of death, we measured proximity to potential informal caregivers, income, urban residence, home ownership, and the number of ADLs and IADLs in the last core interview prior to the respondent's death.

We did not include country-fixed effects in the analysis because within-country changes in LTC spending were small for most countries during the study period. The coefficients of interest would have been primarily identified out of changes in LTC spending in the few countries for which time variation was substantial and would not have accurately reflected the entire sample.

Additionally, there may be a lag before the impact of the short-term changes in LTC spending captured by fixed-effects regressions translate into shifts in place of death.

Even though data on two of the policy variables used in the analysis (home-based and non-home-based LTC) are collected annually, the temporal variation in these variables is limited in most countries in our sample. Consequently, the main source of identification of the model parameters is cross-country variation in policy spending.

Standard errors in all models were clustered at the country level. Our analyses were conducted using STATA version 18.0. We report marginal effects from multinomial logit models. Complete estimates of the multinomial logit models are available in Appendix B.

Limitations

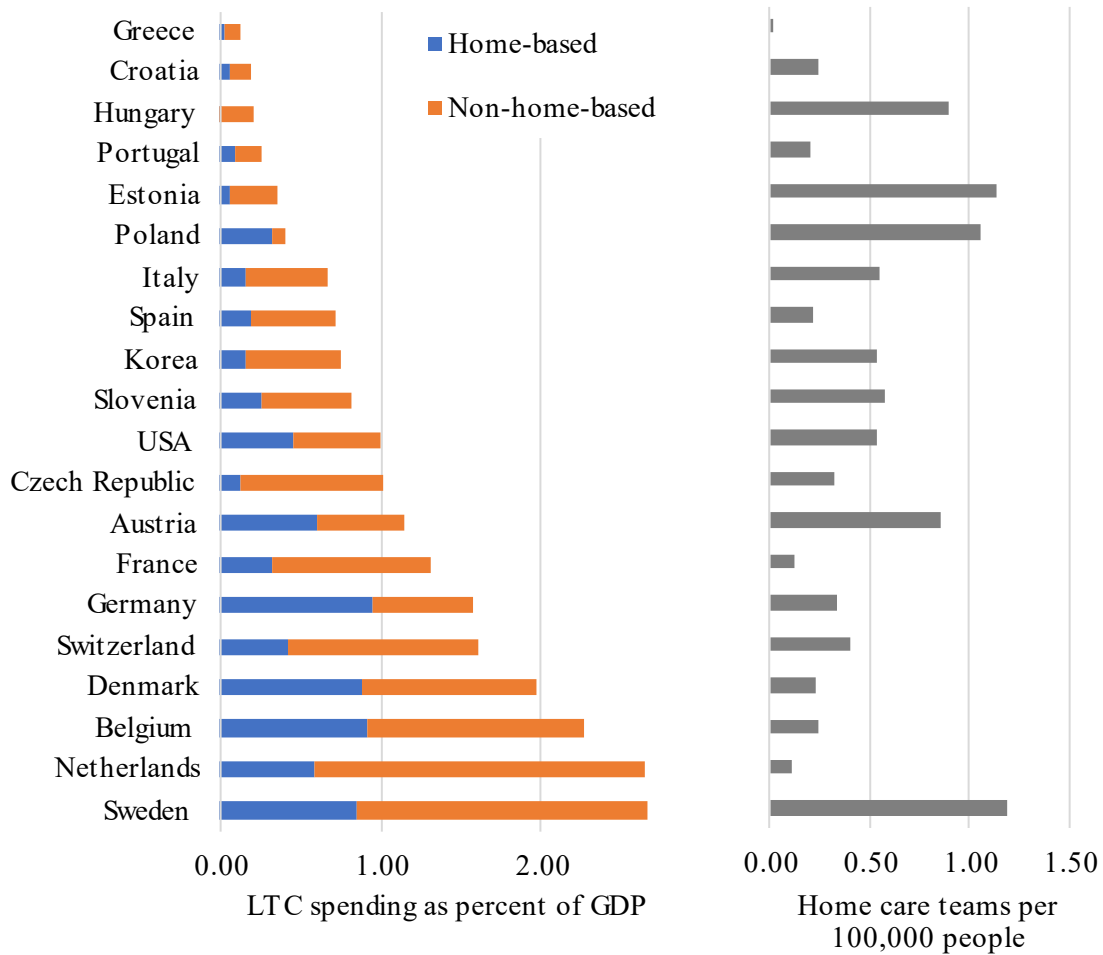
Our study had several limitations. First, the initial SHARE sampling did not include the institutionalized population. Over time, efforts were made to follow individuals who transited from private residences into long-term care facilities, but the institutionalized population is likely still underrepresented in the current sample. Second, due to limited temporal variation in policy variables, we did not use country fixed effects in our empirical analysis. As a result, the empirical estimates are mostly identified from cross-country variation and therefore do not necessarily capture causal effects of policy changes.

