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DISCUSSION PAPER SERIES

IZA DP No. 17777

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ABSTRACT

Absence of Care Among Community-Living Older Persons with Dementia and Disabilities: A Cross-National Analysis of Population Survey from 22 Countries

Assistance with daily activities is crucial for persons living with dementia and disabilities, yet many face significant challenges in accessing adequate care and support. Using harmonized longitudinal survey data (2012-2018) from the United States, England, 18 European countries and Israel, and China, we found that at least one-fifth of persons with dementia and disabilities received no personal assistance for basic or instrumental activities of daily living (ADL/IADL), regardless of regional development level. Care gaps were widespread across both ADL and IADL limitations, as well as for informal and formal care. Disparities were evident, with less-educated individuals more likely to lack formal care, while those living alone often lacked informal support, resulting in the absence of any care. Alarmingly, care availability showed no improvement over time. Our findings underscore the urgent need for policies to address inequities and ensure critical access to care services for this vulnerable population worldwide.

JEL Classification: J14, J18, I11, I18

Keywords: global aging, dementia, disability, ADL, IADL, unmet need, elder care

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1. Introduction

The World Health Organization (WHO) estimates that 16% of the global population experiences disabilities, with many facing disabilities that significantly impact daily activities, particularly pronounced among older adults.[1,2] This growing prevalence imposes a substantial caregiving demand, especially in developing nations.[1,2] As populations age, the need for long-term care has become a pressing public health challenge, with projections indicating a quadrupling of older persons unable to care for themselves by 2050, potentially causing profound societal impacts.[3]

The burden of disability is especially acute for people living with dementia (PLWD), who often experience severe disabilities.[4,5] In 2022, over 55 million people globally were living with dementia, a figure projected to rise to 139 million by 2050.[6] Due to prolonged illness, PLWD often endure years of disability and dependence,[4,5,7] with financial burden and caring costs exceeding 1.3 trillion U.S. dollars annually worldwide.[4,8] These individuals face significantly greater caregiving needs and healthcare costs than those with other conditions, such as heart disease or cancer,[9,10] and many community-dwelling PLWD, particularly those living alone, encounter considerable challenge in accessing essential care services.[11,12]

Despite the critical need for caregiving, global patterns of care received by PLWD with disabilities remain poorly understood.[13] A lack of care can lead to avoidable hospitalization, early institutionalization, increased mortality, higher societal costs, and reduced quality of life.[14–17] Variations across time and countries further complicate generalizations about caregiving trends. Identifying these trends is essential to inform effective public policies and interventions for this vulnerable population.

This study leverages population-based longitudinal survey data from the United States (Health and Retirement Study [HRS, 2012-2018]), England (English Longitudinal Study of Ageing [ELSA, 2012-2018]), 18 European countries and Israel (Survey of Health, Ageing and Retirement in Europe [SHARE, 2013-2017]), and China (China Health and Retirement Longitudinal Study [CHARLS, 2013-2018]) to examine global trends in caregiving gaps among PLWD with disabilities, as measured by basic (ADL) or instrumental activities of daily living (IADL). We hypothesized that: 1) a significant proportion of PLWD receive no care for their disabilities, with little change over time; 2) PLWD with limited economic resources are less likely to receive formal care; 3) PLWD with limited access to care resources (e.g., lower socioeconomic status, living alone) are more likely to report ADL/IADL limitations without receiving any care.

2. Findings

2.1 Sample Characteristics

Table 1 summarizes the sample characteristics of individuals with disabilities who developed dementia (i.e., *Dementia Sample*) during the study period (see Extended Data Fig. 1 for study periods and sample selection). The average age (SD) ranged from 68.8 (9.1) years in CHARLS to 78.7 (9.4) years in SHARE. Sociodemographic differences were notable, with ELSA having the highest proportion of person-waves living alone (42.2%), and CHARLS the lowest (10.2%). Secondary education and above was most prevalent in HRS (44.3%) and least in CHARLS (5.5%).

The extent of ADL/IADL limitations and absence of care varied across countries/regions but followed common patterns. On average, participants reported 3.3-4.0 ADL/IADL limitations, with limitations increasing over time (Table 1 and Extended Data Fig. 2). Significant increases were observed across most countries and regions.

The prevalence of receiving no care for ADL/IADL limitations was high, ranging from 21.4% in the HRS to 32.7% in CHARLS. The absence of care was more pronounced for ADLs than for IADLs. Notably, 48.5% of person-waves in ELSA and 63.1% in CHARLS received no care at all for ADLs. Similarly, more than a third of HRS (39.0%) and SHARE (38.4%) reported receiving no care for ADLs. When examining the types of care, the prevalence of receiving no formal care for ADL/IADL limitations was notably higher, ranging from 58.5% in SHARE to 99.1% in CHARLS, compared to no informal care, which ranged from 24.1% in HRS to 33.7% in CHARLS. The patterns were consistent across ADLs and IADLs (**Table 1**).

2.2 Trends in the Absence of Care

Fig. 1 shows the proportion of sample with dementia who received no care for their ADL/IADL limitations over time estimated using Generalized Estimating Equations (GEE) model, stratified by country/region, type of limitation, and care type. Overall, these proportions remained stable, with at least 20% of PLWD receiving no care at all for their ADL/IADL limitations (Fig. 1a). Care gaps were more pronounced for ADLs, with 35%-67% of sample receiving no care (Fig. 1d), compared to 8%-23% for IADLs (Fig. 1g).

The absence of formal care was consistently higher than informal care (Fig. 1b vs Fig. 1c, Fig. 1e vs Fig. 1f, and Fig. 1h vs Fig. 1i). Around 24%-35% of PLWD received no informal care for their ADL/IADLs (Fig. 1b), while the proportion receiving no formal care ranged from 58% in SHARE to nearly 100% in CHARLS (Fig. 1c). Across all four countries/regions, these proportions showed minimal change over time. Sensitivity analyses confirmed the robustness of these findings (Extended Data Figs. 3 and 4).

Among PLWD with more severe disabilities (two or more ADLs or IADLs), the absence of care remained substantial, with no improvement over time (Extended Data Fig. 5). Between 10%-21% received no care for their limitations (Fig. 1a), and 20-53% received no care for ADLs (Fig. 1d), reflecting slightly better but still inadequate care for this subgroup.

2.3 Absence of Care by Education and Living Arrangement

Our further analyses using GEE models revealed significant disparities in care based on education (less vs. more educated) and living arrangement (living alone vs. not living alone). Fig. 2 illustrates that less-educated individuals were more likely to lack formal care compared to their more-educated counterparts, with differences ranging from 1-2% in CHARLS to 16-18% in SHARE (Figs. 2c, 2f, 2i). Differences in informal care were less pronounced, though in ELSA, less-educated individuals were slightly less likely to lack informal care (Figs. 2b, 2e, 2h). Overall, care gaps were more severe among less-educated individuals in CHARLS but similar across education groups in HRS and SHARE (Figs. 2a, 2d, 2g).

Fig. 3 shows that individuals living alone experienced significantly larger gaps in informal care compared to those living with others, with differences ranging from 4%-29% (Figs. 3b, 3e and 3h). Although the absence of formal care was generally lower among those living alone, particularly in HRS, ELSA, and SHARE (Figs. 3c, 3f and 3i), the overall absence of care for ADL/IADL limitations was still higher in this group (Figs. 3a, 3d and 3g). These patterns were consistent across both ADL and IADL limitations, with notable gaps in HRS, ELSA and CHARLS, where the overall care gap reached as high as 22% (Figs. 3a, 3d and 3g).

2.4 Supplementary Results: Patterns among Non-Dementia Sample

Lastly, we conducted analyses on individuals with disabilities who never developed dementia (i.e., *Non-Dementia Sample*) to compare them with *Dementia Sample*. The two groups differ markedly in sociodemographic characteristics, disabilities, care burden, and the absence of care.

The *Non-Dementia Sample* was generally younger, more likely to live with others, and had higher levels of education compared to the *Dementia Sample* (Supplementary Table 1). They reported fewer ADL/IADL limitations, and the increase in disabilities over time was relatively modest (Extended Data Fig. 6).

Consistent with our main findings, the absence of care over time showed no improvement for the *Non-Dementia Sample* (Extended Data Fig. 7). Approximately 40% of this group received no care for their ADL/IADL limitations, despite having fewer limitations than the *Dementia Sample*. The care gap was particularly pronounced for ADLs compared to IADLs, and for formal care compared to informal care.

3. Discussion

Using harmonized longitudinal survey data from the United States (HRS), England (ELSA), European countries and Israel (SHARE), and China (CHARLS), we provide the first comparative evidence on global trends in the absence of care for PLWD with disabilities. Our findings highlight two critical issues: first, at least 1 in 5 PLWD across both developing and developed countries received no care for their ADL/IADL limitations; and second, this absence of care has not improved over time. This pattern is consistent across ADL and IADL limitations, and applies to both informal and formal care. Alarmingly, about 2 in 5 PLWD received no informal care for their ADL limitations, and at least 3 in 5 (nearly 100% in China) received no formal care. These findings underscore a significant gap in care provision for vulnerable populations worldwide, particularly for PLWD who are less educated or live alone.

The persistent caregiving gap for PLWD with disabilities is particularly concerning, given the increase of ADL/IADL limitations in this population. The lack of care is linked to adverse outcomes such as anxiety, depression, increased emergency room visits, hospitalizations, nursing home admissions, and even premature death.[18–20] PLWD are especially dependent on caregivers due to their heightened care needs, making them highly vulnerable to these negative outcomes when care is absent.[21] Notably, even among PLWD with multiple ADL or IADL limitations and more severe care needs, a significant caregiving gap persists, with no evidence of improvement over time. The growing trend in disabilities, paired with stagnant caregiving availability and resources, underscores the urgent need to address these gaps.

Our findings also reveal a greater absence of formal care compared to informal care for PLWD across countries and regions. While informal care remains the primary source of support and is often viewed as a substitute for formal care, the need for professional services is critical. Paid caregivers and institutional care can address the complex medical and support needs of PLWD while reducing the caregiving burden on families. A balanced integration of formal and informal care is essential to improving health outcomes for both PLWD and their caregivers, highlighting the importance of expanding access to professional care services.[22–24]

However, without sufficient public support, the cost of formal care often exceeds the financial means of older adults. Public spending on long-term care (LTC) varies widely across countries, with China having the lowest share, followed by the U.S. and England, while most European countries allocate a higher proportion to LTC.[25] In the U.S., the majority of home care is informal, provided by families and friends. Medicare covers only short-term, medically necessary home-based services, while Medicaid provides home health care to a limited, low-income, and vulnerable population.[26] In contrast, England and some European countries have adopted innovative care models that shift from nursing-homes to a home-based approaches.[22] For example, England's "extra care housing" offers 24-hour support and communal spaces, combining nursing home-level care with the comfort of living at home.[22] These models aim to make formal care more accessible and improve quality of life for PLWD. However, our findings indicate that the formal care gaps have not significantly improved in England or other European countries studied. Future research is needed to investigate these gaps and assess the effectiveness of home-based care models in addressing the needs of PLWD.

Our findings suggest that LTC systems in both developing and developed countries lack the capacity to meet the care needs of vulnerable populations, particularly PLWD. However, cross-national and regional comparisons should be interpreted cautiously, as care gaps are influenced by factors such as population aging, chronic disease burden, geographical proximity of caregivers, familial structures, cultural stigma, and variations in social cohesion.[13,27–29] Country-specific policies also play a significant role in shaping the accessibility, affordability, and quality of formal care.

In the U.S., Medicare covers healthcare for older adults but offers limited LTC coverage, leaving many PLWD with unmet needs.[30] Workforce shortages in nursing homes, home health, and personal care services, exacerbate the issue, while the absence of nationwide paid leave policies further burdens working caregivers.[26] In England and other European countries, broader public LTC services exist but still fails to provide adequate specialized care for PLWD.[31] England, for example, has a higher proportion of absent formal care compared to other European nations, partly due to its reliance on informal care in planning formal services. By contrast, countries like France implement "carer blind" assessments, which focus solely on formal care needs, independent of available informal support.[25,32,33]

In China, formal care gaps are particularly severe, with nearly 100% lacking access to formal care. This reflects the early-stage development of China's LTC system, which faces challenges such as facility shortages, workforce deficits, limited public funding, and the deeply rooted culture norms like filial piety.[34] Many adult children hesitate to use professional LTC services due to social stigma, which further suppresses demand for formal care and hinder its development.[35] While pilot LTC programs launched in 2016 and the recent emergence of community elderly day care centers offer some promises, these developments remain insufficient, compounded by a lack of policies addressing the specific needs of PLWD, such as financial support and dementia-specific care.[36,37] Traditional preferences for aging in place and affordability concerns exacerbate these challenges, while the provision of some LTC services in hospitals may inflate the observed care gap.[38] Further research should explore how innovative models, such as community day care centers, can close this gap and better meet the growing needs of PLWD.

Moreover, our study highlights a greater absence of care for ADLs compared to IADLs among PLWD, aligning with previous findings from older populations in countries like U.S., England, and China[39–41]. Caregivers often face significant challenges in providing personal and mobility-related care (i.e., ADLs), which requires intensive physical and emotional effort.[36,41] To address this, policy interventions and public programs, such as workforce training and caregiver support initiatives, should prioritize resources to help caregivers meet the basic care needs of PLWD.

Importantly, our findings reveal that PLWD with lower educational attainment face greater gaps in formal care, while those living alone experience larger deficits in informal and overall care. These individuals likely have the highest care needs,[42,43] but are also the least equipped to afford the necessary support. Policymakers must focus on closing these care gaps by expanding access to LTC services, increasing the range of affordable care options, and empowering PLWD to make informed decisions about their care. Addressing these disparities is critical to ensuring equitable and adequate care for the most vulnerable populations.

Contributions

This study advances the literature on caregiving for PLWD by offering a comprehensive, comparative analysis across multiple national contexts. Unlike prior research, which often focuses on individual countries or general caregiving practices, our work emphasizes the global nature of care deficits faced by PLWD. We identify common patterns in care absence by types of care, disabilities, and sociodemographic status. Additionally, our country-specific analyses shed light on diverse strategies and outcomes, highlighting opportunities for cross-national learning and policy innovation to address care gaps and improve outcomes.

