

Severe Cognitive Impairments and Long-term Care in Germany¹

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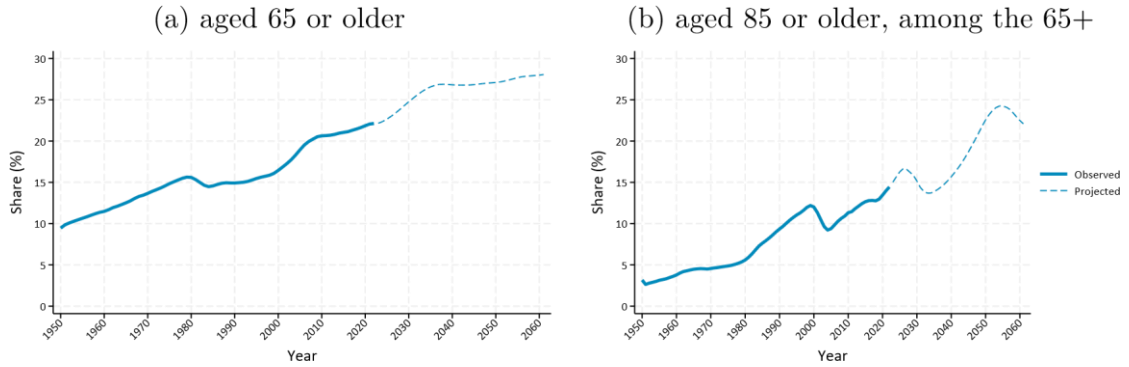
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1 Introduction

A persistent below replacement fertility rate and increasing life expectancy are the two main factors contributing to demographic ageing in Germany. The fertility decline was particularly strong in the mid-1960s after a short baby boom, causing a demographic shift with the baby boomers' generation² reaching retirement age now. The share of people aged 65 and older is expected to increase between 2025 and 2035 by about 17% and at a slower pace by nearly 6% until 2061 (Figure 1a). In addition, the share of the oldest old (aged 85 and older) within the older population will strongly increase: from currently about 16% to 22% in 2061 (Figure 1b). Germany's share of people aged 65 and older is at the average of the European Union and does not represent a particularly old European country in this respect. It is slightly higher than the OECD average, and with about five percentage points throughout the projection period, much higher than in the US. The same holds for the share of the oldest old. For example, in the US, the share of those aged 85 and older within the population above 65 is projected to be 20% in 2061 (REF chapter US).

Figure 1: Percentage of population



Note: This figure represents the share of the German population aged 65 or older from 1950 to 2022 (left) and, among those aged at least 65, the proportion aged 85+ (right). It also includes projections for these shares from 2022 to 2061 (dashed line).

Source: OECD.

Demographic aging poses a growing economic and social challenge in Germany. As the population ages, the demand for both formal and informal long-term care rises, while smaller younger cohorts struggle to meet this demand. Germany is currently facing shortages of formal care workers.

Germany was among the first countries to implement a dedicated social insurance program for long-term care insurance (LTCI)³. Established in 1995, LTCI ensures universal access to care while distributing financial and caregiving responsibilities among individuals, families, and the state. It is a cornerstone of Germany's social welfare model, offering structured support for individuals needing assistance with activities of daily living due to aging, chronic illness, or disability.

² The German baby boomer cohorts were born between 1957 and 1968 (Pötzsch and zur Nieden 2024).

³ Political discussions about the need for LTCI started already in the 1970s. It took more than 20 years to introduce the insurance. See Götting et al. (1994) for more information.

A central and growing focus of Germany’s LTC system is addressing the needs of individuals with dementia and other cognitive impairments. While the prevalence of dementia among the 65+ population in Germany is lower than in many other European countries and the US (Börsch-Supan et al., 2025), it affects an estimated 1.7 million people in Germany. About 70% of nursing home residents have dementia; in turn, however, only about 30% of demented people live in nursing homes (Schäufele et al., 2013). Dementia presents unique challenges that extend beyond physical assistance to include emotional, social, and behavioral support (GBD 2019 Dementia forecasting collaborators, 2022; Georges et al., 2023).

Recognizing these distinct needs, the LTCI system has progressively adapted its eligibility criteria and benefits. A key milestone was the 2017 reform, which introduced a new dependency assessment test that included cognitive and psychological impairments (Geyer et al., 2016; Rothgang and Kalwitzki, 2015, 2016). These changes aim to ensure that individuals with dementia and severe cognitive impairment receive adequate support, whether through professional care, informal caregiving, or specialized dementia facilities.

Despite these advancements, severe cognitive impairment remains a critical challenge for the LTC system, which relies on both professional caregivers and informal family networks. The rising prevalence of dementia exacerbates issues such as caregiver shortages, increasing costs, and the need for specialized training. Policymakers and stakeholders should address the immediate needs of this vulnerable population while developing sustainable strategies for the future.

For instance, the 2017 reform significantly expanded public LTCI coverage, resulting in a significant and sustained increase in beneficiaries. Between 2016 and 2023, the number of insured individuals nearly doubled, exceeding 5 million.

This article provides an overview of the structure, financing, and delivery of LTC in Germany, emphasizing dementia and cognitive impairments as key drivers of system demand. It examines the challenges posed by these conditions and explores pathways for reform and innovation to ensure equitable, high-quality, and sustainable care. The primary empirical data source for our analysis is the Survey of Health and Retirement (SHARE), which collects comprehensive data on respondents’ financial, family, and health circumstances.

We follow Langa et al. (2017) and Crimmins et al. (2011) to measure cognitive abilities using a four-item score that includes subtraction, backward counting, immediate memory, and delayed memory tests. Our results highlight specific LTC arrangement of elderly individuals living at home and experiencing severe cognitive impairments, which are associated with the high cost of care.

In the following, we present Germany’s institutional framework (Section 2), data and descriptive statistics (Section 3 and 4), main results (Section 5), and back-to-the-envelope calculations to provide an insight into the cost of long-term care for elderly individuals with and without cognitive impairment (Section 6).

2 Policy environment

The German LTCI is a mandatory program with a large public branch, funded equally by employer and employee contributions.⁴ Additionally, a much smaller private LTCI branch covers individuals with private health insurance, including the self-employed, civil servants, and high-income earners.

Private LTCI funds are required to provide at least the same level of benefits as the public system. Benefits are available to all insured individuals based on their level of care needs, rather than financial means (i.e., not means-tested).

Until 2017, LTCI classified dependency into three levels based on the frequency and duration of assistance required from a non-professional caregiver (see Schulz (2010) or Geyer et al. (2023) for more details).