Results

Cross-country differences in LTC and EOLC policy

Public funding for total LTC spending, encompassing both home-based and non-home-based care, varied substantially across countries. As shown on the left panel of Exhibit 2, half of the countries in the study spent less than 1% of GDP to finance LTC, while countries such as Belgium, Netherlands, and Sweden spent more than 2% of GDP.

Exhibit 2: Home-based and Non-home-based LTC spending as a percent of GDP and number of HCT per 100,000 people, by country



SOURCE: Authors' calculations using data on LTC spending as a percent of GDP as of 2019 from OECD (2024) and on the number of HCTs per 100,000 from Arias-Casais et al. (2020).

Significant differences were also observed in the allocation of public funds between home-based versus non-home-based programs, reflecting the diversity of approaches employed to deliver LTC. Countries such as Austria, Germany, and Poland allocated more than half of their total public LTC funding to home-based services; eight of the twenty countries allocated more than one-third, while Hungary allocated less than 10%.

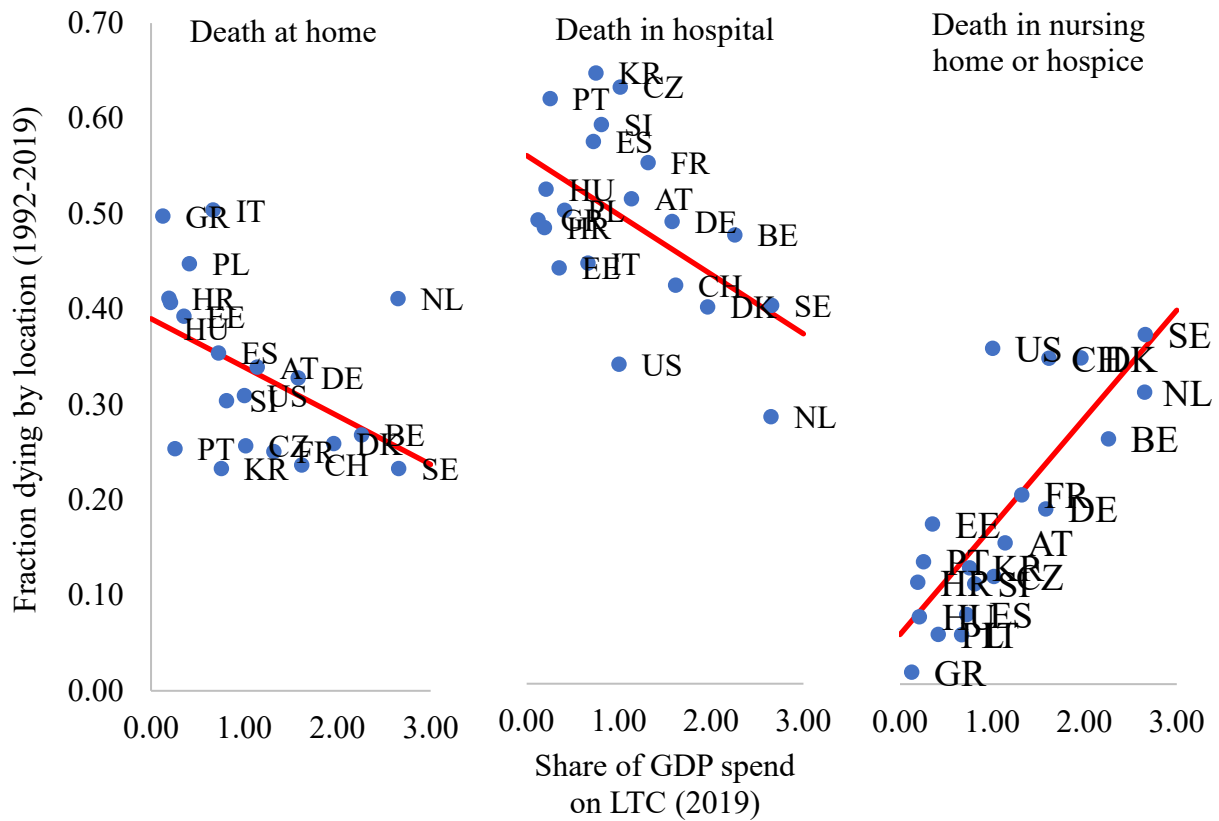
The right panel of Exhibit 2 shows cross-country differences in the number of HCTs in 2019. LTC spending and HCT are negatively but weakly correlated across countries (correlation coefficient = 0.08).