Limitations

A key limitation of the study is the use of a relatively low threshold for defining caregiving need, defined as “any” difficulty with activities of daily living. While the number of limitations serves as a proxy for need, it may not fully capture the severity of these difficulties, raising questions about whether the observed care gaps reflect true unmet needs or cases where caregiving is less critical. Nevertheless, the consistency of caregiving challenges and disparities across countries and regions suggests that these gaps are persistent, regardless of how need is defined or interpreted. Future research should adopt more nuanced measures of difficulty severity to better distinguish actual unmet needs from situations where caregiving might not be necessary.

Additional limitations include reliance on self-reported and proxy-reported measures of ADL/IADL limitations, which may introduce reporting inaccuracies regarding the extent of difficulties and support received. Identifying PLWD using cognitive scales rather than clinicians’ diagnosis, may have led to misclassification, especially for individuals near the dementia threshold. However, sensitivity analyses confirmed the robustness of our findings. Furthermore, by focusing on community-dwelling older adults, we excluded individuals in institutional care, such as nursing homes, limiting insights into care transitions. Lastly, this study did not evaluate the quality of care or individual satisfaction, critical aspects for future research to explore through more comprehensive collection.

4. Conclusions

This study provides the first comparable evidence showing that a significant proportion of PLWD with disabilities receive no formal or informal care, with these gaps persisting over time across both developing and developed countries. Formal care is particularly scarce compared to informal care, and gaps are more pronounced for ADLs than IADLs. We also observed disparities in care absence by educational attainment and living arrangement, with those less educated or living along facing the greatest deficits. These patterns are consistent across countries and regions studied, underscoring an urgent need for transformative policy and practice reforms. Closing these gaps will require substantial investments in care systems, alongside targeted LTC resources for socioeconomically disadvantaged populations. Policymakers should prioritize innovative, cost-effective, and context-specific care models that can be scaled to meet the growing demand. Addressing these gaps is imperative to improving the well-being of this vulnerable population and ensuring equitable access to essential caregiving resources.

5. Methods

5.1 Study Design and Participants

We used data from four HRS-family longitudinal studies, which collected harmonized sociodemographic, economic, health, and cognition data for community-living adults from more than thirty countries. The studies included the Health and Retirement Study (HRS) in the U.S.;[44]

the English Longitudinal Study of Ageing (ELSA);[45] the Survey of Health, Ageing and Retirement in Europe (SHARE), which encompasses 28 countries;[46] and the China Health and Retirement Longitudinal Study (CHARLS).[47]

The four studies have been designed with similar protocols and frameworks to facilitate cross-national comparisons, which encompass both developed and developing countries. Specifically, the HRS is a nationally-representative longitudinal survey of Americans aged 50 and older, conducted biannually since 1992 with approximately 20,000 respondents per wave.[44,48] The ELSA includes a nationally-representative sample of adults aged 50 and older in England, with biannual rounds since 2002 with around 10,000 participants per wave.[45,49] SHARE surveys European adults aged 50 and older, starting biannually since 2004, initially covering 10 European countries with subsequent expansion to 28 countries (including 27 European countries and Israel) in 2017. The SHARE sample size has exceeded 65,000 since 2013.[46] Lastly, CHARLS is a nationally-representative longitudinal survey of about 19,000 Chinese adults aged 45 and older, initiated in 2011/2012.[47,50] In all these surveys, participants completed a standardized questionnaire administered either face-to-face or via the internet/telephone. Further details on the sampling and study protocols can be found in the respective sources.[44–50]

We constructed variables using harmonized HRS-family study data adapted from the RAND HRS and Gateway to Global Aging.[51,52] These publicly available data sources were harmonized to enhance comparability across the studies. Because only de-identified data were used, our study was deemed exempt from review by the institutional review board at Yale University. Participants in the original studies gave informed consent, and each study was approved by a relevant ethics body.[44–50]

Extended Data Fig. 1 shows the sample selection process and final sample sizes. To ensure temporal comparability of measures across surveys, our analysis focused on data from the following sources: HRS (waves 11-14, 2012-2018), ELSA (waves 6-9, 2012-2018), SHARE (waves 5-7, 2013-2017), and CHARLS (waves 2-4, 2013-2018). For each of the four studies, we restricted our samples in each wave to participants aged 50 and older who reported disabilities. From this group, we excluded participants who had no dementia assessment during the study period. The remaining participants included those who developed dementia (referred to as the *Dementia Sample*) and those who never developed dementia (referred to as the *Non-Dementia Sample*) during the study period. The Dementia Samples were the primary focus of our analysis, covering the period from 2012 to 2018 and included participants aged 50 and over, with 1,203 persons (2,717 person-waves) from HRS, 472 persons (1,125 person-waves) from ELSA, 3,041 persons (5,128 person-waves) from SHARE (covering 19 countries; see Supplementary Table 2), and 1,041 persons (2,067 person-waves) from CHARLS. The *Non-Dementia Samples* were used only for the supplementary analysis.

5.2 Dementia Assessment

Dementia status was assessed in participants with disabilities using validated criteria specific to each HRS-family study.[53–56]. For HRS, we employed a well-established algorithm, classifying participants as PLWD if their 27-point cognition summary score was 6 or lower.[53,54] The 27-point cognition scale comprises three cognitive tests: immediate and delayed word recall tests to measure memory (0-20 points), serial sevens subtraction test for working memory (0-5 points); and counting backwards test for speed of mental processing (0-2 points).

For ELSA, SHARE, and CHARLS, an alternative algorithm was used as previously described.[55,56] Participants were classified as PLWD if their cognition summary scores were 1.5 standard deviations (SDs) below the mean of the population stratified by education levels.[55,56] As backward counting was not assessed, we used a 25-point cognition scale with the same word recall tests (0-20 points) and serial sevens test (0-5 points) as in HRS. Given the differences in cognitive scales and algorithms between HRS and the other three studies, we performed sensitivity analyses where participants' cognitive status was evaluated using the same 25-score scale and defined based on the 1.5 SDs threshold.

For each study, dementia status was assigned in each wave, and participants were classified based on whether they developed dementia during the study period. Proxy assessment of cognition was not considered to ensure comparability across four studies.

5.3 Disabilities and Absence of Care

Disabilities were assessed using ADLs and IADLs. The ADLs included six items: dressing, walking across a room, bathing, eating, getting in and out of bed, and toileting, and the IADLs included five items: preparing hot meals, shopping for groceries, making phone calls, taking medications, and managing money.[11,13] ADL/IADL items were similarly assessed in the HRS-family studies. The participants were asked if they had any difficulty with each ADL/IADL because of a health or memory problem or not. This resulted in 11 binary indicators of limitations, one for each ADL/IADL, reflecting different aspects or domains of disabilities. In this study, we measured the extent of disabilities by the number of ADL/IADL limitations (sum scores of ADL/IADLs, range 0–11), ADL limitations (sum scores of ADLs, range 0-6), and IADL limitations (sum scores of ADLs, range 0-5). Definitions and measurements across studies are presented in Supplementary Table 3.

Participants who endorsed limitations were asked if they received any care for these activities, with separate questions for ADLs, IADLs, and the types of care received (formal care vs. informal care). To assess the absence of care for disabilities, we constructed binary variables to indicate if participants received no care at all for their reported ADLs (0/1), IADLs (0/1), and ADLs/IADLs (0/1) limitations. In other words, the absence of care (for ADLs) meant that the participant did not receive any care for any of their reported (ADL) limitations. Additionally, for each type of disabilities, we differentiated between the formal care and informal care. Therefore, the absence of care was defined respectively for ADLs (including 3 binary variables: no care, no informal care, no formal care), IADLs (3 binary variables), and for ADL/IADL altogether (3 binary variables). Survey questions and their similarities and differences across studies are presented in Supplementary Table 4, and availability of data and variables are provided in Supplementary Table 5.

5.4 Main Analyses

The primary analyses focused on the *Dementia Sample*, examining their disabilities and absence of care. Descriptive statistics of the sociodemographic characteristics, ADL/IADL limitations, and care received were estimated for each study using pooled person-wave data. Categorical variables were reported as numbers and percentages, while continuous/count variables were reported as means and standard deviations (SDs). Missing data for the *Dementia Sample* were minimal as shown in Supplementary Table 6.

We used Generalized Estimating Equations (GEE) models to estimate wave-specific proportions of absence of care for each study, accounting for within-person correlation over the follow-up period. Each GEE model employed a binomial family with a logit link and specified an exchangeable correlation structure, which fit the data better than other correlation structures, such as first-order autoregressive (AR-1) and unstructured.[57,58] Supplementary Table 7 provides the estimated correlation (ρ) between pairs of observations for each outcome with more details about correlation structure in the footnotes. Survey weights for the study period (2012-2018) were applied in all analyses to account for sampling design and study attrition.

Interview year was the main independent variable to model trends over time, adjusting for age, sex, and the number of ADLs and IADLs. To obtain wave-specific estimates of prevalence for the absence of care, interview years were specified as indicator variables, and predictive margins were used to obtain the adjusted average levels of the absence of care for each year.[59] The adjusted annual percent change (AAPC) in binary outcomes over time was then modeled with the interview year as a continuous variable. The AAPC was calculated using the formula $(OR_y - 1) \times 100\%$, where OR_y represents the yearly odds ratio.[60]

We further introduced indicator variables for educational attainment (less vs. more educated, stratified by median levels of education) and current-wave living arrangement (living alone vs. not living alone) respectively into the GEE model to examine group differences in the absence of care, while also accounting for covariates and within-person correlation. The statistical significance of each group difference was directly tested in the models and predictive margins were subsequently applied to obtain the adjusted average values for each subgroup.

5.5 Sensitivity and Additional Analyses

To ensure the robustness of our results regarding dementia assessment and sample selection, we conducted two sets of sensitivity analyses for the *Dementia Sample*. First, since the cognitive scale and dementia classification algorithm in HRS differed from those in the other three studies, we applied the same 25-point cognitive scales and classification algorithms (1.5 SD threshold) used in the other studies to HRS. This ensured consistency in dementia assessment across all studies. Second, to account for potential variations in the timing of dementia onset, we restricted our sample to include only person-waves from the first occurrence of dementia onward.

To further evaluate care burden, we analyzed trends in the number of ADL/IADL limitations among the *Dementia Sample*. Specifically, we employed GEE models with a Gaussian family and an identity link to estimate wave-specific numbers of ADL/IADL limitations over the follow-up period, adjusting for age and sex. The adjusted annual change (AAC) was estimated using the coefficient of the interview year.

Additionally, to assess differences in the absence of care among individuals with more severe disabilities, we repeated our primary analysis using GEE models with a logit link to estimate trends in care absence within the *Dementia Sample* with multiple limitations. Specifically, severe disabilities were defined using the median as a cutoff, identifying individuals who had difficulty in 2 or more ADLs (for ADL care provisions), 2 or more IADLs (for IADL care provisions), and either 2 or more ADLs or 2 or more IADLs (for combined ADL/IADL care provisions).

5.6 Supplementary Analyses on Non-Dementia Sample

To determine how the results of the *Dementia Sample* differed from the *Non-Dementia Sample*, we repeated our key analyses for the *Non-Dementia Sample*. Specifically, we used the same approach to estimate 1) descriptive statistics; 2) trends in the absence of care; and 3) trends in the number of disabilities for the *Non-Dementia Sample*.

All analyses were conducted using STATA (version 17.0), with two-sided statistical tests and an alpha level of 0.05 for determining statistical significance. Robust standard errors were estimated. The study adhered to the Strengthening the Reporting of Observational Studies in Epidemiology (STROBE) reporting guidelines.

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Author Contributions

Z.L, Y.Q., S.C., and X.C. conceived of the idea and designed the study. Z.L. and Y.Q. collected the data and performed the analysis. Z.L. and Y.Q. drafted and revised the manuscript. T.G., X.H., H.A., S.C., and X.C. provided critical revisions to the manuscript. H.A., S.C., and X.C. supervised the analysis. Z.L. and Y.Q. contributed equally to this work as the co-first author. S.C. and X.C. served as the corresponding author. X.C. contributed to this work as the senior author.

Data Availability

Raw data are available from HRS (https://hrsdata.isr.umich.edu/data-products), ELSA (https://www.elsa-project.ac.uk/accessing-elsa-data), SHARE (https://share-eric.eu/data/data-access), and CHARLS (https://charls.charlsdata.com/pages/data/111/en.html). Rand HRS are available through the HRS website (https://hrsdata.isr.umich.edu/data-products/rand), and the harmonized data for the HRS-family study are available through the Gateway to Global Aging

Data repository (https://g2aging.org/home). The data files are publicly available upon registration or application on each of the websites. Please note that these data sets do not allow third-party distribution and therefore cannot be deposited in public repositories. To access these data files, please follow the application procedures explained on the respective websites.

Competing Interests Statement

The authors declare no competing interests.