Initially, Germany's LTCI primarily focused on physical impairments. As a result, individuals without physical disabilities found it difficult – if not impossible – to qualify for care benefits. Since support was centered on physical limitations, the system did not provide additional assistance for cognitive impairments.

This approach changed through a series of reforms. In 2002, the government introduced a small cash benefit for individuals with “limited everyday competences.”⁵ Subsequent reforms in 2008 and 2012/13 expanded benefits and eligibility.⁶ Finally, in 2017, LTCI adopted a completely new care assessment framework that considers both cognitive and physical impairments.

The evaluation now consists of six modules:

1. Mobility – Assesses physical impairments.
2. Cognitive and communicative skills – Evaluates understanding and communication abilities.
3. Behavioral and psychological problems – Identifies mental health-related care needs.
4. Activities of daily living (ADLs) – Measures a person's ability to care for themselves.
5. Medical and therapy-related requirements – Assesses self-medication needs and capacity.
6. Daily life management and social interactions – Evaluates independence in everyday activities and social participation.

Each module's activities are evaluated using a point system. The total score determines one of five levels of impairment, each assigned a weighted value. The sum

⁴ In 2025, the general contribution rate is 3.6%. Employees without children under 23 pay an additional 0.6% contribution. Those with two or more children under 23 receive a reduced contribution rate of 0.25 percentage points per child, up to a maximum reduction of one percentage point.

⁵ An additional benefit entitlement is being introduced for people in need of care with a significant need for general supervision and care. This group of people can then claim additional financial assistance from the nursing care insurance worth up to EUR 460 per calendar year for quality-assured care services when receiving care at home.

⁶ In 2008, the additional benefit amount introduced in 2002 is set at EUR 100 per month (basic amount) or EUR 200 per month (increased basic amount); in future, people in "care level 0" (especially those with dementia) can also receive these rates. The LTCI pays a remuneration supplement for the additional care of nursing home residents with dementia (to finance an additional carer for every 25 residents with dementia). A reform in 2012 extended these benefits paid to persons with permanently limited everyday competence in care levels I, II and “zero” who are cared for at home.

of these weighted points classifies individuals into one of five LTC dependence levels (*Pflegegrad*, PG):

1. PG1: 12.5 to 27 points (minor impairment)
2. PG2: 27 to 47.5 points (considerable impairment)
3. PG3: 47.5 to 70 points (serious impairment)
4. PG4: 70 to 90 points (severe impairment)
5. PG5: 90 to 100 points (most severe degree of impairment)

Unfortunately, LTCI does not publish statistics on individual module outcomes. As a result, individuals with the same *Pflegegrad* may have different underlying module scores. While it is possible to link ICD-10 diagnoses to dependence levels, the presence of multiple coexisting conditions (multimorbidity) makes it unclear whether care dependence is directly related to cognitive impairments.

Table 1 presents the distribution of care levels by home care and institutional care in nursing homes. As expected, the proportion of individuals in institutional care increases with higher care levels. However, even at the highest level (PG5), more than 50% of individuals receive care at home.

Table 1: Care levels by type of care (2023)

Care Level	Care at home		Stationary care		Total
	N	%	N	%	
PG 1	778,824	0.996	3,335	0.004	782,159
PG 2	1,922,210	0.947	108,288	0.053	2,030,498
PG 3	1,212,017	0.821	263,494	0.179	1,475,511
PG 4	367,023	0.621	223,604	0.379	590,627
PG 5	113,423	0.521	104,323	0.479	217,746
	4,393,497	0.862	703,044	0.138	5,096,541

Note: This table presents the number and proportion of Germans in each care category, along with the type of care they receive either at home or in a nursing home. The data clearly show that as care needs increase, individuals are more likely to receive institutional care rather than home care.

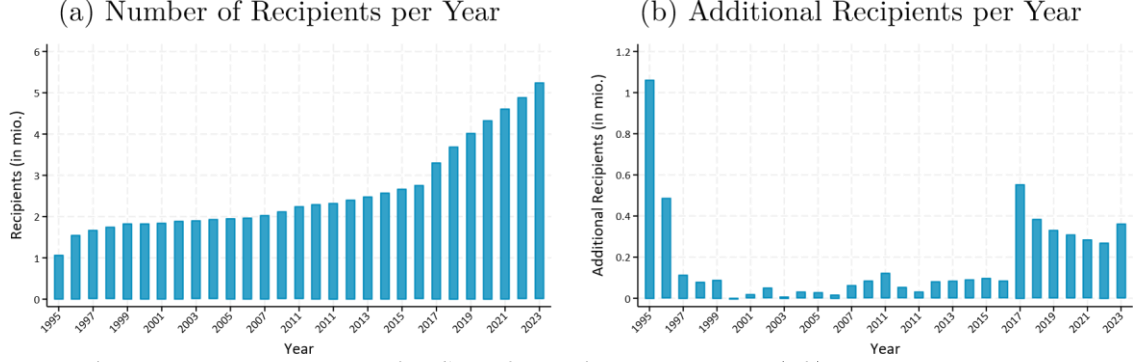
Source: German Ministry of Health.

The 2017 care assessment reform had a significant impact on the number of LTCI beneficiaries (Figure 2a). Between 1996⁷ and 2016, the number of beneficiaries grew by nearly 80%, rising from 1.5 million to 2.7 million. This trend accelerated between 2016 and 2023, with an additional 90% increase, bringing the total to 5.2 million recipients in 2024.

The growth in beneficiaries continued after the 2017 reform. Although the increase fell below 300,000 in 2021 and 2022 – likely due to the COVID-19 pandemic – it rebounded in 2023, rising by 360,000 (Figure 2b).

⁷ LTCI was introduced in several steps. In a first step, benefits for care at home were introduced, in a second step, benefits for institutional care started on July 1, 1996. Therefore, there was a strong increase of beneficiaries between 1995 and 1996.

Figure 2: Beneficiaries of LTCI



Note: These figures show the total number of LTC beneficiaries from 1995 and 2023 (left) and the year-over-year change in beneficiary numbers (right). The data include all beneficiaries at year-end, with a small number disability facilities (Behindertenhilfe).

Source: German Ministry of Health.

3 Data

Survey of Health, Ageing, and Retirement in Europe. The primary data source for the empirical analysis and the description of cognitive decline is the Survey of Health, Ageing, and Retirement in Europe (SHARE) (Börsch-Supan et al., 2013; SHARE-ERIC, 2024). Launched in 2004, SHARE has been conducted every two years, with regular replenishments to ensure representation of the European population aged 50 and older. In recent waves, for some countries such as Germany, the survey includes both individuals living at home and in nursing home.