LTC spending and place of death

In Exhibit 3, we examine the relationship between place of death and overall public LTC spending. The middle panel replicates previous findings that the probability of dying in a hospital is negatively and significantly associated with total LTC spending (Orlovic et al., 2017). We find that LTC spending is also negatively and significantly associated with the probability of dying at home (first panel). The lower shares of hospital and home deaths in countries with high LTC spending are balanced out by a rise in the share of deaths in institutional settings (panel 3).

To provide a more nuanced understanding of the role of different long-term care policies, in Exhibit 4, we detail the marginal effects of the policy variables on place of death. Spending in home-based LTC and the number of HCTs per 100,000 people are both associated with fewer hospital deaths and increased home deaths. Conversely, non-home-based LTC spending is linked to more institutional deaths, which are mostly offset by decreases in home deaths, with no noticeable change in hospital deaths.

Exhibit 3: Place of death by LTC spending as percent of GDP



SOURCE: Author's calculations using HRS, KLoSA, and SHARE data (2004-2019) and LTC spending as a percent of GDP as of 2019 (2018 for Israel) from OECD Stat, Health expenditure and financing dataset. **NOTES:** Red lines correspond to fitted models relating the fraction dying by location to the share of GDP spent on LTC. *Notes.* AT = Austria; BE = Belgium; HR = Croatia; CZ = Czech Republic; DK = Denmark; EE = Estonia; FR = France; DE = Germany; GR = Greece; HU = Hungary; IT = Italy; KR = Korea; NL = the Netherlands; PL = Poland; PT = Portugal; SI = Slovenia; ES = Spain; SE = Sweden; CH = Switzerland; US = the United State of America.

Exhibit 4: Place of death by LTC spending as percent of GDP

	Location of Death		
	Home	Institution	Hospital
Home-based LTC spending	0.14*** (0.047)	0.0096 (0.039)	-0.15*** (0.052)
Non-home-based LTC spending	-0.079* (0.041)	0.075*** (0.027)	0.0040 (0.055)
Home-based EOLC spending (Home-based palliative care teams)	0.12*** (0.037)	-0.020 (0.024)	-0.096* (0.050)

SOURCE: Author's analysis using HRS, KLoSA, and SHARE data (1992-2019) and LTC spending as a percent of GDP from OECD Stat, Health expenditure and financing dataset. **NOTES:** The marginal effects are obtained from multinomial logit regressions.

Policy impacts by socioeconomic and type of illness categories

Holding other factors constant, higher home-based LTC spending was associated with increased home deaths and fewer hospital deaths for individuals aged 50 to 64 and 80+ at the time of death, those afflicted with memory-related diseases at the time of death, individuals who co-resided with a partner or their kids at the last interview before death, and those in the first, second, and fourth non-zero income quartiles (Exhibit 5). More home deaths were also observed among individuals who died of cardiovascular disease, although the corresponding decrease in hospital deaths was not statistically significant for this category, while institutional deaths were higher among individuals who died of cancer.

Increased spending on non-home-based LTC was linked with a shift in deaths from home to institutions for individuals in the oldest age category, those dying with memory-related diseases, people who co-resided with their kids or with others in their last interview before death, and those in the lowest non-zero income quartile. More institutional deaths were also observed for individuals dying of conditions other than cancer, cardiovascular disease, or memory-related, those co-residing with a partner in the last interview before death, and those in the second, third, and fourth non-zero income quartiles. For individuals who died of cardiovascular disease and those living alone but near kids, higher non-home-based LTC spending was associated with fewer home deaths, but the increase in institutional deaths was not statistically significant. Finally, deaths were shifted from homes to hospitals for individuals with no income and from hospitals to homes for those in the youngest age category.

Increased availability of HCTs was associated with a shift in place of death from hospitals to homes for individuals aged 50 to 64, those who died of cancer, cardiovascular disease, and other non-memory-related conditions, individuals co-residing with others in the last interview before death, and those in the highest income quartile. More home deaths were also observed among

those aged 65 to 79 and 80 or older, co-residing with a partner in the last core interview, and in the first and third non-zero income quantiles, although the corresponding decrease in hospital deaths was not statistically significant for these categories. For individuals co-residing with their kids in the last core interview and those with no income, a higher number of HCTs was associated with fewer hospital deaths offset by an increase in institutional deaths. Finally, a shift from institutional toward home deaths was observed for those living alone but near kids and those living alone with no kids in the last interview before death, as well as those in the second non-zero income quantile.