Table 1 | Characteristics of the *Dementia Sample* in the HRS, ELSA, SHARE, and CHARLS, 2012-2018

	HRS (United States)		ELSA (England)		SHARE (19 Countries)		CHARLS (China)	
	Mean (SD) or n (%)	N	Mean (SD) or n (%)	N	Mean (SD) or n (%)	N	Mean (SD) or n (%)	N
Sociodemographic Characteristics								
Age, mean (SD)	75.0 (11.8)	2717	75.6 (10.9)	1125	78.7 (9.4)	5128	68.8 (9.1)	2067
Female, n (%)	1690 (62.2)	2717	623 (55.4)	1125	3052 (59.5)	5128	1170 (56.6)	2067
Living alone, n (%)	778 (28.6)	2717	475 (42.2)	1125	1853 (36.1)	5128	211 (10.2)	2067
Education, n (%)								
Less than secondary	1512 (55.6)	2717	454 (44.3)	1025	3079 (60.0)	5128	1953 (94.5)	2067
Upper secondary and vocational training	1079 (39.7)	2717	446 (43.5)	1025	1472 (28.7)	5128	102 (4.9)	2067
Tertiary	126 (4.6)	2717	125 (12.2)	1025	577 (11.3)	5128	12 (0.6)	2067
Disabilities								
Number of ADL/IADL limitations, mean (SD)	4.0 (2.9)	2715	3.3 (2.6)	1125	3.7 (2.9)	5128	3.3 (2.6)	2066
Number of ADL limitations, mean (SD)	2.0 (1.8)	2717	1.9 (1.7)	1125	1.9 (1.8)	5128	1.5 (1.7)	2066
Number of IADL limitations, mean (SD)	2.0 (1.6)	2715	1.3 (1.4)	1125	1.8 (1.6)	5128	1.7 (1.4)	2067
Absence of Care for Sample with Any ADL/IADL Limitation								
No care for ADL/IADL, n (%)	581 (21.4)	2716	282 (25.6)	1102	NA	NA[†]	675 (32.7)	2066
No informal care for ADL/IADL, n (%)	652 (24.1)	2706	333 (30.9)	1079	NA	NA[†]	697 (33.7)	2066
No formal care for ADL/IADL, n (%)	2320 (86.0)	2697	772 (71.6)	1078	2998 (58.5)	5121	2047 (99.1)	2066
Absence of Care for Sample with Any ADL Limitation								
No care for ADL, n (%)	795 (39.0)	2040	447 (48.5)	922	708 (38.4)	1844[†]	817 (63.1)	1294
No informal care for ADL, n (%)	921 (45.3)	2034	482 (52.3)	922	951 (51.5)	1846[†]	234 (67.4)	347[†]
No formal care for ADL, n (%)	1721 (85.4)	2016	767 (83.2)	922	2717 (70.8)	3838	344 (99.1)	347[†]
Absence of Care for Sample with Any IADL Limitation								
No care for IADL, n (%)	304 (13.8)	2197	68 (9.6)	707	NA	NA[†]	388 (22.7)	1710

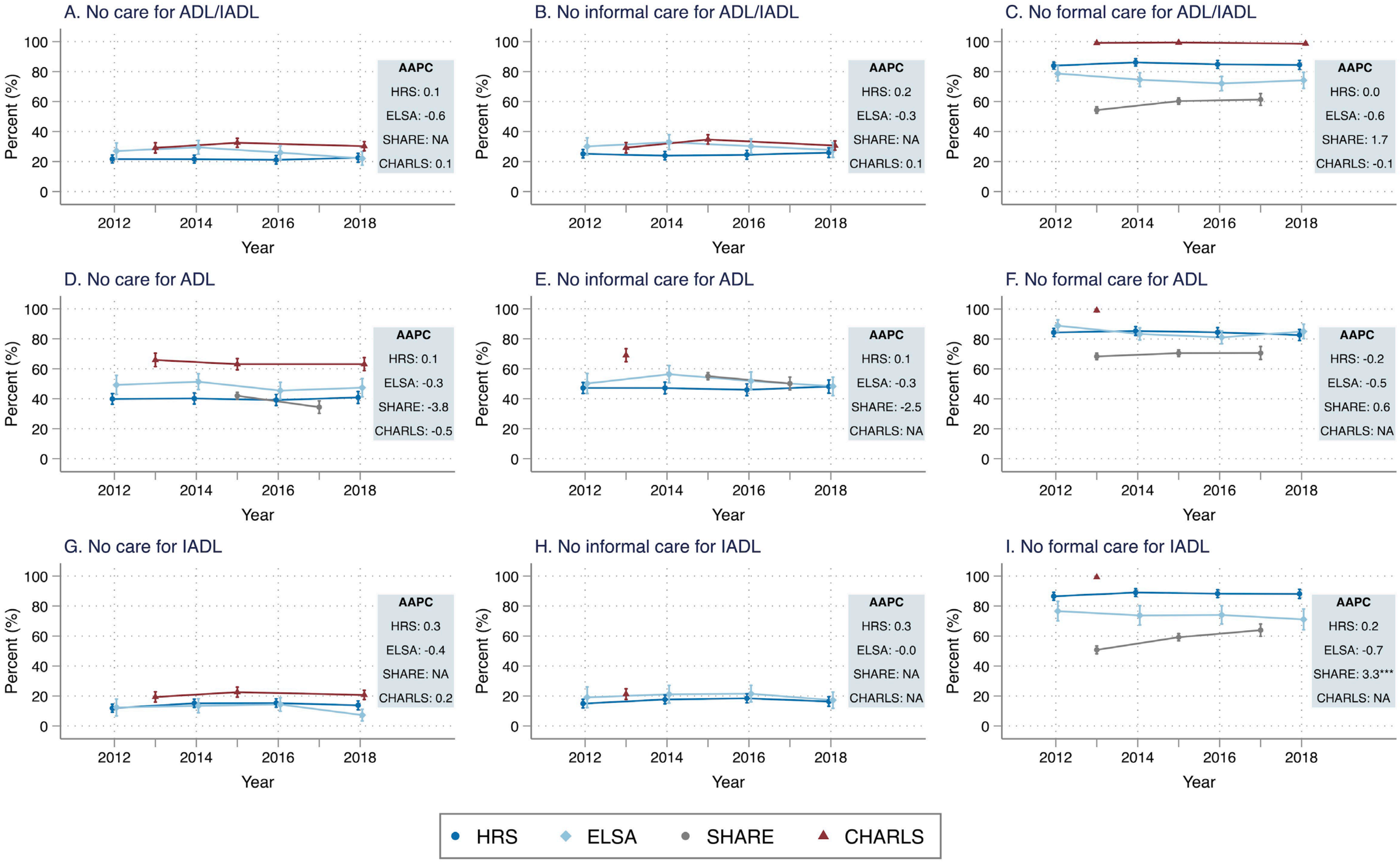
No informal care for IADL, n (%)	357 (16.3)	2184	131 (19.0)	690	NA	NA[†]	119 (23.0)	518[†]
No formal care for IADL, n (%)	1950 (89.3)	2184	486 (70.5)	689	2244 (56.8)	3952	514 (99.2)	518[†]

Dementia Sample represents samples (person-waves) with disabilities who developed dementia during the study periods, who were included in the analyses. The descriptive statistics were estimated based on pooled person-wave data. N represents the total included person-waves, which could be different across measures depending on variable definitions and included survey waves. Supplementary Table S4 lists the included survey waves, while Supplementary Table S5 details the eligible sample for each measure along with the extent of missing data among those eligible. *Abbreviations*: HRS = Health and Retirement Study; ELSA = English Longitudinal Study on Ageing; SHARE = Survey of Health, Ageing and Retirement in Europe; CHARLS = China Health and Retirement Longitudinal Study; ADL/IADL= basic or instrumental activities of daily living; ADL = basic activities of daily living; IADL = instrumental activities of daily living.

[†] The sample size in these cells was relatively smaller because the relevant survey questions were included only in specific survey waves. For details on the waves included for each measure, see Supplementary Table S4. “NA” indicates that the measure was not collected in any of the survey waves.

Figures

Fig. 1 | Trends in the proportion of persons receiving no care for ADL and IADL among persons with dementia and disabilities in the HRS, ELSA, SHARE, and CHARLS (*Dementia Sample*, 2012-2018).