Similar to the Health and Retirement Study (HRS) in the U.S., SHARE collects extensive data on respondents’ financial and family situations, health, and other aspects of their lives. As of 2024, the survey has interviewed 158,764 individuals across 29 countries. Contrary to the HRS, individuals who refuse to participate to the survey cannot have a proxy respondent. Proxy respondents only answer the interview for the respondent if he agree to participate but wants help from someone for part or all the questionnaire.

Sample. For our analysis, we select German respondents from wave 9 which covers 4,467 individuals living in private households in 2022. We restrict the sample to individuals aged 65 and older who participate to the cognitive functioning questionnaire, which leaves us with 2,070 observations.

Wave 9 of SHARE includes a comprehensive questionnaire assessing cognitive functioning and autonomy. The questionnaire comprises memory tests, numeracy tests, and verbal fluency tasks, enabling the calculation of the Langa-Weir cognitive score (Langa et al., 2017). Additionally, it collects data on socio-demographic characteristics, including household composition, employment status, education level, income, and wealth, among other variables.

Note that the sample does not include individuals residing in nursing homes, because of limitation regarding measure of cognitive functioning of respondents living in nursing home.

Our sample does not include individuals residing in nursing homes because they are severely undersampled and of those few observations many did not provide measures of cognitive functioning. As such, when interpreting the results, one has to consider that an important group of individuals with cognitive impairment is not reflected. We focus on determinant of formal and informal care use at home for individuals suffering from cognitive impairments living at home. To quantify individuals suffering from cognitive impairments that live in nursing homes, we will provide aggregated estimates of their number and the cost associated this type of care in Section 6.

Respondents unable to answer the questions independently may be accompanied by a proxy who responds on their behalf. Proxy responses account for 1.8% of the sample. In the cognitive functioning module of SHARE, proxies were not permitted to answer questions when respondents were unable to do so themselves. Consequently, no data are available on the cognitive abilities of these respondents or the reasons for their inability to complete the cognitive functioning questionnaire. However, proxies were required to answer a set of questions regarding the health of the surveyed individual, including one question about the respondent’s memory and another about changes in memory over the two years preceding the interview. Using these data, we classified respondents as having cognitive impairment if the proxy reported poor or declining memory (Börsch-Supan et al., 2025).

Measure of cognitive abilities. Following the methodology outlined by Langa et al. (2017) and Crimmins et al. (2011), we measure cognitive abilities using a four-item score. This score assesses respondents’ ability to subtract 7 repeatedly from 100 (5 points), count backwards from 20 (2 points), and memorize a list of words, recalling it immediately (10 points) and again after a delay (10 points). The resulting cognitive score ranges up to 27 points. We classify individuals as suffering from severe cognitive impairments (SCI) if their score is 6 or lower (Langa et al., 2017). Mild-cognitive impairment is defined as having a score between 6 and 12 (Langa et al., 2017). Alternative measures of cognitive abilities, such as O’Donovan et al. (2023) lead to similar conclusions (see Appendix A for more details). Besides, in order to provide another angle of comparison between countries, we also provide measure of LTC use and cost of the bottom-6% of the distribution of cognitive score (Appendix A).

Measure of autonomy. Respondents’ autonomy is commonly assessed using their ability to perform instrumental activities of daily living (IADLs), which include tasks typically performed in daily life, such as grocery shopping, cooking, cleaning, using the phone, and managing paperwork and medications. A more severe form of limitation is measured through the ability to perform basic activities essential for independent living, known as Activities of Daily Living (ADLs). These include dressing, eating, bathing, walking across a room, getting in and out of bed, and toileting. ADLs are a well-known indicator of autonomy (Katz, 1963; Katz et al., 1970).

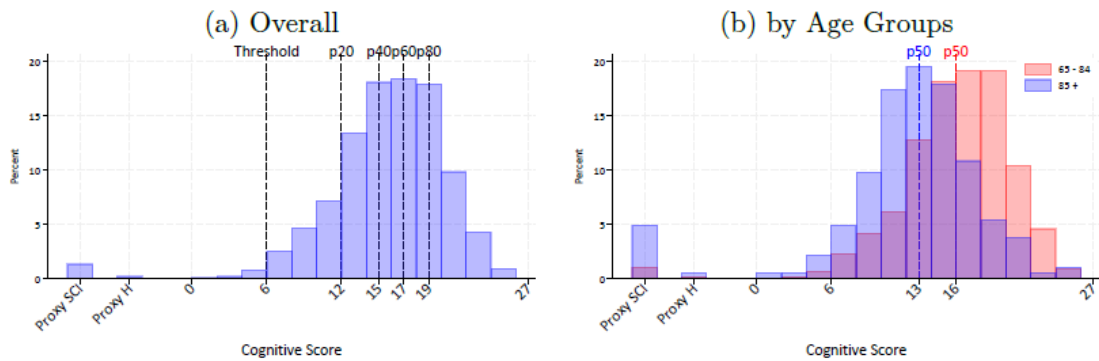
Long-term care utilization. LTC encompasses all forms of assistance provided to individuals to compensate for limitations in ADLs and IADLs. This includes support

with tasks such as bathing, dressing, eating, house cleaning, and grocery shopping. LTC excludes medical care, which is classified as healthcare rather than long-term care. LTC can be delivered by professionals (formal care) or by relatives or friends (informal care). We rely on survey questions regarding assistance received from a partner, family members or friends for ADLs and IADLs, as well as paid professional help for these activities. Additionally, we have data on self-reported hours of formal care received. Informal care hours are imputed using a procedure suggested by Barczyk and Kredler (2019). This involves estimating the number of informal care hours for respondents who reported receiving informal care, using all ADLs and IADLs as separate predictors, alongside the respondent’s age and self-reported frequency of help (daily, weekly, monthly, or less often). The imputation method’s validity was confirmed using data from the first two waves of SHARE, which include questions on both care frequency and assistance with ADLs and IADLs. Care reported by respondents living with one of their children may differ from care reported by those living without any children. Therefore, we performed grouped imputation to account for these differences. We also tested alternative imputation methods, including those without grouped imputation and those incorporating more health predictors and frequency-of-help questions. The results were not sensitive to these alternative methods.

4 Descriptive Statistics

Cognitive Impairments. Figure 3a shows the distribution of cognitive scores. Information collected in proxy interviews are presented on the left side of the distribution. Overall, we obtain a weighted prevalence of severe cognitive impairments of 3.88% among the German older than 65 living at home. This is consistent with recent estimation of the prevalence of SCI in Europe (Börsch-Supan et al., 2025).