Exhibit 5. Marginal effects of policy measures on place of death by demographic categories

	Home-based LTC spending			Non-home-based LTC spending			Home-based EOLC spending (Home-based palliative care teams)		
	Home	Institution	Hospital	Home	Institution	Hospital	Home	Institution	Hospital
Age at death									
1. Age 50-64	0.15*** (0.050)	-0.0023 (0.034)	-0.15*** (0.054)	0.10** (0.045)	0.013 (0.022)	-0.12*** (0.042)	0.20*** (0.056)	-0.023 (0.027)	-0.18*** (0.059)
2. Age 65-79	0.094 (0.067)	-0.014 (0.036)	-0.079 (0.078)	-0.012 (0.050)	0.055* (0.030)	-0.043 (0.073)	0.14** (0.057)	-0.0093 (0.021)	-0.13* (0.075)
3. Age 80+	0.16*** (0.056)	0.027 (0.047)	-0.19*** (0.051)	-0.16*** (0.043)	0.100*** (0.032)	0.057 (0.053)	0.084*** (0.033)	-0.026 (0.032)	-0.058 (0.038)
Disease leading to death									
1. Memory-related disease	0.28*** (0.11)	-0.0045 (0.096)	-0.28*** (0.085)	-0.22*** (0.055)	0.14** (0.072)	0.079 (0.075)	0.064 (0.044)	-0.031 (0.048)	-0.033 (0.053)
2. Cancer (no memory-related disease)	0.10 (0.095)	0.061** (0.031)	-0.16* (0.090)	0.043 (0.090)	0.028* (0.016)	-0.071 (0.088)	0.16** (0.073)	-0.0090 (0.020)	-0.15** (0.077)
3. Cardiovascular (no memory-related disease)	0.096** (0.043)	-0.0025 (0.022)	-0.094* (0.055)	-0.066** (0.032)	0.042* (0.024)	0.023 (0.040)	0.089** (0.035)	-0.0027 (0.021)	-0.086** (0.042)
4. Other conditions (not memory-related, cancer, or cardiovascular)	0.035 (0.050)	-0.016 (0.040)	-0.019 (0.054)	-0.036 (0.052)	0.080*** (0.021)	-0.044 (0.052)	0.16*** (0.037)	-0.037 (0.029)	-0.13** (0.054)

Table continues on the next page.

Exhibit 5 (continued). Marginal effects of policy measures on place of death by demographic categories

	Home-based LTC spending			Non-home-based LTC spending			Home-based palliative care teams		
	Home	Institution	Hospital	Home	Institution	Hospital	Home	Institution	Hospital
Caregiver proximity at last interview before death									
1. Co-reside with partner	0.13** (0.052)	0.022 (0.032)	-0.15** (0.064)	-0.028 (0.051)	0.057*** (0.020)	-0.030 (0.064)	0.13** (0.051)	-0.021 (0.021)	-0.11* (0.065)
2. Co-reside with kids only	0.48*** (0.11)	-0.18 (0.12)	-0.30*** (0.096)	-0.26*** (0.070)	0.21*** (0.079)	0.057 (0.095)	0.049 (0.076)	0.16*** (0.053)	-0.21** (0.083)
3. Co-reside with others	0.077 (0.091)	0.022 (0.044)	-0.099 (0.072)	-0.12** (0.063)	0.12*** (0.019)	0.0085 (0.059)	0.16*** (0.061)	0.040* (0.024)	-0.20*** (0.052)
4. Live alone but near kids	0.058 (0.052)	0.051 (0.055)	-0.11* (0.060)	-0.11*** (0.041)	0.063* (0.036)	0.049 (0.042)	0.12*** (0.040)	-0.12*** (0.043)	0.0025 (0.032)
5. Live alone, no nearby kids	0.055 (0.051)	0.056 (0.063)	-0.11 (0.068)	-0.041 (0.046)	0.0061 (0.037)	0.035 (0.066)	0.071 (0.047)	-0.045 (0.049)	-0.026 (0.075)
6. Live alone, no kids	0.021 (0.062)	0.061 (0.063)	-0.082 (0.057)	-0.053 (0.043)	0.052 (0.057)	0.0015 (0.064)	0.10*** (0.032)	-0.093** (0.047)	-0.012 (0.058)
Income at last interview before death									
0. No income	0.29* (0.15)	0.050 (0.091)	-0.34* (0.18)	-0.20** (0.092)	-0.054 (0.034)	0.25*** (0.090)	0.098 (0.11)	0.18** (0.090)	-0.28** (0.14)
1. Lowest quartile (non-zero income)	0.16*** (0.055)	-0.0065 (0.058)	-0.16** (0.064)	-0.13*** (0.040)	0.11*** (0.037)	0.012 (0.055)	0.10*** (0.031)	-0.0095 (0.046)	-0.091 (0.057)
2. Second quartile (non-zero income)	0.15** (0.074)	-0.0018 (0.050)	-0.15** (0.075)	-0.082* (0.047)	0.095** (0.047)	-0.013 (0.072)	0.12*** (0.038)	-0.077*** (0.026)	-0.041 (0.055)
3. Third quartile (non-zero income)	0.11* (0.064)	0.00031 (0.047)	-0.11* (0.066)	-0.054 (0.054)	0.072** (0.029)	-0.018 (0.068)	0.12** (0.047)	-0.011 (0.027)	-0.11 (0.066)
4. Highest quartile (non-zero income)	0.14*** (0.047)	-0.0070 (0.040)	-0.14** (0.054)	-0.032 (0.044)	0.077*** (0.029)	-0.044 (0.057)	0.15*** (0.040)	-0.052* (0.027)	-0.098** (0.049)