A. No care for ADL/IADL

B. No informal care for ADL/IADL

C. No formal care for ADL/IADL

D. No care for ADL

E. No informal care for ADL

F. No formal care for ADL

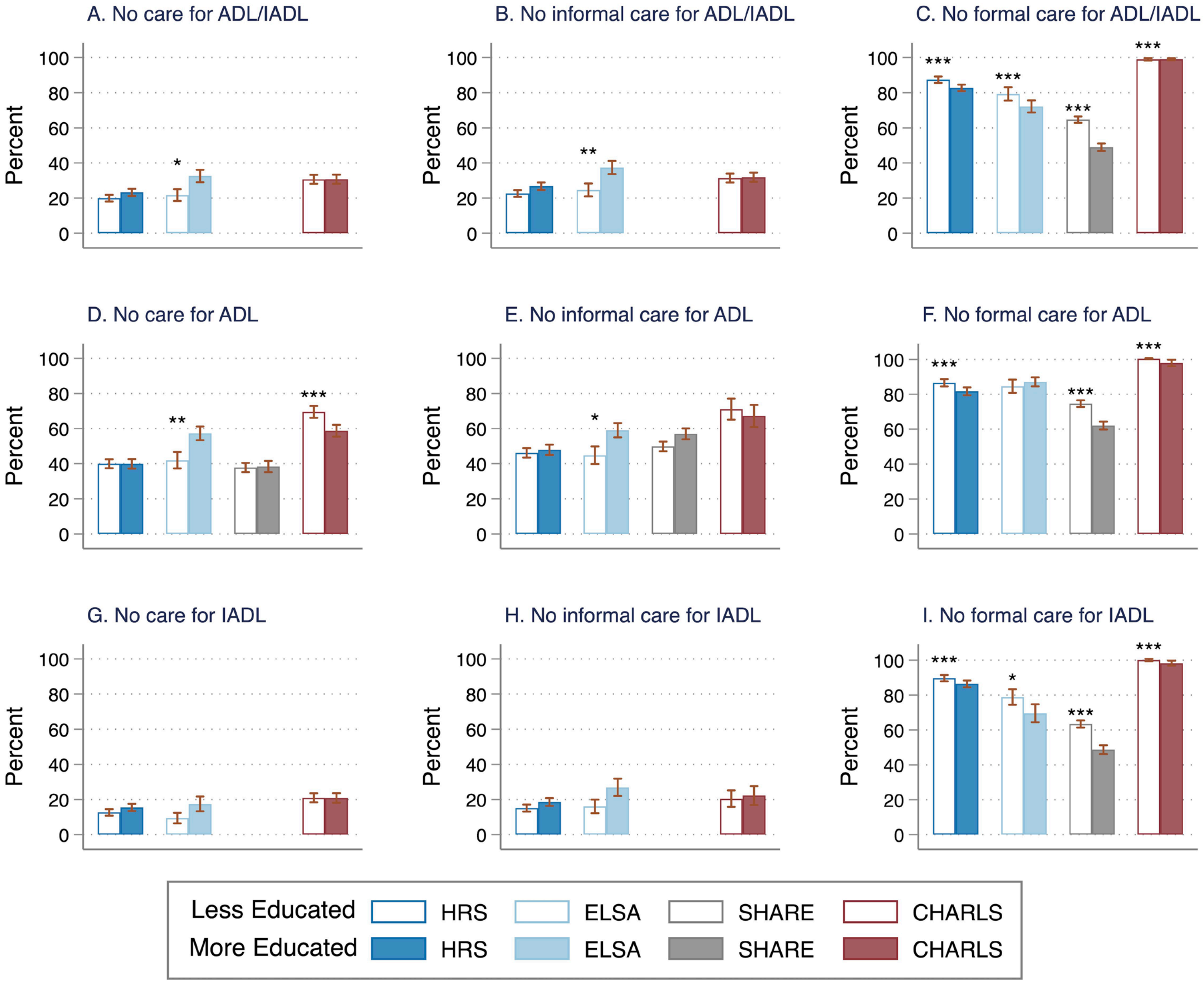
G. No care for IADL

H. No informal care for IADL

I. No formal care for IADL

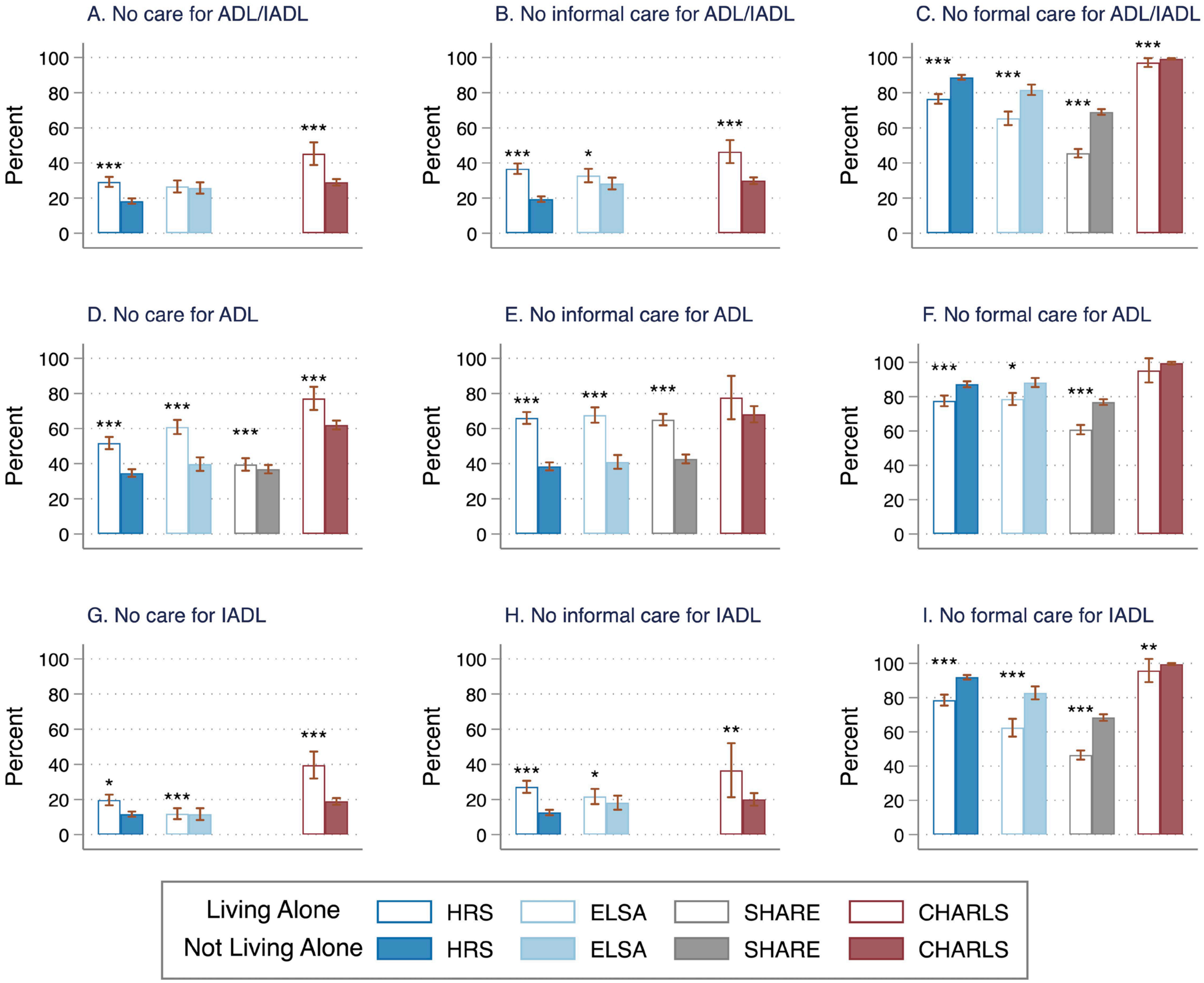
a, Care absence for ADL/IADL limitations (HRS: n=2,704; ELSA: n=1,035; SHARE: NA; CHARLS: n=2,037). **b**, Absence of informal care for ADL/IADL limitations (HRS: n=2,694; ELSA: n=1,012; SHARE: NA; CHARLS: n=2,037). **c**, Absence of formal care for ADL/IADL limitations (HRS: n=2,686; ELSA: n=1,011; SHARE: n=5,120; CHARLS: n=2,037). **d**, Care absence for ADL limitations (HRS: n=2,027; ELSA: n=865; SHARE: n=1,843; CHARLS: n=1,273). **e**, Absence of informal care for ADL limitations (HRS: n=2,021; ELSA: n=865; SHARE: n=1,845; CHARLS: 338). **f**, Absence of formal care for ADL limitations (HRS: n=2,004; ELSA: n=865; SHARE: n=3,759; CHARLS: 338). **g**, Care absence for IADL limitations (HRS: n=2,190; ELSA: n=656; SHARE: NA; CHARLS, n=1,686). **h**, Absence of informal care for IADL limitations (HRS: n=2,177; ELSA: n=639; SHARE: NA; CHARLS: 501). **i**, Absence of formal care for IADL limitations (HRS: n=2,177; ELSA: n=638; SHARE: n=3,876; CHARLS: 501). In panels (**a-i**), data are presented as adjusted means ± 95% confidence intervals (CIs). Dotted points represent the estimated proportion of people receiving no care (**a, d, g**), no informal care (**b, e, h**) and no formal care (**c, f, i**) at each wave, as estimated using the GEE model among the *Dementia Sample*. Error bars indicate the 95% CIs. Estimates for certain waves in SHARE and CHARLS are unavailable due to lack of data (details provided in Supplementary Tables 3 & 4). Corrections for multiplicity were not made. Outcomes in panels (**a-c**) include samples with at least one ADL/IADL limitation. Panels (**d-f**) are limited to samples with at least one ADL limitation, and panels (**g-i**) to those with at least one IADL limitation. Adjusted Annual Percent Change (AAPC) estimates derived from the GEE model are shown on the right of each panel. Asterisks denote the significance of the AAPC (time trend): *** $p<0.001$, ** $p<0.01$, * $p<0.05$. “NA” indicates unavailable estimates. Two-sided tests were performed using GEE model, with detailed test statistics and P values provided in the corresponding **Source Data** for the figure.

Fig. 2 | Proportion of persons receiving no care for ADL and IADL among persons with dementia and disabilities in the HRS, ELSA, SHARE, and CHARLS, stratified by median levels of education (*Dementia Sample*, 2012-2018).



a, Care absence for ADL/IADL limitations (HRS: n=2,692; ELSA: n=944; SHARE: NA; CHARLS: n=2,037). **b**, Absence of informal care for ADL/IADL limitations (HRS: n=2,682; ELSA: n=923; SHARE: NA; CHARLS: n=2,037). **c**, Absence of formal care for ADL/IADL limitations (HRS: n=2,674; ELSA: n=922; SHARE: n=5,120; CHARLS: n=2,037). **d**, Care absence for ADL limitations (HRS: n=2,023; ELSA: n=791; SHARE: n=1,843; CHARLS: n=1,273). **e**, Absence of informal care for ADL limitations (HRS: n=2,017; ELSA: n=791; SHARE: n=1,845; CHARLS: n=338). **f**, Absence of formal care for ADL limitations (HRS: n=2,000; ELSA: n=791; SHARE: n=3,759; CHARLS: n=338). **g**, Care absence for IADL limitations (HRS: n=2,181; ELSA: n=597; SHARE: NA; CHARLS: n=1,686). **h**, Absence of informal care for IADL limitations by education (HRS: n=2,168; ELSA: n=582; SHARE: NA; CHARLS: n=501). **i**, Absence of formal care for IADL limitations by education (HRS: n=2,168; ELSA: n=581; SHARE: n=3,876; CHARLS: n=501). In panels (**a-i**), data are presented as adjusted means ± 95% confidence intervals (CIs). Vertical bars represent the estimated proportion of people receiving no care (**a, d, g**), no informal care (**b, e, h**) and no formal care (**c, f, i**) for people who were less educated vs those who were more educated, as estimated using the GEE model among the *Dementia Sample*. Error bars indicate the 95% CIs. Participants were classified as "more educated" if their years of education were above median, and "less educated" otherwise. Estimates for certain measures in SHARE and CHARLS are unavailable due to lack of data (details provided in Supplementary Tables 3 & 4). Corrections for multiplicity were not made. Outcomes in panels (**a-c**) include samples with at least one ADL/IADL limitation. Panels (**d-f**) are limited to samples with at least one ADL limitation, and panels (**g-i**) to those with at least one IADL limitation. Asterisks above each bar denote the significance of the group differences by education, directly tested in the GEE model: *** $p<0.001$, ** $p<0.01$, * $p<0.05$. Two-sided tests were performed, with detailed test statistics and *P* values provided in the **Source Data** for the figure.

Fig. 3 | Proportion of persons receiving no care for ADL and IADL among persons with dementia and disabilities in the HRS, ELSA, SHARE, and CHARLS, stratified by living arrangement (*Dementia Sample*, 2012-2018).



a, Care absence for ADL/IADL limitations (HRS: n=2,704; ELSA: n=1,035; SHARE: NA; CHARLS: n=2,037). **b**, Absence of informal care for ADL/IADL limitations (HRS: n=2,694; ELSA: n=1,012; SHARE: NA; CHARLS: n=2,037). **c**, Absence of formal care for ADL/IADL limitations (HRS: n=2,686; ELSA: n=1,011; SHARE: n=5,120; CHARLS: n=2,037). **d**, Care absence for ADL limitations (HRS: n=2,027; ELSA: n=865; SHARE: n=1,843; CHARLS: n=1,273). **e**, Absence of informal care for ADL limitations (HRS: n=2,021; ELSA: n=865; SHARE: n=1,845; CHARLS: 338). **f**, Absence of formal care for ADL limitations (HRS: n=2,004; ELSA: n=865; SHARE: n=3,759; CHARLS: 338). **g**, Care absence for IADL limitations (HRS: n=2,190; ELSA: n=656; SHARE: NA; CHARLS, n=1,686). **h**, Absence of informal care for IADL limitations (HRS: n=2,177; ELSA: n=639; SHARE: NA; CHARLS: 501). **i**, Absence of formal care for IADL limitations (HRS: n=2,177; ELSA: n=638; SHARE: n=3,876; CHARLS: 501). In panels (**a-i**), data are presented as adjusted means ± 95% confidence intervals (CIs). Vertical bars represent the estimated proportion of people receiving no care (**a, d, g**), no informal care (**b, e, h**) and no formal care (**c, f, i**) for people who were "living alone" vs those who were "not living alone", as estimated using the GEE model among the *Dementia Sample*. Error bars indicate the 95% CIs. Estimates for certain measures in SHARE and CHARLS are unavailable due to lack of data (details provided in Supplementary Tables 3 & 4). Corrections for multiplicity were not made. Outcomes in panels (**a-c**) include samples with at least one ADL/IADL limitation. Panels (**d-f**) are limited to samples with at least one ADL limitation, and panels (**g-i**) to those with at least one IADL limitation. Asterisks above each bar denote the significance of the group differences by education, directly tested in the GEE model: *** $p<0.001$, ** $p<0.01$, * $p<0.05$. Two-sided tests were performed, with detailed test statistics and *P* values provided in the **Source Data** for the figure.

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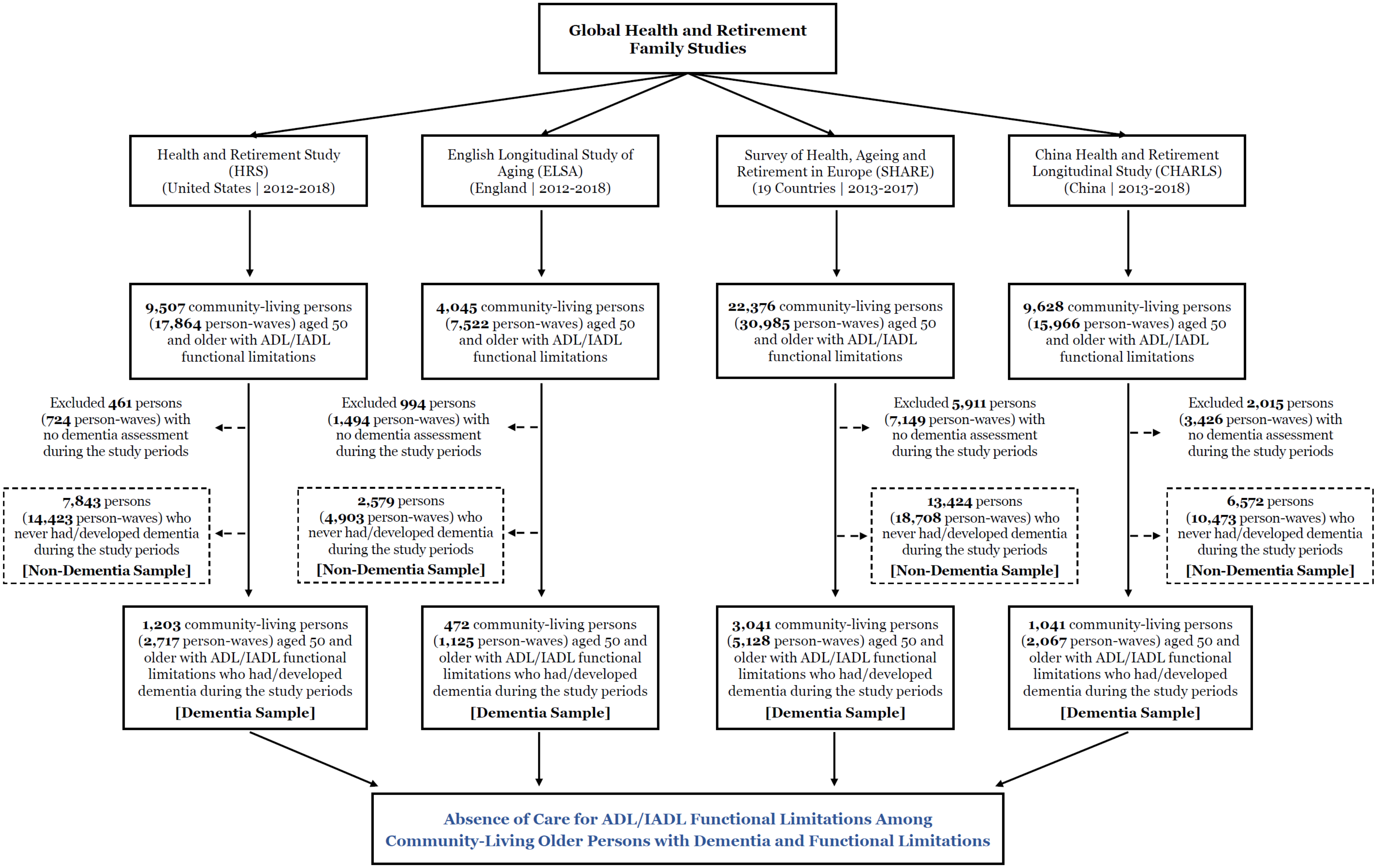
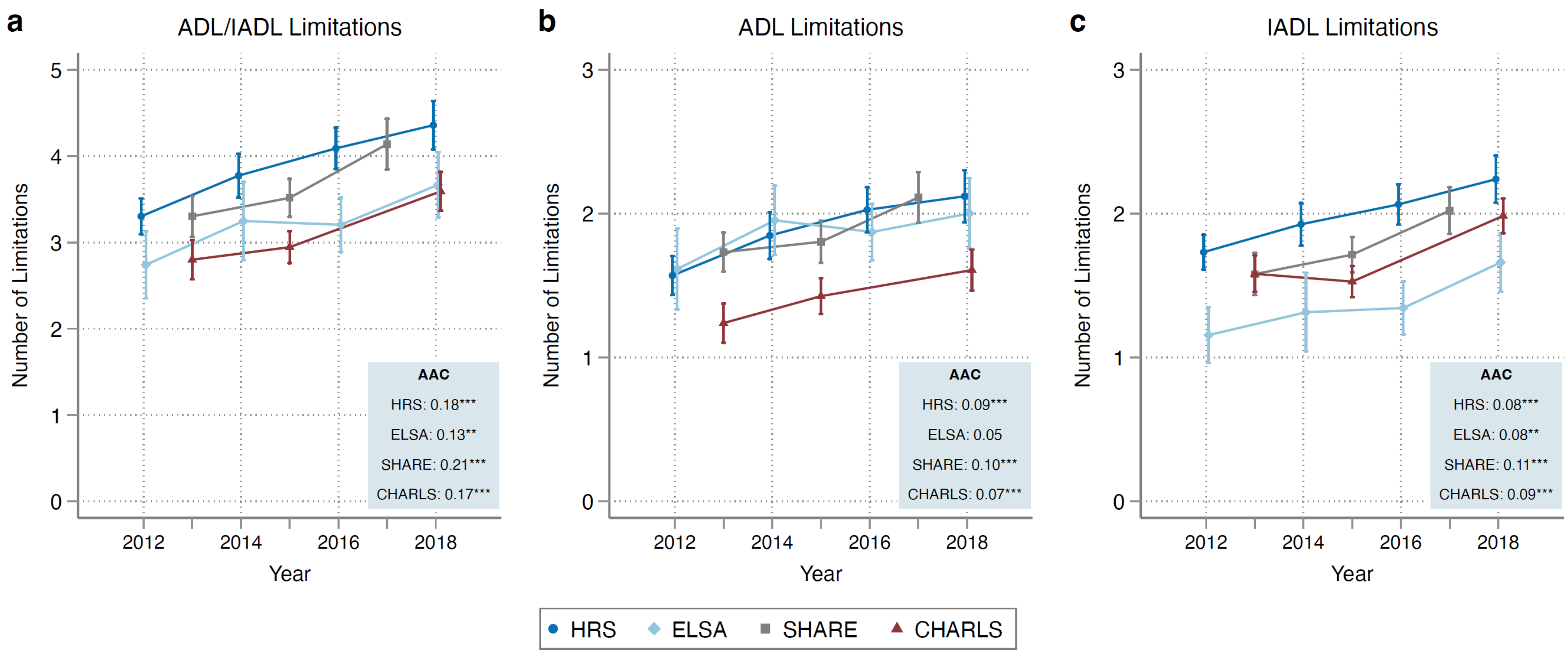
Extended Data Fig. 1 | Flow chart of study design and sample selection process.