Figure 3: Distribution of Cognition Scores



Note: These figures represent the distribution of cognitive scores among the German elderly in 2022 (a) and by age groups (b). In panel (a), the scores corresponding to the threshold of 6 for severe cognitive impairments (SCI) are shown, along with the 20th, 40th, 60th, and 80th percentiles. In panel (b), the median score is displayed. The share of proxy respondents is represented on the left side of the distribution. These proxies represent individuals who were unable to complete the cognitive test. Based on proxy responses, individuals were classified as suffering from severe cognitive impairments (poor or declining memory) and assigned to the Proxy-SCI category. If the proxy indicated no cognitive impairment, the individual was categorized as Proxy H (healthy).

Sample: German population aged 65 and over living in private household.

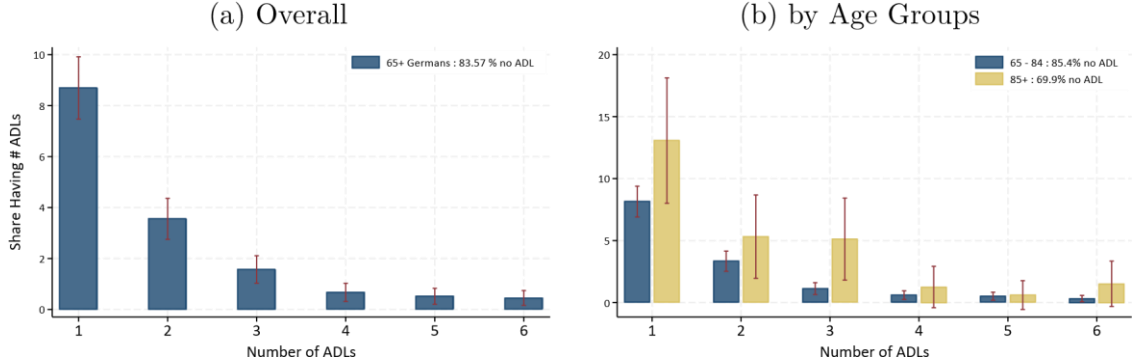
Data: SHARE Data wave 9.

This is less than what was observed in the US (Hale et al., 2020), even if not directly comparable. Indeed, the 6% prevalence estimated in the US include elderly people living in nursing homes or residential care facilities. We do not have such statistics in Germany, but several studies point out that around 70% of German living in nursing home suffer from dementia. Given that about 4% of the elderly people live in such facilities, it would lead to about 6% of severe cognitive impairment.

The distribution is slightly skewed, which is likely due to questions assessing executive functions, such as backward counting and subtraction. These tasks tend to affect individuals differently, particularly depending on their level of education (Pellicer-Espinosa and Díaz-Orueta, 2022). Figure 3b shows that the skew originates from the younger part of the sample. Looking at the 85+ part of the sample, we do observe a normal distribution (excluding the proxy interviews). This may originate from older Germans having rarely pursued higher education, or from our cognitive items suffering from too low of an upper bound on cognitive performances.

Limitation in Activities of Daily Living. Figure 4a shows the share of respondents unable to perform a certain number of ADLs, while Figure 4b presents the same data, grouped by age: 65 to 84 years and 85 years or older. As expected, a greater share of people without ADL limitations is found in the younger group. While 84.3% (weighted 83.57%) of the full sample reports no ADL limitations, more than 85.7% (weighted 85.3%) of respondents aged 65 to 84, and 69.6% (weighted 69.9%) of those aged 85 and older, report no limitations in ADLs.

Figure 4: Distribution of Activities of Daily Living (ADLs) Limitations



Note: These figures represent the distribution of the number of limitations in Activities of Daily Living (ADLs) among elderly Germans in 2022, broken down by age group. The confidence intervals are shown in red. We have not included the 83.57% of people with no ADL limitations, as it would make the figures harder to interpret.

Sample: German population aged 65 and over.

Data: SHARE Data wave 9.

Suffering from cognitive impairments can result in an inability to perform everyday tasks, such as those required for ADLs. Similarly, a loss of autonomy can negatively impact cognitive performances over time due to reduced activity. This relationship is illustrated in Table 2 among elderly German living at home, which shows the

interactions between cognitive impairment and ADL categories.⁸ The majority of the sample (66.37%) is both cognitively healthy and autonomous. The second-largest group (15.06%) consists of people with mild cognitive impairment (MCI) but no ADL limitations. The third and fourth groups represent cognitively healthy individuals with 1 and 2 or more ADL limitations, respectively, accounting for 5.85% and 3.80% of the sample. Among those suffering from severe cognitive impairment (SCI), including proxy responses, about half have no ADL limitations, while more than a third are in the group of people suffering from at least two ADL limitations.

Table 2: Joint Distribution of Cognition Score and ADL Limitations

ADL categories	1 Healthy	2 MCI	3 SCI	4 Proxy SCI	5 Proxy Healthy	Total
0 ADL	66.37	15.06	1.63	0.38	0.13	83.57
1 ADL	5.85	2.30	0.39	0.09	0.00	8.63
2+ ADL	3.80	2.49	0.36	1.03	0.11	7.80
Total	76.02	19.86	2.38	1.51	0.24	100.00
Observations	2,070					

Note: This table represents the share of Germans aged 65 and over living at home, given their situation in terms of Activities of Daily Living (ADL) limitations (no ADL, 1 ADL, 2 or more ADLs) and their cognitive situation (Severe Cognitive Impairment (score below 6), Mild Cognitive Impairment (score between 6 and 12), cognitively healthy, or had its cognitive questionnaire answered by a proxy, who reported them as healthy or suffering from cognitive impairments.

Sample: German population aged 65 and over.

Data: SHARE Data wave 9.

Health and Care by Impairments Groups. Health and long-term care use differ between healthy individuals (no SCI and no ADL), those with ADL limitations but no SCI, and individuals with SCI. The cognitive score for the group suffering SCI is 10.83 points lower than that among those without SCI (Column (5), Table 3). It is also noticeable that among individuals with no SCI, those with ADL limitations have on average a lower cognitive score (13.71) compared to those with no ADL (15.78) (Column (1) and (2), Table 3). Respondents without SCI also have on average 1.34 fewer ADL limitations than those with SCI. Similarly, they report 2.11 fewer IADL limitations (Column (5), Table 3). Overall, in 2022, 32% used any informal care and 16% of the weighted sample utilized any formal care (Column (6), Table 3). Limitations in ADL and IADL observed among individuals suffering from severe cognitive impairment (SCI) are reflected in differences in long-term care usage. Compared to individuals without SCI, those with SCI are 29 percentage points more likely to use any form of long-term care, 17 percentage points more likely to use informal care, and 32 percentage points more likely to use formal care (Table 3, Column (5)). The higher number of ADL limitations among SCI individuals compared to those without SCI helps explain these differences.