SOURCE: Author's analysis using HRS, KLoSA, and SHARE data (1992-2019) and LTC spending as a percent of GDP from OECD Stat, Health expenditure and financing dataset. **NOTES:** The marginal effects are obtained from multinomial logit regressions. Example of interpretation of marginal effect: ME (home-based LTC spending | Age at death = 50-64) – The probability of individuals aged 50 to 64 dying at home is 15 percentage points higher for every additional 1 percentage-point increase in home-based LTC spending, keeping all other regressors constant. Home-based and non-home-based LTC spending are measured as a share of the country's GDP. Non-hospital-based palliative care is measured as the number of specialized home care teams per 10,000 inhabitants. Additional regressors included in the regressions and not shown in the table: education, ADL and IADL limitations, home ownership, indicators for death year, adult women's employment rate, and public pension retirement age for women (potential caregivers). Sample size is 23,451 individuals from 20 countries. Robust standard errors in parentheses, *** p<0.01, ** p<0.05, * p<0.1

Discussion

Our findings illustrate the impact of various long-term care policies on place of death across demographic, socioeconomic, and health-related categories.

Home-based LTC spending and the availability of HCTs were generally associated with fewer hospital deaths and more home deaths. There was an age gradient in the impact of HCTs, which were most likely to shift deaths from hospitals to homes among younger age groups. This suggests that palliative care availability outside of a hospital setting is a more significant limiting factor for home deaths in younger cohorts. Conversely, home-based health LTC spending was negatively correlated with hospital deaths for the oldest age group, indicating that the provision of in-home health services, personal assistance, and support for caregivers are more important in avoiding hospital deaths at older ages than the availability of home-based palliative care.

Among individuals who died of cancer, higher home-based LTC spending was linked to an increase in institutional deaths, while the change in home deaths was not statistically significant. This paradoxical finding is likely explained by the fact that palliative care has historically focused on individuals with cancer, and as a result, cancer patients are several times more likely to receive palliative and hospice care at the end of life than non-cancer patients (OECD, 2023). Therefore, while home-based LTC policies may successfully increase the length of time cancer patients live at home, many may ultimately receive end-of-life care in hospices, thereby increasing the number of deaths in institutional settings.

Increased availability of HCTs was linked to shifts from hospital to home deaths for individuals who died of cancer, cardiovascular disease, and other non-memory-related conditions. Conversely, home-based LTC spending was associated with similar shifts in place of death for individuals with memory-related diseases. While HCTs are most likely to influence the

place of death for those nearing the end of life, home-based LTC spending can affect care dynamics at earlier stages by delaying transitions into long-term care facilities. Individuals with memory-related conditions such as dementia are significantly more likely to be institutionalized than those without such conditions (Joling et al., 2020; Luppá et al., 2008; Nihtilä et al., 2008; Schulze et al., 2015). Once institutionalized, death at home becomes generally unfeasible. Consequently, it is not surprising that home-based LTC policies have a stronger impact on place of death than the availability of palliative care outside of a hospital setting for this group.

Higher home-based LTC spending was associated with shifts in deaths away from hospitals among individuals who co-resided with a spouse or a child in the last interview before death. This finding suggests that the effectiveness of policies designed to support individuals remaining at home until the end of life may be contingent on the availability of informal caregivers.

More HCTs were associated with shifts in deaths away from hospitals to homes or institutions and from institutions (which include hospices) to homes, among all caregiver proximity categories except for individuals living alone and with no nearby children. This is consistent with previous findings that the availability of palliative care at the individual's place of residence (HCTs include palliative care times operating both in homes and in long-term care facilities) increases home and institutional deaths and reduces hospitalizations in the last months of life (Alonso-Babarro et al., 2013; Costa et al., 2016; Miller et al., 2016).