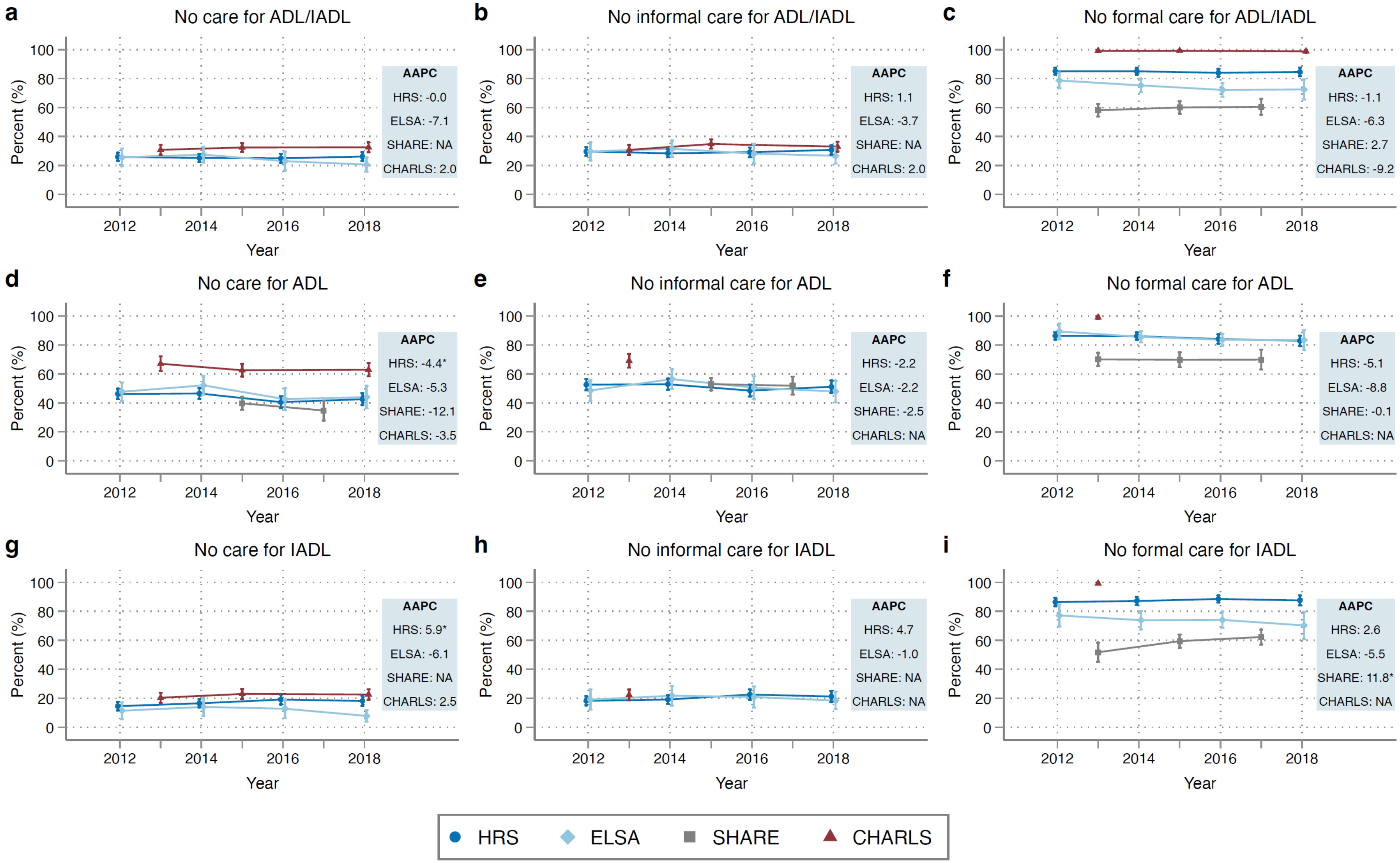
ADL = basic activities of daily living; IADL = instrumental activities of daily living. For each of the four studies, samples (age 50+) with ADL/IADL disabilities were included, and those who developed dementia during the study period (referred to as *Dementia Sample*) were included in our primary analyses. Samples who never developed dementia (rectangles with dashed line, referred to as *Non-Dementia Sample*) were used only for the supplementary analyses.

Extended Data Fig. 2 | Trends in the number of ADL and IADL among persons with dementia and disabilities in the HRS, ELSA, SHARE, and CHARLS (*Dementia Sample*, 2012-2018).



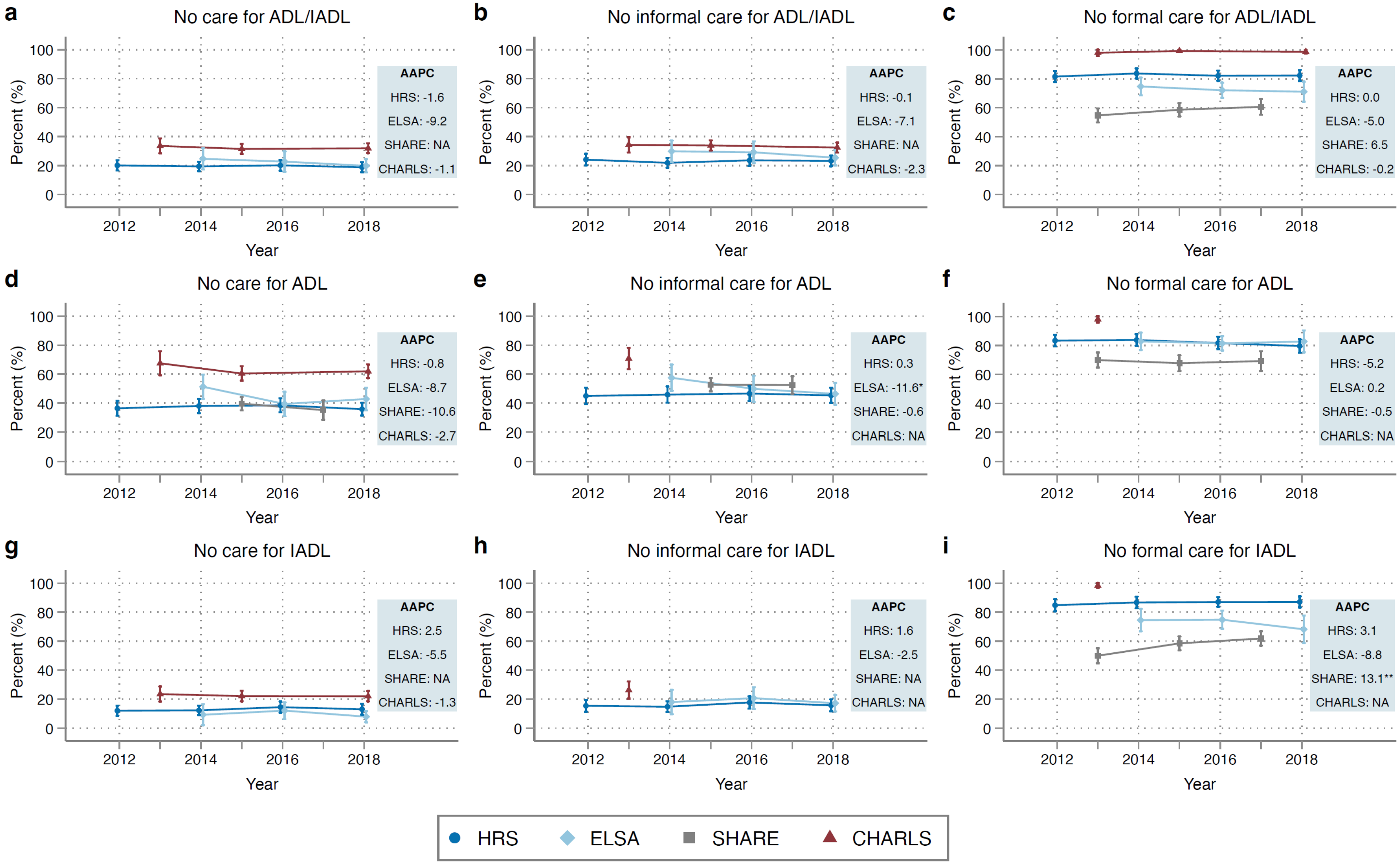
a, Number of ADL/IADL limitations (HRS: n=2,705; ELSA: n=1,058; SHARE: 5,127; CHARLS: n=2,038). **b**, Number of ADL limitations (HRS: n=2,707; ELSA: n=1,058; SHARE: 5,127; CHARLS: n=2,038). **c**, Number of IADL limitations (HRS: n=2,705; ELSA: n=1,058; SHARE: n=5,127; CHARLS: n=2,039). In panels (**a-c**), data are presented as adjusted means ± 95% confidence intervals (CIs). Dotted points represent the estimated average number of ADL/IADL limitations (**a**), ADL limitations (**b**) and IADL limitations (**c**) at each wave, as estimated using the GEE model among the *Dementia Sample*. Error bars indicate the 95% CIs. Corrections for multiplicity were not made. Adjusted Annual Change (AAC) estimates derived from the GEE model are shown on the right of each panel. Asterisks denote the significance of the AAC (time trend): *** $p<0.001$, ** $p<0.01$, * $p<0.05$. Two-sided tests were performed using GEE model, with detailed test statistics and P values provided in the corresponding **Source Data** for the figure.

Extended Data Fig. 3 | Sensitivity analysis using alternative cognitive scale and dementia classification: trends in the proportion of people receiving no care for ADL and IADL among persons with dementia and disabilities in the HRS, ELSA, SHARE, and CHARLS, 2012-2018.