However, when we compare individuals with severe cognitive impairment (SCI) to those without SCI but with 2 or more ADLs (which is close to the average number of ADLs among SCI individuals), we find that individuals with SCI, on average, receive

⁸ Note that we present descriptive evidence that is consistent with the hypothesis. However, with the available data, it is not possible to establish causal relationships.

less care than those with 2 or more ADLs. As a result, individuals with ADL limitations are more likely to use care than those with SCI.

Almost 30% of individuals with severe cognitive impairment report not receiving any care (formal or informal). One could imagine unmet LTC needs for these individuals. Surprisingly, self-reported unmet needs include no individuals with SCI (see Appendix B). The result is still true when focusing on elderly individuals with ADLs.

Table 3: Cognition, Autonomy and Help by Impairments' Groups

	(1) No Severe Cognitive Impairment 0/IADL	(2) 2+ADLs	(3) All (1)&(2)	(4) SCI	(5) Mean Diff Mean Diff (4)-(3)	(6) Total Total (4)&(3)
Cognitive Score						
Cog. Score	15.78 (3.74)	13.71 (3.94)	15.65 (3.78)	4.79 (1.46)	-10.83***	15.39 (4.10)
Autonomy						
Nb of ADLs	0.09 (0.29)	2.83 (1.16)	0.27 (0.80)	1.61 (2.20)	1.34***	0.33 (0.93)
Nb of IADLs	0.18 (0.58)	2.21 (1.42)	0.31 (0.84)	2.41 (2.34)	2.11***	0.39 (1.02)
Care Received						
Any Care	0.34 (0.48)	0.76 (0.43)	0.37 (0.48)	0.68 (0.47)	0.29***	0.38 (0.49)
Received IC	0.29 (0.46)	0.60 (0.49)	0.31 (0.46)	0.49 (0.50)	0.17**	0.32 (0.47)
Received FC	0.12 (0.32)	0.57 (0.50)	0.15 (0.36)	0.47 (0.50)	0.32***	0.16 (0.37)
Weekly Hours of IC	4.25 (9.18)	25.39 (27.61)	5.66 (12.53)	10.20 (17.00)	5.92*	5.83 (12.75)
Weekly Hours of FC	6.63 (13.72)	7.43 (10.51)	6.86 (12.84)	11.98 (20.35)	6.06	7.53 (14.09)
Monthly Hours of IC	16.99 (36.73)	101.55 (110.42)	22.62 (50.10)	40.79 (67.99)	23.70*	23.33 (51.01)
Monthly Hours of FC	26.52 (54.86)	29.71 (42.04)	27.46 (51.36)	47.91 (81.39)	24.24	30.11 (56.34)
Observations	1,871	127	1,998	72		2,070

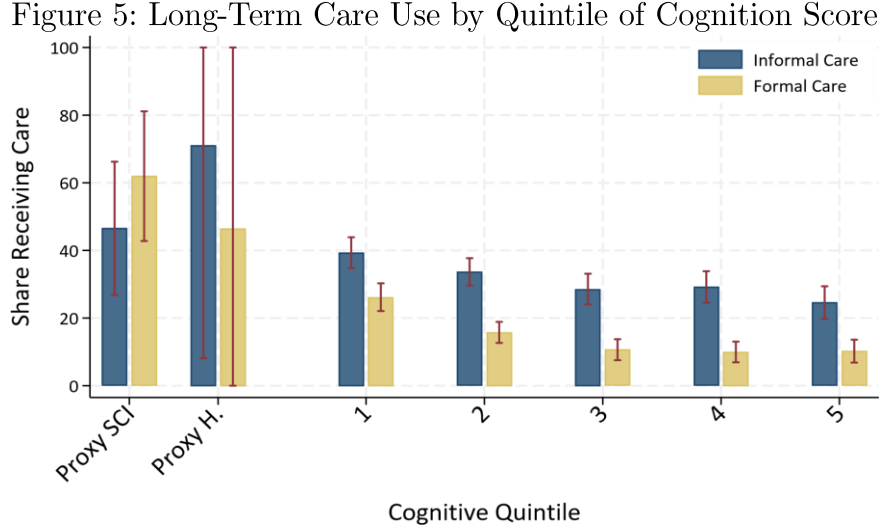
Note: This table presents the average and standard deviation (in parentheses) of the cognitive score, autonomy levels, and use of formal care (FC) and informal care (IC) among three groups: (1) individuals with no severe cognitive impairments and no severe ADL limitations (cognitive score > 6 and 0 or 1 ADL limitation); (2) individuals with no severe cognitive impairments but suffering from ADL limitations (cognitive score > 6 and 2+ ADLs); (3) an aggregate of the two previous groups, representing the 'no SCI' group; and (4) respondents suffering from severe cognitive impairments (cognitive score ≤ 6). The significance of the mean differences between individuals with no SCI and those with SCI is assessed using t-tests.

Sample: German population aged 65 and over.

Data: SHARE Data wave 9.

When examining the hours of care received, respondents with SCI use on average 5.92 additional hours of informal care per week and 6.06 additional hours of formal care than individuals with no SCI (Column (5), Table 3). It is noteworthy that individuals with ADL limitations consume less hours of formal care than individuals with SCIs but remarkably more informal care. On average, those with ADL limitations receive more than twice the amount of informal care each week compared to respondents with SCIs.

Formal and Informal care Use by Cognitive Score. The use of care – whether formal or informal – appears to be correlated with cognitive performances (Figure 5). Around 40% of people in the lowest cognitive quintile used informal care, while this share decreases and stabilizes at about 30% or less for individuals in higher cognitive quintiles.



Note: This figure represents the share of Germans aged 65 and over who receive either informal or formal care, based on their position within the cognitive quintile distribution. The first quintile represents the 20% with the lowest cognitive scores. Confidence intervals are displayed in red. Proxy respondents are shown at the left of the distribution, representing individuals who were unable to complete the cognitive test themselves. Based on their proxy's responses, these individuals were classified as suffering from severe cognitive impairments (poor or declining memory) and are included in the Proxy-SCI category. If the proxy indicated no cognitive impairment, the individual was classified in the Proxy-H category (healthy category).

Sample: German population aged 65 and over.

Data: SHARE Data wave 9.

Similarly, approximately 25% of people in the lowest quintile of cognitive scores utilized formal care, with this share decreasing as cognitive performance improves. In contrast, only about 10% of individuals in the highest quintile used formal care.

Demographics. We further compare economics and demographics characteristics among elderly individuals with and without severe cognitive impairment (Table 4), separating those without SCI into those with no ADL limitations (Column 1) and those with ADL limitations (Column 2).