Not surprisingly, policies that fund care provided in institutional settings, captured by non-home-based LTC spending, were associated with more institutional deaths. Shifts from home to institutional deaths were particularly evident among two groups of individuals. The first group was those in the oldest age category or dying with memory-related diseases, who typically face the greatest functional limitations and are thus more likely to require institutional care. Greater

public funding of institutional care enables this transition to support care needs, which makes transitions back into a home environment unlikely as death approaches. The second group consisted of individuals residing with their kids or others in the last core interview before death. Their proximity to an informal caregiver provides these groups with a choice in terms of place of residence and eventual place of death that can be impacted by policy. Indeed, the shift from home toward institutional deaths was not observed for individuals with the lowest proximity to potential informal caregivers, suggesting that place of death for this group is less modifiable, regardless of the level of non-home-based LTC spending.

We did not find noticeable income gradients on the effects of any of the policies considered, with the exception of non-home-based LTC, which had a stronger impact on reducing home deaths for individuals in the lowest income quartiles. This suggests a role of policy in alleviating financial barriers that prevent low-resource individuals from accessing long-term care facilities.

Conclusions and Policy Implications

Our findings have several policy implications. Most notably, our results emphasize that the type of resources promoted by policy for providing LTC is strongly related to the care people receive and where they receive it, and where people receive care immediately preceding death strongly affects where they die. Policies that support living at home for longer or that provide access to palliative care outside of hospital settings tend to shift deaths away from hospitals and into homes. Alternatively, policies that support institutionalized care increase the share of individuals dying in institutions and generally decrease home deaths. Governments aiming to support home death must provide access to LTC services that enable individuals to stay at home as long as it is safe for them to do so.

Another recurring finding was that individual circumstances modify the relationship between LTC policy and place of death. We observed this in three ways particularly relevant for policy. First, living alone, particularly with no kids nearby, is associated with a lower likelihood of dying at home. Without a natural support network at home, countries aiming to promote home death for all must facilitate remaining at home as one's health declines, which may be achieved through additional investments in paid care or the creation of robust community support networks. Second, increases in institutional LTC spending may unintentionally promote transitions from home to institutional settings for those with potential caregivers. Caregiving is costly, and if policy enables institutional alternatives without alleviating the costs of providing care at home, then there are strong incentives for people with care needs and their potential caregivers to substitute away from care in a home environment to an institution. To avoid promoting substitution away from home care and towards institutional care, expansions in LTC services need to incorporate policies capable of offsetting this substitution, such as policies that support and facilitate family caregiving. Policies enabling family caregiving are likely less costly than fulfilling care needs with institutional care or paid caregivers. Third, supporting palliative care at home is associated with more home deaths for younger individuals and those dying from non-memory-related diseases, such as cancer and cardiovascular disease. In these cases, dying individuals typically have sufficient functional and cognitive abilities to remain in the community if some help is provided. Providing home-based palliative care alternatives are likely less costly and can preempt transitions to institutionalized care.

Our findings highlight the interrelationship between LTC policy, palliative care policy, and place of death. Future research aimed at understanding the effectiveness of policies designed to support dying in place or identifying new policies must consider this complex interplay and its

consequences for the dynamics of care need and receipt as individuals' health declines and, ultimately, the place and circumstances in which people die.

Notes

- ¹ We recognize there is some ambiguity in these definitions as some nonmodifiable characteristics, such as sex and education, can change. For simplicity and recognizing our focus on care dynamics of older people, we assume these are independent from other factors determining care in the current period.
- ² This paper uses data from SHARE Waves 2, 3, 4, 5, 6, 7, and 8 (DOIs: 10.6103/SHARE.w2.900, 10.6103/SHARE.w3.900, 10.6103/SHARE.w4.900, 10.6103/SHARE.w5.900, 10.6103/SHARE.w6.900, 10.6103/SHARE.w7.900, and 10.6103/SHARE.w8.900) see Börsch-Supan et al. (2013) for methodological details. The SHARE data collection has been funded by the European Commission, DG RTD through FP5 (QLK6-CT-2001-00360), FP6 (SHARE-I3: RII-CT-2006-062193, COMPARE: CIT5-CT-2005-028857, SHARELIFE: CIT4-CT-2006-028812), FP7 (SHARE-PREP: GA N°211909, SHARE-LEAP: GA N°227822, SHARE M4: GA N°261982, DASISH: GA N°283646) and Horizon 2020 (SHARE-DEV3: GA N°676536, SHARE-COHESION: GA N°870628, SERISS: GA N°654221, SSHOC: GA N°823782, SHARE-COVID19: GA N°101015924) and by DG Employment, Social Affairs & Inclusion through VS 2015/0195, VS 2016/0135, VS 2018/0285, VS 2019/0332, VS 2020/0313 and SHARE-EUCOV: GA N°101052589 and EUCOVII: GA N°101102412. Additional funding from the German Ministry of Education and Research, the Max Planck Society for the Advancement of Science, the U.S. National Institute on Aging (U01_AG09740-13S2, P01_AG005842, P01_AG08291, P30_AG12815, R21_AG025169, Y1-AG-4553-01, IAG_BSR06-11, OGHA_04-064, BSR12-04, R01_AG052527-02, HHSN271201300071C, RAG052527A) and from various national funding sources is gratefully acknowledged (see www.share-eric.eu).