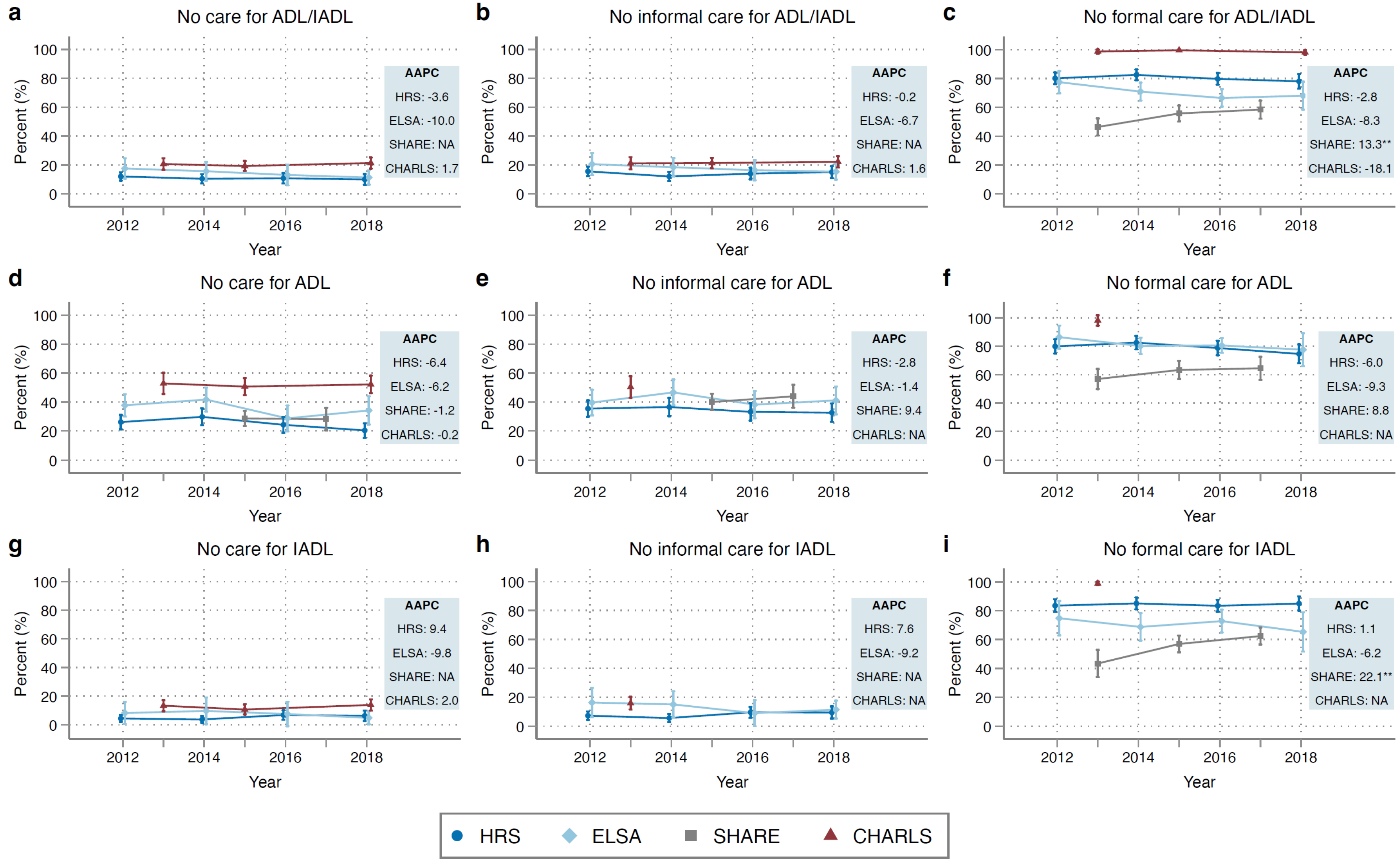
a, Care absence for ADL/IADL limitations (HRS: n=4,191; ELSA: n=1,035; SHARE: NA; CHARLS: n=2,037). **b**, Absence of informal care for ADL/IADL limitations (HRS: n=4,180; ELSA: n=1,012; SHARE: NA; CHARLS: n=2,037). **c**, Absence of formal care for ADL/IADL limitations (HRS: n=4,168; ELSA: n=1,011; SHARE: n=5,120; CHARLS: n=2,037). **d**, Care absence for ADL limitations (HRS: n=3,159; ELSA: n=865; SHARE: n=1,843; CHARLS: n=1,273). **e**, Absence of informal care for ADL limitations (HRS: n=3,151; ELSA: n=865; SHARE: n=1,845; CHARLS: 338). **f**, Absence of formal care for ADL limitations (HRS: n=3,127; ELSA: n=865; SHARE: n=3,759; CHARLS: 338). **g**, Care absence for IADL limitations (HRS: n=3,253; ELSA: n=656; SHARE: NA; CHARLS, n=1,686). **h**, Absence of informal care for IADL limitations (HRS: n=3,236; ELSA: n=639; SHARE: NA; CHARLS: 501). **i**, Absence of formal care for IADL limitations (HRS: n=3,236; ELSA: n=638; SHARE: n=3,876; CHARLS: 501). In panels (**a-i**), data are presented as adjusted means ± 95% confidence intervals (CIs). Dotted points represent the estimated proportion of people receiving no care (**a, d, g**), no informal care (**b, e, h**) and no formal care (**c, f, i**) at each wave, as estimated using the GEE model among samples who developed dementia. In this sensitivity analysis, participants' dementia status was all evaluated using the same 25-score scale and defined based on 1.5 SDs threshold in the four surveys. Error bars indicate the 95% CIs. Estimates for certain waves in SHARE and CHARLS are unavailable due to lack of data (details provided in Supplementary Tables 3 & 4). Corrections for multiplicity were not made. Outcomes in panels (**a-c**) include samples with at least one ADL/IADL limitation. Panels (**d-f**) are limited to samples with at least one ADL limitation, and panels (**g-i**) to those with at least one IADL limitation. Adjusted Annual Percent Change (AAPC) estimates derived from the GEE model are shown on the right of each panel. Asterisks denote the significance of the AAPC (time trend): *** $p<0.001$, ** $p<0.01$, * $p<0.05$. "NA" indicates unavailable estimates. Two-sided tests were performed using GEE model, with detailed test statistics and P values provided in the corresponding **Source Data** for the figure.

Extended Data Fig. 4 | Sensitivity analysis using restricted sample with person-waves from the first occurrence of dementia onward: trends in the proportion of people receiving no care for ADL and IADL among persons with dementia and disabilities in the HRS, ELSA, SHARE, and CHARLS, 2012-2018.



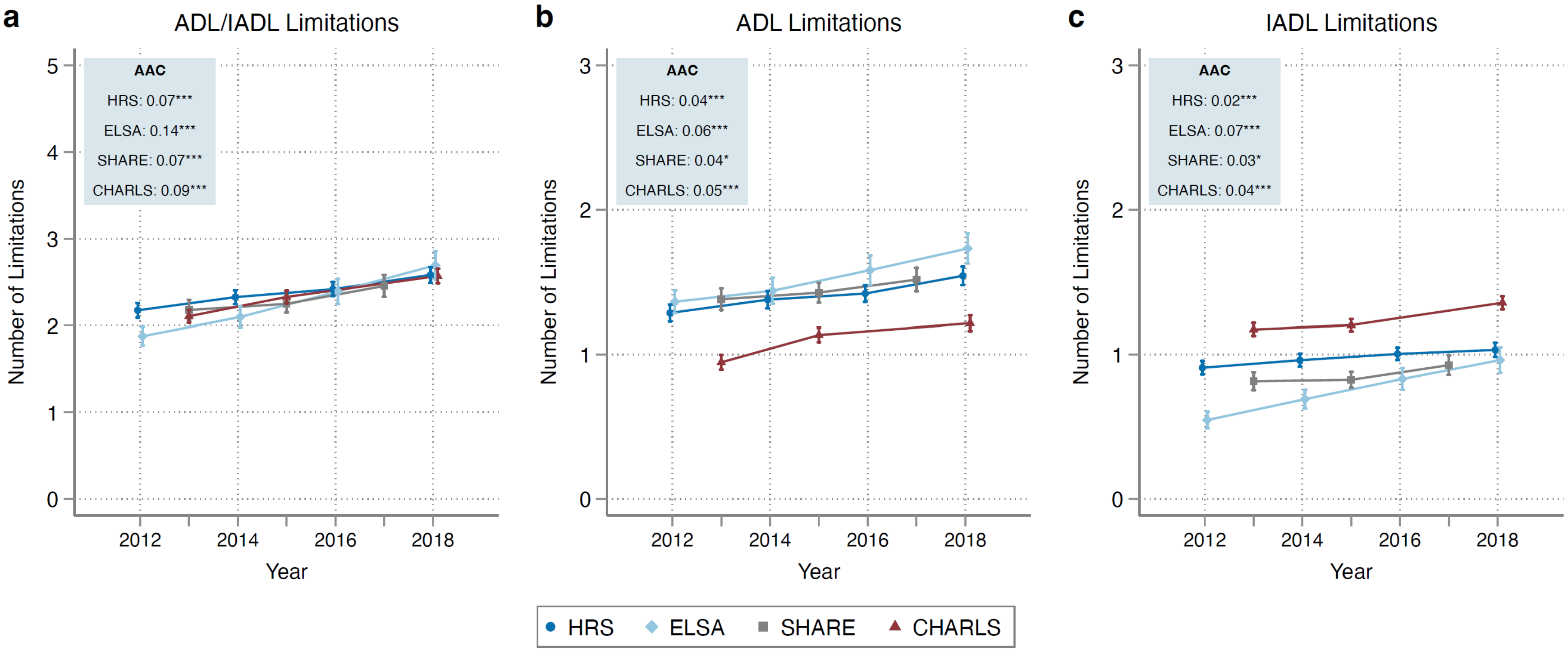
a, Care absence for ADL/IADL limitations (HRS: n=2,068; ELSA: n=638; SHARE: NA; CHARLS: n=1,558). **b**, Absence of informal care for ADL/IADL limitations (HRS: n=2,061; ELSA: n=624; SHARE: NA; CHARLS: n=1,558). **c**, Absence of formal care for ADL/IADL limitations (HRS: n=2,055; ELSA: n=623; SHARE: n=4,553; CHARLS: n=1,558). **d**, Care absence for ADL limitations (HRS: n=1,555; ELSA: n=524; SHARE: n=1,744; CHARLS: n=978). **e**, Absence of informal care for ADL limitations (HRS: n=1,549; ELSA: n=524; SHARE: n=1,746; CHARLS: 149). **f**, Absence of formal care for ADL limitations (HRS: n=1,537; ELSA: n=524; SHARE: n=3,326; CHARLS: 149). **g**, Care absence for IADL limitations (HRS: n=1,703; ELSA: n=425; SHARE: NA; CHARLS, n=1,295). **h**, Absence of informal care for IADL limitations (HRS: n=1,694; ELSA: n=415; SHARE: NA; CHARLS: 228). **i**, Absence of formal care for IADL limitations (HRS: n=1,694; ELSA: n=414; SHARE: n=3,470; CHARLS: 228). In panels (**a-i**), data are presented as adjusted means ± 95% confidence intervals (CIs). Dotted points represent the estimated proportion of people receiving no care (**a, d, g**), no informal care (**b, e, h**) and no formal care (**c, f, i**) at each wave, as estimated using the GEE model among samples who developed dementia. In this sensitivity analysis, samples were restricted to person-waves at the first occurrence of dementia and thereafter, addressing potential differences in the timing of dementia occurrence. Error bars indicate the 95% CIs. Estimates for certain waves in SHARE and CHARLS are unavailable due to lack of data (details provided in Supplementary Tables 3 & 4). Corrections for multiplicity were not made. Outcomes in panels (**a-c**) include samples with at least one ADL/IADL limitation. Panels (**d-f**) are limited to samples with at least one ADL limitation, and panels (**g-i**) to those with at least one IADL limitation. Adjusted Annual Percent Change (AAPC) estimates derived from the GEE model are shown on the right of each panel. Asterisks denote the significance of the AAPC (time trend): *** $p<0.001$, ** $p<0.01$, * $p<0.05$. “NA” indicates unavailable estimates. Two-sided tests were performed using GEE model, with detailed test statistics and *P* values provided in the corresponding **Source Data** for the figure.

Extended Data Fig. 5 | Additional analysis: trends in the proportion of people receiving no care for ADL and IADL among persons with dementia who had more severe disabilities in the HRS, ELSA, SHARE, and CHARLS, 2012-2018.



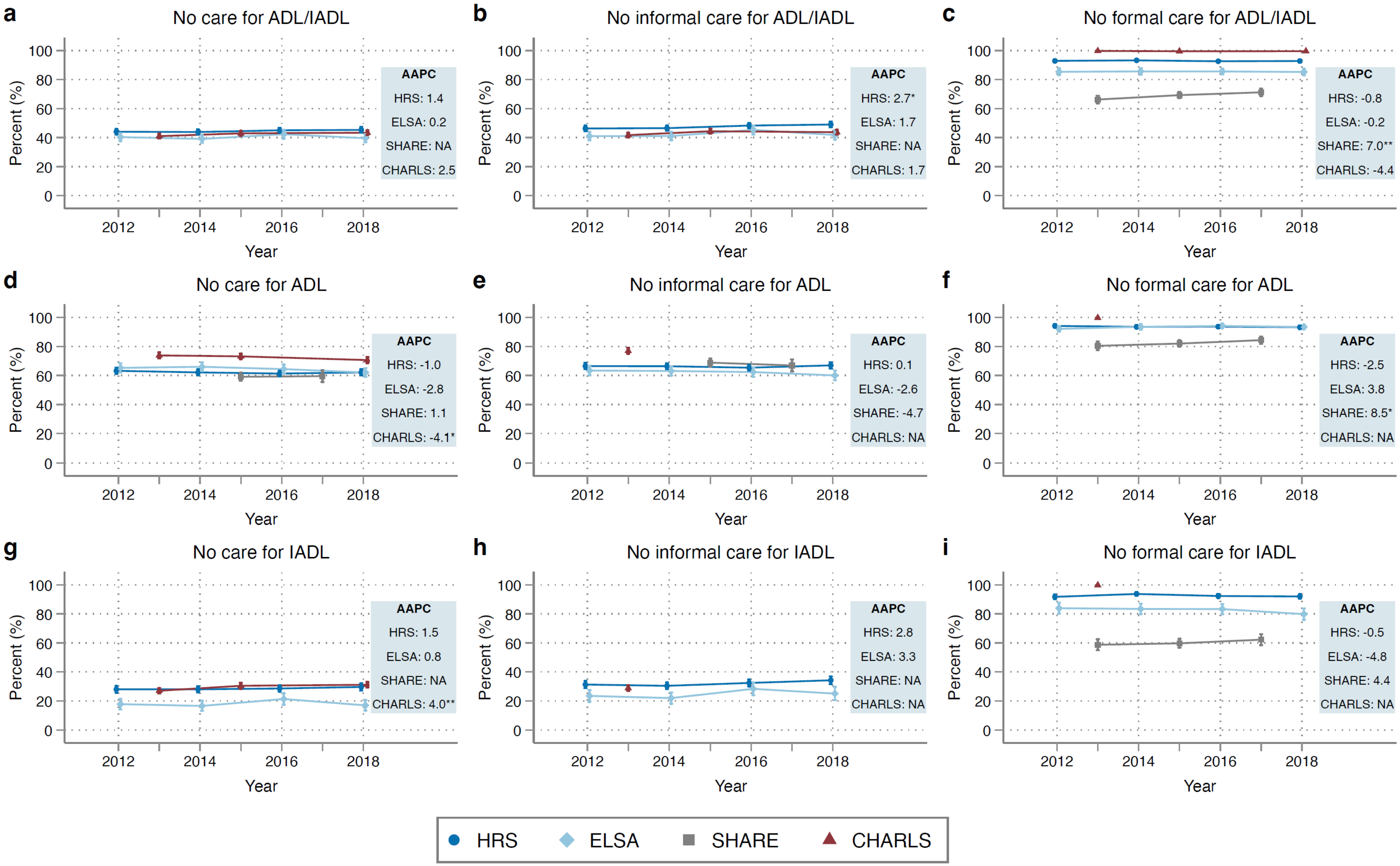
a, Care absence for ADL/IADL limitations (HRS: n=1,868; ELSA: n=628; SHARE: NA; CHARLS: n=1,172). **b**, Absence of informal care for ADL/IADL limitations (HRS: n=1,862; ELSA: n=618; SHARE: NA; CHARLS: n=1,172). **c**, Absence of formal care for ADL/IADL limitations (HRS: n=1,856; ELSA: n=618; SHARE: n=3,285; CHARLS: n=1,172). **d**, Care absence for ADL limitations (HRS: n=1,344; ELSA: n=513; SHARE: n=1,114; CHARLS: n=713). **e**, Absence of informal care for ADL limitations (HRS: n=1,338; ELSA: n=513; SHARE: n=1,116; CHARLS: 175). **f**, Absence of formal care for ADL limitations (HRS: n=1,326; ELSA: n=513; SHARE: n=2,255; CHARLS: 74). **g**, Care absence for IADL limitations (HRS: n=1,405; ELSA: n=359; SHARE: NA; CHARLS, n=932). **h**, Absence of informal care for IADL limitations (HRS: n=1,398; ELSA: n=357; SHARE: NA; CHARLS: 265). **i**, Absence of formal care for IADL limitations (HRS: n=1,398; ELSA: n=357; SHARE: n=2,452; CHARLS: 265). In panels (**a-i**), data are presented as adjusted means ± 95% confidence intervals (CIs). Dotted points represent the estimated proportion of people receiving no care (**a, d, g**), no informal care (**b, e, h**) and no formal care (**c, f, i**) at each wave, as estimated using the GEE model among the *Dementia Sample*. In this additional analysis, sample were restricted to those who had more severe disabilities. Error bars indicate the 95% CIs. Estimates for certain waves in SHARE and CHARLS are unavailable due to lack of data (details provided in Supplementary Tables 3 & 4). Corrections for multiplicity were not made. Outcomes in panels (**a-c**) include samples with at least one ADL/IADL limitation. Panels (**d-f**) are limited to samples with at least one ADL limitation, and panels (**g-i**) to those with at least one IADL limitation. Adjusted Annual Percent Change (AAPC) estimates derived from the GEE model are shown on the right of each panel. Asterisks denote the significance of the AAPC (time trend): *** p<0.001, ** p<0.01, * p<0.05. “NA” indicates unavailable estimates. Two-sided tests were performed using GEE model, with detailed test statistics and P values provided in the corresponding **Source Data** for the figure.