As expected, the group suffering cognitive impairments is on average 6.30 years older than those without SCI (Column (5), Table 4). Additionally, the SCI group is on average less educated and 4 percentage points less likely to still be employed. These differences can likely be attributed to younger cohorts remaining in the workforce and benefiting from longer education. Finally, those with SCI have on average 167,590 euros less wealth and 7,780 euros less yearly income. These disparities align with the higher likelihood of working and having received more education among those with no SCI.

Table 4: Demographic Characteristics by Cognitive Impairments or ADL Limitations

	(1)	(2)	(3)	(4)	(5)	(6)
	No Severe Cognitive Impairment			SCI		
	0/1 ADL	2+ ADLs	All (1) & (2)		Mean Diff (4) - (3)	Total (4) & (3)
Demographics						
Age	75.30 (7.00)	79.11 (7.58)	75.55 (7.10)	82.22 (7.03)	6.30***	75.81 (7.21)
Female	0.56 (0.50)	0.53 (0.50)	0.56 (0.50)	0.51 (0.50)	-0.11	0.56 (0.50)
Family						
Living as Couple	0.61 (0.49)	0.48 (0.50)	0.61 (0.49)	0.51 (0.50)	-0.08	0.60 (0.49)
Any Children	0.90 (0.30)	0.90 (0.30)	0.90 (0.30)	0.89 (0.32)	-0.02	0.90 (0.30)
Number of Children	2.00 (1.18)	2.09 (1.20)	2.01 (1.18)	2.15 (1.30)	0.09	2.01 (1.19)
Education						
Less than Highschool	0.10 (0.31)	0.17 (0.38)	0.11 (0.31)	0.34 (0.48)	0.17**	0.12 (0.32)
Highschool Grad	0.51 (0.50)	0.46 (0.50)	0.51 (0.50)	0.51 (0.50)	0.05	0.51 (0.50)
Some College	0.39 (0.49)	0.37 (0.49)	0.38 (0.49)	0.15 (0.36)	-0.23***	0.38 (0.48)
Labour & Wealth						
Works (1/0)	0.04 (0.19)	0.00 (0.00)	0.04 (0.19)	0.00 (0.00)	-0.04***	0.03 (0.18)
Tot. HH Income (k €)	38.86 (21.99)	30.97 (15.21)	38.34 (21.69)	30.36 (15.64)	-7.78***	38.03 (21.54)
HH net Worth (k €)	350.41 (443.69)	200.77 (333.90)	340.44 (438.76)	175.37 (217.35)	-167.59***	334.02 (433.42)
Observations	1,871	127	1,998	72	2,070	2,070

Note: This table presents the average and standard deviation (in parentheses) of socio-demographic characteristics of German elderly individuals in 2022, categorized by their health status: Column (1): Healthy individuals (cognitive score > 6 and no more than one ADL limitation). Column (2): individuals with ADL limitations (2+ ADL limitations). Column (3): The combined group of the two previous categories (“no severe cognitive impairment” or “no SCI”). Column (4): People suffering severe cognitive impairments individuals cognitive score ≤ 6). HH stands for household. The significance of the mean differences between individuals with no SCI and those with SCI is assessed using t-tests. Monthly values for formal and informal care are directly derived from weekly values.

Sample: German population aged 65 and over.

Data: SHARE Data wave 9.

5 Main Results

Association between Care Use and Cognitive Impairments. An individual’s reception of care may be influenced by multiple factors. Therefore, to better understand the association between cognitive impairments and LTC, we use the OLS regression:

$$LTC = a + \beta_1 SCI + \beta_2 ADL + \beta_3 (SCI \times ADL) + \gamma X + \varepsilon \quad (1)$$

LTC represents our outcomes of interest. We examine three different outcomes: receiving any form of long-term care (Table 5), receiving informal care (Tables 6 and 7), and receiving formal care (Tables 8 and 9). The variable *SCI* is a binary indicator, equal to one if the respondent suffers from severe cognitive impairment (i.e., a cognitive score below 6). The most basic specification controls only for having 2 or more ADLs and an interaction variable between *SCI* and *ADL*. In a second specification, we add age as a control variable. The third specification includes additional controls for gender, marital status, children, household income, wealth, and education.

Receiving any Care. Table 5 shows the probability of receiving any form of care among the German elderly living at home, estimated using a linear probability model. As observed previously, both *ADL* and cognitive limitations are significantly associated with an increased likelihood of receiving care. However, once we control for age, correlation between *SCI* and long-term care use disappears. In our preferred specification (column 3), having 2 or more *ADL*s is associated with a 33.2 percentage point higher likelihood of receiving any care. Suffering cognitive impairments is not significantly associated with the likelihood of receiving care, nor the cumulation of *SCI*s and *ADL*s. Note that we also find the impact of *SCI* on care reception to be significant when using the alternative threshold, possibly due to greater sample size (Appendix A).

Table 5: Association between *SCI* and Any Long-Term Care Use

	1	2	3
<i>SCI</i>	0.207*** (2.65)	0.0872 (1.08)	0.0736 (0.95)
<i>ADL</i>	0.419*** (10.11)	0.344*** (8.37)	0.332*** (8.12)
<i>SCI</i> x <i>ADL</i>	-0.0476 (-0.48)	-0.0264 (-0.26)	-0.00000358 (-0.00)
Age		-0.0426 (-1.52)	-0.0287 (-0.99)
Female			0.0835** (2.15)
Living as Couple			-0.102*** (-2.93)
Female x Couple			-0.00550 (-0.12)
Additional Controls			X
Observations	2,070	2,070	2,070

t statistics in parentheses

* $p < .10$, ** $p < .05$, *** $p < .01$

Note: This table presents the regression coefficients from three OLS regressions examining the relationship between individual socio-economic characteristics and the probability of using formal or informal care. Specification (3) controls for age (and its square), having and number of children, total household income and net worth, and education. The coefficients for these variables are small and non-significant.

Sample: German population aged 65 and over living at home.

Data: SHARE Data wave 9.

Table 6: Association between SCI and Probability to Report any Informal Care Use

	1	2	3
SCI	0.196** (2.47)	0.0996 (1.23)	0.0833 (1.09)
ADL	0.306*** (6.55)	0.245*** (5.38)	0.235*** (5.14)
SCI x ADL	-0.316** (-2.30)	-0.298** (-2.17)	-0.271** (-1.99)
Age		-0.0295 (-0.93)	-0.0170 (-0.52)
Female			0.105*** (2.62)
Living as Couple			-0.0659* (-1.88)
Female x Couple			-0.0763* (-1.66)
Additional Controls			X
Observations	2,070	2,070	2,070

t statistics in parentheses

* $p < .10$, ** $p < .05$, *** $p < .01$

Note: This table presents the regression coefficients from three OLS regressions examining the association between socio-economic characteristics and the probability of using informal care. Specification (3) controls for age (squared), having children and the number of children, total household income, household net worth, and education. The coefficients for these variables are small and not statistically significant.