References

- Alonso-Babarro, A., Astray-Mochales, J., Domínguez-Berjón, F., Gènova-Maleras, R., Bruera, E., Díaz-Mayordomo, A., & Centeno Cortes, C. (2013). The association between in-patient death, utilization of hospital resources and availability of palliative home care for cancer patients. *Palliative Medicine*, 27(1), 68–75.
- Arias-Casais, N., López-Fidalgo, J., Garralda, E., Pons, J. J., Rhee, J. Y., Lukas, R., de Lima, L., & Centeno, C. (2020). Trends analysis of specialized palliative care services in 51 countries of the WHO European region in the last 14 years. *Palliative Medicine*, 34(8), 1044–1056.
- Bergmann, M., Kneip, T., De Luca, G., & Scherpenzeel, A. (2019). *Survey participation in the Survey of Health, Ageing and Retirement in Europe (SHARE), Wave 1-7. Based on Release 7.0.0.* (41–2019; SHARE Working Paper Series).

- Billingham, M. J., & Billingham, S.-J. (2013). Congruence between preferred and actual place of death according to the presence of malignant or non-malignant disease: a systematic review and meta-analysis. *BMJ Supportive & Palliative Care*, 3(2), 144. <https://doi.org/10.1136/bmjspcare-2012-000292>
- Börsch-Supan, A., Brandt, M., Hunkler, C., Kneip, T., Korbmacher, J., Malter, F., Schaan, B., Stuck, S., & Zuber, S. (2013). Data resource profile: the Survey of Health, Ageing and Retirement in Europe (SHARE). *International Journal of Epidemiology*, 42(4), 992–1001.
- Cohen, J., Bilsen, J., Hooft, P., Deboosere, P., Van Der Wal, G., & Deliens, L. (2006). Dying at home or in an institution: using death certificates to explore the factors associated with place of death. *Health Policy*, 78(2–3), 319–329.
- Cohen, J., Houttekier, D., Onwuteaka-Philipsen, B., Miccinesi, G., Addington-Hall, J., Kaasa, S., Bilsen, J., & Deliens, L. (2010). Which patients with cancer die at home? A study of six European countries using death certificate data. *J Clin Oncol*, 28(13), 2267–2273.
- Costa, V., Earle, C. C., Esplen, M. J., Fowler, R., Goldman, R., Grossman, D., Levin, L., Manuel, D. G., Sharkey, S., Tanuseputro, P., & You, J. J. (2016). The determinants of home and nursing home death: a systematic review and meta-analysis. *BMC Palliative Care*, 15(1), 8. <https://doi.org/10.1186/s12904-016-0077-8>
- Gomes, B., Calanzani, N., Gysels, M., Hall, S., & Higginson, I. J. (2013). Heterogeneity and changes in preferences for dying at home: a systematic review. *BMC Palliative Care*, 12(1), 7. <https://doi.org/10.1186/1472-684X-12-7>
- Gomes, B., & Higginson, I. J. (2006). Factors influencing death at home in terminally ill patients with cancer: systematic review. *BMJ*, 332(7540), 515–521. <https://doi.org/10.1136/bmj.38740.614954.55>
- Health and Retirement Study. (2023). RAND HRS Longitudinal File 2020 (v1) public use dataset. . In *Produced and distributed by the University of Michigan with funding from the National Institute on Aging (grant numbers NIA U01AG009740 and NIA R01AG073289)*. : Vol.
- Higginson, I. J., Daveson, B. A., Morrison, R. S., Yi, D., Meier, D., Smith, M., Ryan, K., McQuillan, R., Johnston, B. M., Normand, C., Bennett, E., Cooper, F., Daveson, B., de Wolf-Linder, S., Dzingina, M., Ellis-Smith, C., Evans, C., Ferguson, T., Henson, L., ... BuildCARE, on behalf of. (2017). Social and clinical determinants of preferences and their achievement at the end of life: prospective cohort study of older adults receiving palliative care in three countries. *BMC Geriatrics*, 17(1), 271. <https://doi.org/10.1186/s12877-017-0648-4>