Extended Data Fig. 6 | Supplementary analysis: trends in the number of ADL and IADL among persons with disabilities who never developed dementia in the HRS, ELSA, SHARE, and CHARLS (*Non-Dementia Sample*, 2012-2018).



a, Number of ADL/IADL limitations (HRS: n=14,284; ELSA: n=4,415; SHARE: 16,366; CHARLS: n=10,287). **b**, Number of ADL limitations (HRS: n=14,284; ELSA: n=4,415; SHARE: 16,366; CHARLS: n=10,288). **c**, Number of IADL limitations (HRS: n=14,285; ELSA: n=4,415; SHARE: n=16,366; CHARLS: n=10,288). In panels (**a-c**), data are presented as adjusted means ± 95% confidence intervals (CIs). Dotted points represent the estimated average number of ADL/IADL limitations (**a**), ADL limitations (**b**) and IADL limitations (**c**) at each wave, as estimated using the GEE model among the *Non-Dementia Sample*. Error bars indicate the 95% CIs. Corrections for multiplicity were not made. Adjusted Annual Change (AAC) estimates derived from the GEE model are shown on the right of each panel. Asterisks denote the significance of the AAC (time trend): *** $p<0.001$, ** $p<0.01$, * $p<0.05$. Two-sided tests were performed using GEE model, with detailed test statistics and P values provided in the corresponding **Source Data** for the figure.

Extended Data Fig. 7 | Supplementary analysis: trends in the proportion of people receiving no care for ADL and IADL among persons who never developed dementia in the HRS, ELSA, SHARE, and CHARLS (*Non-Dementia Sample*, 2012-2018).



a, Care absence for ADL/IADL limitations (HRS: n=14,229; ELSA: n=4,313; SHARE: NA; CHARLS: n=10,278). **b**, Absence of formal care for ADL/IADL limitations (HRS: n=14,200; ELSA: n=4,247; SHARE: NA; CHARLS: n=10,279). **c**, Absence of informal care for ADL/IADL limitations (HRS: n=14,154; ELSA: n=4,245; SHARE: n=16,349; CHARLS: n=10,278). **d**, Care absence for ADL limitations (HRS: n=10,728; ELSA: n=3,755; SHARE: n=5,995; CHARLS: n=6,050). **e**, Absence of formal care for ADL limitations (HRS: n=10,702; ELSA: n=3,755; SHARE: n=5,998; CHARLS: 1,686). **f**, Absence of informal care for ADL limitations (HRS: n=10,634; ELSA: n=3,755; SHARE: n=12,563; CHARLS: 1,686). **g**, Care absence for IADL limitations (HRS: n=8,899; ELSA: n=1,984; SHARE: NA; CHARLS, n=7,713). **h**, Absence of formal care for IADL limitations (HRS: n=8,871; ELSA: n=1,940; SHARE: NA; CHARLS: 2,248). **i**, Absence of informal care for IADL limitations (HRS: n=8,870; ELSA: n=1,936; SHARE: n=8,395; CHARLS: 2,248). In panels (**a-i**), data are presented as adjusted means ± 95% confidence intervals (CIs). Dotted points represent the estimated proportion of people receiving no care (**a, d, g**), no informal care (**b, e, h**) and no formal care (**c, f, i**) at each wave, as estimated using the GEE model among the *Non-Dementia Sample*. In this additional analysis, sample were restricted to those who had more severe disabilities. Error bars indicate the 95% CIs. Estimates for certain waves in SHARE and CHARLS are unavailable due to lack of data (details provided in Supplementary Tables 3 & 4). Corrections for multiplicity were not made. Outcomes in panels (**a-c**) include samples with at least one ADL/IADL limitation. Panels (**d-f**) are limited to samples with at least one ADL limitation, and panels (**g-i**) to those with at least one IADL limitation. Adjusted Annual Percent Change (AAPC) estimates derived from the GEE model are shown on the right of each panel. Asterisks denote the significance of the AAPC (time trend): *** $p<0.001$, ** $p<0.01$, * $p<0.05$. "NA" indicates unavailable estimates. Two-sided tests were performed using GEE model, with detailed test statistics and P values provided in the corresponding **Source Data** for the figure.

Supplementary Material

Title: Absence of Care Among Community-Living Older Persons with Dementia and Disabilities: A Cross-National Analysis of Population Survey from 22 Countries

Supplementary Table 1. Characteristics of the *Non-Dementia Sample* in the HRS, ELSA, SHARE, and CHARLS, 2012-2018

Supplementary Table 2. Countries included in each study

Supplementary Table 3. Survey questions of ADL and IADL disabilities in the HRS, ELSA, SHARE, and CHARLS.

Supplementary Table 4. Survey questions of care received for ADL and IADL disabilities in the HRS, ELSA, SHARE, and CHARLS.

Supplementary Table 5. Availability of data (surveys and waves) for binary variables denoting absence of care

Supplementary Table 6. Missingness of variables, n (%), among all eligible samples (person-waves) who were asked the survey questions (*Dementia Sample*, 2012-2018)

Supplementary Table 7. Estimated correlation (ρ) between pairs of observations within a person in the GEE model (*Dementia Sample*, 2012-2018)

Supplementary Table 1. Characteristics of the *Non-Dementia Sample* in the HRS, ELSA, SHARE, and CHARLS, 2012-2018

	HRS (United States)		ELSA (England)		SHARE (19 Countries)		CHARLS (China)	
	Mean (SD) or n (%)	N	Mean (SD) or n (%)	N	Mean (SD) or n (%)	N	Mean (SD) or n (%)	N
Sociodemographic Characteristics								
Age, mean (SD)	68.8 (11.6)	14423	70.5 (10.0)	4903	72.1 (10.6)	18708	65 (8.7)	10473
Female, n (%)	8853 (61.4)	14423	2795 (57.0)	4903	11195 (59.8)	18708	6266 (59.8)	10473
Living alone, n (%)	3954 (27.4)	14423	1518 (31.0)	4903	5798 (31.0)	18708	844 (8.1)	10473
Education, n (%)								
Less than secondary	3290 (22.8)	14421	1749 (39.4)	4437	9705 (51.9)	18708	9866 (94.2)	10473
Upper secondary and vocational training	8934 (62.0)	14421	2158 (48.6)	4437	6324 (33.8)	18708	530 (5.1)	10473
Tertiary	2197 (15.2)	14421	530 (11.9)	4437	2679 (14.3)	18708	77 (.7)	10473
Disabilities								
Number of ADL/IADL limitations, mean (SD)	2.7 (2.2)	14422	2.4 (2.0)	4903	2.4 (2.1)	18708	2.5 (2.1)	10471
Number of ADL limitations, mean (SD)	1.6 (1.5)	14422	1.7 (1.4)	4903	1.4 (1.4)	18708	1.2 (1.4)	10472
Number of IADL limitations, mean (SD)	1.1 (1.2)	14423	.8 (1.0)	4903	.9 (1.2)	18708	1.3 (1.2)	10472
Absence of Care for Sample with Any ADL/IADL Limitation								
No care for ADL/IADL, n (%)	6120 (42.6)	14368	1945 (40.6)	4789	NA	NA[†]	4510 (43.1)	10464
No informal care for ADL/IADL, n (%)	6455 (45)	14339	1983 (42.0)	4720	NA	NA[†]	4588 (43.8)	10465
No formal care for ADL/IADL, n (%)	13280 (92.9)	14293	4011 (85.0)	4718	13426 (71.9)	18682	10418 (99.6)	10464
Absence of Care for Sample with Any ADL Limitation								
No care for ADL, n (%)	6325 (58.4)	10827	2647 (63.1)	4192	3665 (61.1)	6003[†]	4509 (73.1)	6166
No informal care for ADL, n (%)	6708 (62.1)	10801	2543 (60.7)	4192	4091 (68.1)	6006[†]	1323 (77.2)	1714[†]
No formal care for ADL, n (%)	10034 (93.5)	10733	3928 (93.7)	4192	12284 (85.3)	14403	1709 (99.7)	1714[†]
Absence of Care for Sample with Any IADL Limitation								
No care for IADL, n (%)	2448 (27.2)	8997	372 (17.0)	2185	NA	NA[†]	2315 (29.5)	7858

No informal care for IADL, n (%)	2693 (30.0)	8969	504 (23.6)	2140	NA	NA†	682 (29.8)	2288†
No formal care for IADL, n (%)	8320 (92.8)	8968	1751 (82.0)	2136	6505 (65.3)	9966	2283 (99.8)	2288†

Notes: *Non-Dementia Sample* represents samples (person-waves) with disabilities who never developed dementia during the study periods, who were included in the supplementary analyses. The descriptive statistics were estimated based on pooled person-wave data. N represents the total included person-waves, which could be different across measures depending on variable definitions and included survey waves. Supplementary Table S4 lists the included survey waves, while the extent of missing data among those eligible was similar as *Dementia Sample* and the data are available upon request.

Abbreviations: HRS = Health and Retirement Study; ELSA = English Longitudinal Study on Ageing; SHARE = Survey of Health, Ageing and Retirement in Europe; CHARLS = China Health and Retirement Longitudinal Study; ADL/IADL= basic or instrumental activities of daily living; ADL = basic activities of daily living; IADL = instrumental activities of daily living.

† The sample size in these cells was relatively smaller because the relevant survey questions were included only in specific survey waves. For details on the waves included for each measure, see Supplementary Table S4. “NA” indicates that the measure was not collected in any of the survey waves.

Supplementary Table 2. Countries included in each study

Study	Countries
HRS	United States
ELSA	England
SHARE	Austria, Germany, Sweden, Netherland, Spain, Italy, France, Denmark, Greece, Switzerland, Belgium, Israel, Czech Republic, Poland, Luxembourg, Portugal, Slovenia, Estonia, Croatia
CHARLS	China

Notes: HRS = Health and Retirement Study; ELSA = English Longitudinal Study on Ageing; SHARE = Survey of Health, Ageing and Retirement in Europe (SHARE); CHARLS = China Health and Retirement Longitudinal Study.

Supplementary Table 3. Survey questions of ADL and IADL disabilities in the HRS, ELSA, SHARE, and CHARLS.

	HRS (2012-2018)	ELSA (2012-2018)	SHARE (2013-2017)	CHARLS (2013-2018)
ADL limitation	Here are a few more everyday activities. Please tell me if you have any difficulty with these because of a physical, mental, emotional or memory problem. Again, exclude any difficulties you expect to last less than three months. Because of a health or memory problem do you have any difficulty with: • Dressing, including putting on shoes and socks. • Walking across a room. • Bathing or showering. • Eating, such as cutting up your food. • Getting in or out of bed. • Using the toilet, including getting up or down.	Here are a few more everyday activities. Please tell me if [^you have / [^name] has] any difficulty with these because of a physical, mental, emotional or memory problem. Again, exclude any difficulties you expect to last less than three months. Because of a health or memory problem, [^do you /does he /does she] have difficulty doing any of the activities on this card? • Dressing, including putting on shoes and socks. • Walking across a room. • Bathing or showering. • Eating, such as cutting up [^your / his / her] food. • Getting in or out of bed. • Using the toilet, including getting up or down.	Here are a few more everyday activities. Please tell me if you have any difficulty with these because of a physical, mental, emotional or memory problem. Again, exclude any difficulties you expect to last less than three months. • Dressing, including putting on shoes and socks. • Walking across a room. • Bathing or showering. • Eating, such as cutting up your food. • Getting in or out of bed. • Using the toilet, including getting up or down.	Here are a few more everyday activities. Please tell me if you have any difficulty with these because of a physical, mental, emotional or memory problem. Again, exclude any difficulties you expect to last less than three months. Because of a health or memory problem do you have any difficulty with: • Dressing? Dressing includes taking clothes out from a closet, putting them on, buttoning up, and fastening a belt. • Bathing or showering • Eating, such as cutting up your food? (Definition: By eating, we mean eating food by oneself when it is ready) • Getting in or out of bed. • Using the toilet, including getting up or down. • Controlling urination and defecation?
IADL limitation	Here are a few other activities which some people have difficulty with because of a physical, mental, emotional, or memory problem. Please tell me whether you have any	Asked together with ADL (See the leading question above) • Preparing a hot meal. • Shopping for groceries.	Asked together with ADL (See the leading question above) • Preparing a hot meal. • Shopping for groceries.	Asked together with ADL (See the leading question above) • Preparing hot meals? (Definition: By preparing hot meals, we mean preparing

	difficulty with each activity I name. If you don't do the activity at all, just tell me so. Exclude any difficulties that you expect to last less than three months. • Preparing a hot meal. • Shopping for groceries. • Making phone calls. • Taking medications. • Managing your money, such as paying bills and keeping track of expenses.	• Making telephone calls. • Taking medications. • Managing money, such as paying bills and keeping track of expenses.	• Making telephone calls. • Taking medications. • Managing money, such as paying bills and keeping track of expenses.	ingredients, cooking, and serving food) • Shopping for groceries? By shopping, we mean deciding what to buy and paying for it. • Making phone calls? • Taking medications? By taking medications, we mean taking the right portion of medication right on time. • Managing your money, such as paying your bills, keeping track of expenses, or managing assets?