Sample: German population aged 65 and over.

Data: SHARE Data wave 9.

Table 7: Association between SCI and Informal Care Hours

	1	2	3
SCI	-0.396 (-0.15)	-0.743 (-0.27)	-2.147 (-0.72)
ADL	27.85*** (10.14)	27.32*** (10.02)	26.88*** (9.84)
SCI x ADL	-8.334 (-1.13)	-8.541 (-1.18)	-7.895 (-1.07)
Age		3.639** (2.14)	3.587** (2.10)
Female			-2.456 (-1.04)
Living as Couple			-0.161 (-0.07)
Female x Couple			1.684 (0.60)
Tot. HH Income (thousands)			0.0210 (0.54)
HH net Worth (thousands)			-0.00256* (-1.90)
Additional Controls			X
Observations	614	614	614

t statistics in parentheses

* $p < .10$, ** $p < .05$, *** $p < .01$

Note: This table presents the regression coefficients from three OLS regressions examining the association between socio-economic characteristics and weekly hours of informal care reported. Specification (3) controls for age (squared), gender crossed with marital status, having children and the number of children, and education. The coefficients for these variables are small and not statistically significant. “HH” refers to household.

Sample: German population aged 65 and over.

Data: SHARE Data wave 9.

Receiving Formal Care. Both having ADL limitations and severe cognitive impairments are associated with a significant higher likelihood of receiving formal care in the first configuration (Table 8). These effects remain important even after adding controls but the SCI effect loses significance. In our preferred specification (column 3), having limitation with ADLs is associated with a 38.5 percentage points higher likelihood of receiving formal care, and suffering from SCI may be associated with a 10.8 percentage points higher likelihood of receiving formal care, but fails to be significant at 10%. There is no cumulative effect of suffering from SCI and having ADLs.

Table 9 shows that without controlling for socio-demographics characteristics, ADL limitations and cognitive impairments are not associated with a greater weekly hours of formal care received among those receiving formal care, but the cumulation of SCI and ADLs leads to a significantly greater number of weekly hours (13.09 hours with no controls, 12.42 with age controlled). This effect vanishes when control variables are added, due possibly to the small sample size.

6 Costs of Care for SCI

ADLs limitation is a better predictor of long-term care use than SCI. Thus, compared to individuals with no SCI, elderly individuals with SCI living at home, other things being equal, are more likely to use formal care, but no significant differences are observed in the number of hours used. Cost associated with this difference in long-term care arrangement is an important information in term of public policies. Thus, in this section, we assess the cost of care for individuals with SCI. Having estimation of this cost is important to help policymakers favor cost-effective plans for future care needs.

We estimate the potential annual cost of long-term care by impairment status to have an approximation of the cost of impairments, particularly severe cognitive impairments, for elderly people.

Method for Cost Estimation. We use the mean cost of an hour of paid at-home care as a reference of hourly care wage. Thus, we value the care wage at a value of EUR 16 per hour of care (Geyer et al., 2023). We then sum these costs using our analytic weights, separately for each groups, namely, healthy individuals, people suffering from ADLs and people suffering from SCIs.

Following the method proposed by Gruber et al. (2023), we consider the value of care as the opportunity cost of the carer providing time to help a relative rather than engaging in other activities. Since carers' wages are not available in SHARE data, we impute their wages. Carers' time is valued at their imputed hourly wage if it exceeds the care wage or at the care wage if they are either not working or earning a lower hourly wage. Hourly wages were imputed based on carers' marital status, age, and level

Table 8: Association between SCI and Probability of Formal Care Use

	1	2	3
SCI	0.199*** (2.64)	0.109 (1.44)	0.108 (1.46)
ADL	0.447*** (9.55)	0.390*** (8.31)	0.385*** (8.28)
SCI x ADL	-0.0230 (-0.19)	-0.0117 (-0.09)	0.000675 (0.01)
Age		-0.0624** (-2.07)	-0.0504* (-1.67)
Female			0.0284 (0.89)
Living as Couple			-0.0858*** (-3.20)
Female x Couple			0.0608* (1.70)
Additional Controls			X
Observations	2,070	2,070	2,070

t statistics in parentheses

* $p < .10$, ** $p < .05$, *** $p < .01$

Note: This Table shows the regression coefficients of three OLS regressions on the association between socio-economics characteristics and probability of using formal care. Specification (3) includes control for age (squared), gender cross married, having children and number of children, total household income and household net worth and education. Coefficient are small and non-significant for these variables.

Sample: German population aged 65 and over.

Data: SHARE Data wave 9.

Table 9: Association between SCI and Formal Care Hours

	1	2	3
SCI	-2.699 (-1.31)	-2.899 (-0.95)	-1.398 (-0.44)
ADL	0.797 (0.41)	1.113 (0.56)	2.002 (0.92)
SCI x ADL	13.09** (2.12)	12.42* (1.94)	10.61 (1.62)
Age		-6.985** (-2.20)	-6.118* (-1.95)
Female			-1.290 (-0.41)
Living as Couple			-3.805 (-1.11)
Female x Couple			2.098 (0.51)
Tot. HH Income (thousands)			0.150 (1.41)
HH net Worth (thousands)			-0.00250 (-0.79)
Additional Controls			X
Observations	229	229	229

t statistics in parentheses

* $p < .10$, ** $p < .05$, *** $p < .01$

Note: This Table shows the regression coefficients of three OLS regressions on the association between socio-economics characteristics and weekly hours of formal care reported. Specification (3) includes control for age (squared), gender cross married, having children and number of children, and education. Coefficient are small and non-significant for these variables. HH means household.

Sample: German population aged 65 and over.

Data: SHARE Data wave 9.

of education, grouped by gender, using data from the Socio-Economic Panel Study (SOEP)⁹ as in Geyer et al. (2023). Information on carers' working status is available for the respondent, their partner, and their children. Thus, other carers' wages were considered equivalent to the care wage. Lastly, while respondents may receive help from multiple carers, we impute only one carer wage per respondent, representing their primary carer—the one providing assistance most frequently. Using this estimated cost of one hour of informal care, we multiply it by the number of care hours received and sum them across three impairment groups: those with no SCI and less than one ADL; those with no SCI and 2 ADLs or more; those with SCI.

Estimated costs of care Table 10 summarizes the total and per capita costs of care for each of our three impairment categories for elderly people living at home, and for people living in nursing home, with no detail by impairment categories (Geyer et al., 2023; Federal Statistical Office, Destatis). We find that caring for the elderly people living at home represents a total cost of 104 billion euros every year (Column (5)), with informal care representing 86% of these costs. This implies that representing the situation only through formal assistance would lead to severe underestimation of the burden the phenomenon represents.