- Joling, K. J., Janssen, O., Francke, A. L., Verheij, R. A., Lissenberg-Witte, B. I., Visser, P., & van Hout, H. P. J. (2020). Time from diagnosis to institutionalization and death in people with dementia. *Alzheimer's & Dementia*, 16(4), 662–671.
- Luppa, M., Luck, T., Brähler, E., König, H.-H., & Riedel-Heller, S. G. (2008). Prediction of institutionalisation in dementia: a systematic review. *Dementia and Geriatric Cognitive Disorders*, 26(1), 65–78.
- Miller, S. C., Lima, J. C., Intrator, O., Martin, E., Bull, J., & Hanson, L. C. (2016). Palliative care consultations in nursing homes and reductions in acute care use and potentially burdensome end-of-life transitions. *Journal of the American Geriatrics Society*, 64(11), 2280–2287.
- Ng, C. W. L., Cheong, S. K., Govinda Raj, A., Teo, W. S. K., & Leong, I. Y. O. (2016). End-of-life care preferences of nursing home residents: Results of a cross-sectional study. *Palliative Medicine*, 30(9), 843–853. <https://doi.org/10.1177/0269216316634242>
- Nihtilä, E. K., Martikainen, P. T., Koskinen, S. V. P., Reunanen, A. R., Noro, A. M., & Häkkinen, U. T. (2008). Chronic conditions and the risk of long-term institutionalization among older people. *European Journal of Public Health*, 18(1), 77–84.
- OECD. (2023). *Time for Better Care at the End of Life*. <https://doi.org/10.1787/722b927a-en>
- OECD. (2024). *Health expenditure and financing: Long-term care (health), government and compulsory schemes*. OECD.
- Orlovic, M., Marti, J., & Mossialos, E. (2017). Analysis Of End-Of-Life Care, Out-Of-Pocket Spending, And Place Of Death In 16 European Countries And Israel. *Health Affairs*, 36(7), 1201–1210. <https://doi.org/10.1377/hlthaff.2017.0166>
- Park, H. Y., Wang, Y., Wilkens, J., Phillips, D., & Lee, J. (2023). *Harmonized KLoSA, Version E.2. The Gateway to Global Aging Data*. <https://doi.org/10.34729/815E-WN35>
- Pivodic, L., Pardon, K., Morin, L., Addington-Hall, J., Miccinesi, G., Cardenas-Turanzas, M., Onwuteaka-Philipsen, B., Naylor, W., Ramos, M. R., & Van den Block, L. (2016). Place of death in the population dying from diseases indicative of palliative care need: a cross-national population-level study in 14 countries. *J Epidemiol Community Health*, 70(1), 17–24.
- Radbruch, L., & Payne, S. (2009). White Paper on standards and norms for hospice and palliative care in Europe: part 1. *European Journal of Palliative Care*, 16(6), 278–289. http://www.haywardpublishing.co.uk/_year_search_review.aspx?JID=4&Year=2009&Edition=127

RAND Corporation. (2023). *RAND HRS Longitudinal File 2020 (VI)*. Produced by the RAND Center for the Study of Aging, with funding from the National Institute on Aging and the Social Security Administration.

Reyniers, T., Deliens, L., Pasman, H. R., Morin, L., Addington-Hall, J., Frova, L., Cardenas-Turanzas, M., Onwuteaka-Philipsen, B., Naylor, W., & Ruiz-Ramos, M. (2015). International variation in place of death of older people who died from dementia in 14 European and non-European countries. *Journal of the American Medical Directors Association, 16*(2), 165–171.

Schulze, J., van den Bussche, H., Kaduszkiewicz, H., Koller, D., & Hoffmann, F. (2015). Institutionalization in incident dementia cases in comparison to age- and sex- matched controls: a 5-year follow-up from Germany. *Social Psychiatry and Psychiatric Epidemiology, 50*(1), 143–151. <https://doi.org/10.1007/s00127-014-0911-3>

Temkin-Greener, H., Zheng, N. T., Xing, J., & Mukamel, D. B. (2013). Site of Death Among Nursing Home Residents in the United States: Changing Patterns, 2003–2007. *Journal of the American Medical Directors Association, 14*(10), 741–748. <https://doi.org/https://doi.org/10.1016/j.jamda.2013.03.009>

van Oorschot, B., Mücke, K., Cirak, A., Henking, T., & Neuderth, S. (2019). Gewünschter Sterbeort, Patientenverfügungen und Versorgungswünsche am Lebensende: erste Ergebnisse einer Befragung von Pflegeheimbewohnern. *Zeitschrift Für Gerontologie Und Geriatrie, 52*(6), 582–588. <https://doi.org/10.1007/s00391-018-1432-6>