We observe that among people living at home, cost of formal care of those suffering from SCI is 6 times larger than the cost of those with no SCI (column (3) and (4)). Moreover, people with SCI experience a cost of formal care 1.4 times higher than people with no SCI and having 2+ADLs limitations consume (column (2) and (4)). Since average cost of nursing home is close to two thousand euros in Germany (Geraedts et al., 2016), nursing home cost is higher per capita than at home care. In addition, we know that more than half of the nursing home residents in Germany suffer from SCI (Schäufele et al., 2013). Thus, The difference in cost that we observe between those having ADLs limitations and those having SCI would be higher if we would have included elderly people living in nursing home and not only those living at home.

Lastly, one may notice that, among elderly individuals living at home, informal care used by people with no SCI and having ADLs limitations is 3.4 times larger than among those with SCI (column (2) and (4)). It may reflect the fact that when informal care for people suffering from SCI turns to be very high, the family prefer to opt for nursing home care instead of at home care.

⁹ The SOEP data is a longitudinal household survey conducted in Germany that collects detailed data on various socio-economic aspects such as income, employment, health, and family dynamics (Goebel et al., 2024). Running since 1984, it provides a representative sample of German households, facilitating long-term socio-economic analysis. The survey is widely used in social sciences and policy research. For more information, see Goebel et al. (2019).

Table 10: Estimated Annual Costs of Care by Cognition Status

	(1)	(2)	(3)	(4)	(5)	(6)
	No SCI			SCI		
	0 or 1 ADL	2+ ADLs	All	SCI	Total	<i>NursingHome</i> ¹
Demographics						
Sample	1,871	127	1,998	72	2,070	
Population (in thousands)	16,722	1,135	17,856	644	18,500	703
Formal Care						
Per Capita Cost of Formal Care (in €)	510	2,924	663	4,123	784	44,097
(in \$ ²)	537	3,079	698	4,341	825	46,434
Total Cost of Formal Care (in m€)	8,526	3,319	11,845	2,653	14,498	31,000
in % of <i>GDP</i> ³	0.20	0.08	0.28	0.06	0.34	
(in m\$ ²)	8,978	3,495	12,472	2,794	15,266	32,643
Informal Care						
Per Capita Cost of Informal Care (in €)	3,649	21,473	4,782	6,261	4,834	
(in \$ ²)	3,842	22,611	5,035	6,593	5,090	
Total Cost of Informal Care (in m€)	61,023	24,372	85,396	4,029	89,424	
in % of <i>GDP</i> ³	1.43	0.57	2.00	0.09	2.09	
(in m\$ ²)	64,257	25,664	89,921	4,242	94,163	
Long Term Care : (FC + IC)						
Per Capita Cost of Care (in €)	4,159	24,397	5,446	10,384	5,617	
(in \$)	4,379	25,690	5,735	10,934	5,915	
Total Cost of Care (in m€)	69,549	27,691	97,240	6,682	103,922	
in % of <i>GDP</i> ³	1.63	0.65	2.27	0.16	2.43	
(in m\$ ²)	73,235	29,159	102,393	7,036	109,430	

Note: This Table represents the estimated costs of formal and care of the German elderly people in 2022. The population is divided between healthy people, people suffering from two or more ADLs limitations but not from SCI, and people suffering from SCI. Column (3) is contains all and exclusively individuals from column (1) and (2) Formal care costs are devised by multiplying the average number of hours of formal care received in a year by someone in a given group by a “care wage”. Informal care costs are devised by multiplying the average number of hours of informal care received in a year by someone in a given group either by a “care wage” or the hourly wage forgone by carers. These per capita costs are then multiplied by the number of people fitting these categories within the 65+ German population.

¹ Nursing homes’ estimations came from Geyer et al. (2023).

² Average euro to dollar exchange rate in 2022 according to the [European Central Bank](#) : 1€ = 1.0530\$

³ Germany’s GDP in 2022 in 2022 US dollar: 4.5 trillion dollars (GDP from [World Bank data](#) & Inflation Adjustments from the [Bureau of Labor Statistics](#)).

Sample: German population aged 65 and over.

Data: SHARE Data wave 9.

Note that all the cost per capita computed are an average of individuals with needs and benefiting from help, and individuals with the same needs but not having any needs. Appendix C provides additional computation of cost, focusing only on individuals receiving care. These number provide an idea of what would be the cost is no one would have forgone LTC. It shows a 30% greater cost per capita for people suffering from SCI and a three times greater cost among those not suffering from SCI.

7 Conclusion

Germany experiences an unprecedented increase in LTC recipients. Part of it is due to reforms which made LTC benefits easier accessible for individuals with cognitive impairments. The other reason is the general demographic change and Germany’s ageing population. Demand for LTC is expected to increase and once the baby-boomers

will reach the age of dependency, Germany will face even more challenges regarding financing of long-term care needs.

Previous studies document the cost of long-term care, how it evolves with ageing population, and the challenges that it raises (Geyer et al. 2023). However, less is known about the specific case of elderly people suffering from cognitive impairment.

Disease-related cognitive and motor decline, as well as behavioral changes, reduce the ability to live independently. They lead to three types of cost: psychological, social and economic. Psychological and social costs include social exclusion and stigmatization, burden and stress for the person suffering from such diseases and his relatives. These costs are difficult to measure and out of the scope of this paper. Economic costs, however, include the extensive medical; nursing care as well as at-home long-term care required for people suffering from cognitive impairment. Measuring these economic cost is the goal of this study.

We use the European survey SHARE, wave 9, to measure the prevalence of cognitive impairment in Germany, defined using Langa et al. (2017). We observe 4% of elderly people living at home with severe cognitive impairment. These individuals are 30% more likely to receive any care, and when they receive any, they receive on average 6 more hours of formal care and 6 more hours of informal care per week.

When analyzing the drivers of this greater use of long-term care for people having SCI, one can observe that the main driver is not the cognitive impairment *per-se* but the limitation in activities of daily living it leads to. Thus, once controlling for ADLs, SCI does not explain any additional probability to use formal or informal care. However, because people with SCI are more likely to have ADLs, the annual cost of their care is estimated to 10,000 euros per year per individual on average, while 5,000 euros for elderly people not suffering from SCI.

Note that this study excludes individuals living in nursing home, who have a higher prevalence of SCI, and greater care needs. We estimate that these individuals experience an annual cost of long-term care around 44,000 euros per capita per year. While the data available improve the understanding regarding ageing and cognitive decline, there is still need for more data and better information. In particular, comprehensive data on nursing home residents is missing, and it is necessary to perform imputations regarding informal care hours.

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