Notes: The number of ADL/IADL limitations was constructed as the sum of the ADL and IADL limitations.

Supplementary Table 4. Survey questions of care received for ADL and IADL disabilities in the HRS, ELSA, SHARE, and CHARLS.

	HRS (2012-2018)	ELSA (2012-2018)	SHARE (2013-2017)	CHARLS (2013-2018)
Received any care for ADL limitations	If the respondent reports having difficulty with any ADL items, then they are asked immediately whether someone helps them with such activity (hence the definitions of each items have been clearly explained in the previous question). The questions are listed below: • Does anyone ever help you dress? • Does anyone ever help you get across a room • Does anyone ever help you bathe? • Does anyone ever help you eat • Does anyone ever help you get in or out of bed? • Does anyone ever help you use the toilet?	Starting in Wave 6 (2012-2018), if the respondent reports having difficulty with at least one ADL activity, then they are asked whether someone helps them with each activity. The questions are listed below: • [^Have/Has] [^you/[^name]] received help from anyone with dressing, including putting on shoes and socks, in the last month? • [^Have/Has] [^you/[^name]] received help from anyone with walking across a room, in the last month? • [^Have/Has] [^you/[^name]] received help from anyone with bathing or showering, in the last month? • [^Have/Has] [^you/[^name]] received help from anyone with eating, such as cutting up food, in the last month? • [^Have/Has] [^you/[^name]] received help from	Unlike HRS, ELSA, CHARLS, SHARE does not ask the respondents whether they receive help for each individual ADL items. Instead, SHARE asks if they receive informal helps from inside and outside the household respectively, and if they receive formal care at home. For informal care received inside household, the types of care are assumed to be ADL-related helps. • Is there someone living in this household who has helped you regularly during the last twelve months with personal care, such as washing, getting out of bed, or dressing? For informal care received outside household, the types of care (ADL vs IADL) can only be identified since Wave 6 (2015-2017). • Thinking about the last twelve months, has any family member from outside the household, any friend or neighbour given you any kind of help listed on this card?	If the respondent reports having difficulty with any ADL items, then they are asked immediately whether someone helps them with such activity (hence the definitions of each items have been clearly explained in the previous question). The questions are listed below: • Does anyone ever help you dress? • Does anyone ever help you bathe? • Does anyone ever help you eat • Does anyone ever help you get in or out of bed? • Does anyone ever help you use the toilet?

		anyone with getting in or out of bed, in the last month? - [^Have/Has] [^you/[^name]] received help from anyone with using the toilet, including getting up or down, in the last month?	- Which types of help has this person provided in the last twelve months? [personal care, e.g., dressing, bathing or showering, eating, getting in or out of bed, using the toilet] For formal care, the types of care (ADL vs IADL) are identifiable in all waves from 2013 to 2017. - During the last twelve months, did you receive in your own home any professional or paid services listed on this card due to a physical, mental, emotional or memory problem? [Help with personal care, e.g., getting in and out of bed, dressing, bathing and showering] Therefore, complete care for ADLs, including care received inside or outside the household and formal home care can only be measured in 2015- 2017.	
Received any care for IADL limitations	If the respondent reports having difficulty with any IADL items, then they are asked immediately whether someone helps them with such activity (hence the definitions of each items have been clearly explained in the previous	Starting in Wave 6 (2012-2018), if the respondent reports having difficulty with at least one IADL activity, then they are asked whether someone helps them with each activity. The questions are listed below:	Unlike HRS, ELSA, CHARLS, SHARE does not ask the respondents whether they receive help for each individual IADL items. Instead, SHARE asked if they receive informal helps from inside and outside the household respectively, and if	If the respondent reports having difficulty with any IADL items, then they are asked immediately whether someone helps them with such activity (hence the definitions of each items have been clearly explained in the previous

	question). The questions are listed below: - Does anyone help you prepare hot meals? - Does anyone help you shop for groceries? - Does anyone help you make telephone calls? - Does anyone help you take medications? - Does anyone help you manage your money?	- [^Have/Has] [^you/[^name]] received help from anyone with shopping for groceries, in the last month? - [^Have/Has] [^you/[^name]] received help from anyone with taking medications, in the last month? - [^Have/Has] [^you/[^name]] received help from anyone with doing work around the house or garden, in the last month? - [^Have/Has] [^you/[^name]] received help from anyone with managing money, such as paying bills and keeping track of expenses, in the last month?	they receive formal care at home. For informal care received inside household, NO care is asked for IADL items. For informal care received outside household, the types of care (ADL vs IADL) can only be identified since Wave 6 (2015-2017). For formal care, the types of care (ADL vs IADL) are identifiable in all waves from 2013 to 2017. Therefore, complete care for IADLs (including both informal and formal) can NOT be meaningfully measured in SHARE because informal care received from inside the household are not asked for IADLs.	question). The questions are listed below: - Does anyone help you do household chores? - Does anyone help you prepare hot meals? - Does anyone help you shop for groceries? - Does anyone help you make telephone calls? - Does anyone help you take medications? - Does anyone help you manage your money?
Received any informal care for ADL limitations	If someone helps with any ADL activity, the respondents are asked for the relationships of up to 7 people who most often help them with ADLs (ADL items altogether). The questions are listed below: Who most often helps you with [getting across a room/dressing /bathing/eating/getting (in/out of) bed/using the toilet]?	Starting in Wave 6 (2012-2018), respondents who receive help are asked to separately list the relationships for all the people who help according to the following groupings of ADL items: mobility (walking 100 yards, climbing several flights of stairs, climbing one flight of stairs, walking across a room, getting in or out of bed, using the toilet),	SHARE asks the respondents if they receive informal helps from inside and outside the household respectively. For informal care received inside household, the types of care are assumed to be ADL-related helps. - Is there someone living in this household who has helped you regularly during the last	In wave 2 (2013), the respondents who received help are asked for the relationship of up to 7 most often helpers for all ADL items altogether (but not for each). However, in wave 3-4 (2015-2018), the respondents who received help are asked for the most often helpers for ADL and IADL items altogether (but not separately for ADL items and

	• Spouse or partner • Son • Stepson • Spouse or partner of son • Daughter • Stepdaughter • Spouse or partner of daughter • Grandchild • Father • Father-in-law • Mother • Mother-in-law • Brother • Brother-in-law • Sister • Sister-in-law • Other relative • Other individual • Former child-in-law • Grandchild's spouse or partner	bathing/showering or getting dressed, eating. Informal helpers include: • Husband/Wife/Partner • Son • Daughter • Grandchild • Sister • Brother • Other relative • Friend • Neighbor	twelve months with personal care, such as washing, getting out of bed, or dressing? For informal care received outside household, the types of care (ADL vs IADL) can only be identified since Wave 6 (2015-2017). • Thinking about the last twelve months, has any family member from outside the household, any friend or neighbor given you any kind of help listed on this card? • Which types of help has this person provided in the last twelve months? [personal care, e.g., dressing, bathing or showering, eating, getting in or out of bed, using the toilet]	IADL items). Therefore, helpers' types can only be identified for ADL items in 2013, but not in later waves. The questions in 2013 are listed below: Who most often helps you with [dressing/bathing/eating/getting in out of bed/using the toilet]? • Spouse • Ex-spouse • Mother • Father • Mother-in-law • Farther-in-law • Children [preload name] • Sibling • Sibling of spouse • Brother-in-law, sister-in-law • Grandson • Granddaughter • Other relative
Received any formal care for ADL limitations	Asked together with ADL informal helpers. See the detailed description above. Who most often helps you with [getting across a room/dressing /bathing/eating/getting (in/out of) bed/using the toilet]? • Nursing home • Organization • Employee of facility • Paid helper	Asked together with ADL informal helpers. See the detailed description above. A list of formal caregivers include: • Home care worker/ home help/ personal assistant; • A member of the reablement / intermediate care staff team; • Voluntary helper;	For formal care, the types of care for ADLs are identifiable in all waves during 2013-2017. • During the last twelve months, did you receive in your own home any professional or paid services listed on this card due to a physical, mental, emotional or memory problem? [Help with personal care, e.g., getting in and	Asked together with ADL informal helpers in 2013. See the detailed description above. Who most often helps you with [dressing/bathing/eating/getting in out of bed/using the toilet]? • Paid helper (such as nanny) • Volunteer or employee of facility • Nursing home

		• Warden / Sheltered housing Manager; • Cleaner; • Council's handyman; • Member of staff at the care/nursing home • Other formal helper	out of bed, dressing, bathing and showering]	
Received any informal care for IADL limitations	If someone helps with any ADL activity, the respondents are asked for the relationships of up to 7 people who most often help them with IADLs (IADL items altogether). The questions are listed below: Who most often helps you with [prepare hot meals, /shop for groceries, /make telephone calls, /take medications]? Who most often helps you manage your money? • Spouse or partner • Son • Stepson • Spouse or partner of son • Daughter • Stepdaughter • Spouse or partner of daughter • Grandchild • Father • Father-in-law • Mother • Mother-in-law • Brother • Brother-in-law • Sister	Starting in Wave 6 (2012-2018), respondents who receive help are asked to separately list the relationships for all the people who help according to the following groupings of IADL items: shopping for groceries or doing work around the house or garden, taking medication, or managing money. Informal helpers include: • Husband/Wife/Partner • Son • Daughter • Grandchild • Sister • Brother • Other relative • Friend • Neighbor	SHARE asked if they receive informal helps from inside and outside the household respectively. For informal care received inside household, NO care is asked for IADL items. For informal care received outside household, the types of care (ADL vs IADL) can only be identified since Wave 6 (2015-2017). • Thinking about the last twelve months, has any family member from outside the household, any friend or neighbour given you any kind of help listed on this card? • Which types of help has this person provided in the last twelve months? [practical household help, e.g. with home repairs, gardening, transportation, shopping, household chores; Help with paperwork, such as filling out forms,	In wave 2 (2013), the respondents who received help are asked for the relationship of up to 6 most often helpers for all IADL items altogether (but not for each). However, in wave 3-4 (2015-2018), the respondents who received help are asked for the most often helpers for ADL and IADL items altogether (but not separately for ADL items and IADL items). Therefore, helpers' types can only be identified for IADL items in 2013, but not in later waves. The questions in 2013 are listed below: Who most often helps you with [doing household chores/preparing hot meals/shopping/making telephone calls/taking medications]? • Spouse • Ex-spouse • Mother • Father • Mother-in-law • Farther-in-law

	- Siter-in-law - Other relative - Other individual - Former child-in-law - Grandchild's spouse or partner		settling financial or legal matters] Therefore, informal care for IADLs can NOT be meaningfully measured in SHARE because informal care received from inside the household are not asked for IADLs.	- Children [preload name] - Sibling - Sibling of spouse - Brother-in-law, sister-in-law - Grandson - Granddaughter - Other relative
Received any formal care for IADL limitations	Asked together with IADL informal helpers. See the detailed description above. Who most often helps you with [prepare hot meals, /shop for groceries, /make telephone calls, /take medications]? Who most often helps you manage your money? - Nursing home - Organization - Employee of facility - Paid helper	Asked together with IADL informal helpers. See the detailed description above. A list of formal helpers include: - Home care worker/ home help/ personal assistant; - A member of the reablement / intermediate care staff team; - Voluntary helper; - Warden / Sheltered housing Manager; - Cleaner; - Council's handyman; - Member of staff at the care/nursing home - Other formal helper	For formal care, the types of care for IADLs are identifiable in all waves during 2013-2017. - During the last twelve months, did you receive in your own home any professional or paid services listed on this card due to a physical, mental, emotional or memory problem? [Help with domestic tasks, e.g., cleaning, ironing, cooking; Help with meals, i.e., ready-made meals provided by a municipality or a private provider; Help with other activities, e.g., filling a drug dispenser]	Asked together with IADL informal helpers in 2013. See the detailed description above. Who most often helps you with [doing household chores/preparing hot meals/shopping/making telephone calls/taking medications] - Paid helper (such as nanny) - Volunteer or employee of facility - Nursing home

Notes: The (informal/formal) care received for ADL/IADL altogether were mostly constructed based on the (informal/formal) care received for ADLs and IADLs separately. In some cases, such as CHARLS 2015-2018, the informal/formal care received for ADL/IADL were asked in one question for all ADL/IADL items but not for ADLs and IADLs separately; and the informal/formal care received were constructed based on that question.

Supplementary Table 5. Availability of data (surveys and waves) for binary variables denoting absence of care

Variables	Available surveys and waves
Absence of Care for Sample with Any ADL/IADL Limitation	
A. No care for ADL/IADL	HRS (2012-2018), ELSA (2012-2018), CHARLS (2013-2018)
B. No informal care for ADL/IADL	HRS (2012-2018), ELSA (2012-2018), CHARLS (2013-2018)
C. No formal care for ADL/IADL	HRS (2012-2018), ELSA (2012-2018), SHARE (2013-2017), CHARLS (2013-2018)
Absence of Care for Sample with Any ADL Limitation	
D. No care for ADL	HRS (2012-2018), ELSA (2012-2018), SHARE (2015-2017), CHARLS (2013-2018)
E. No informal care for ADL	HRS (2012-2018), ELSA (2012-2018), SHARE (2015-2017), CHARLS (2013)
F. No formal care for ADL	HRS (2012-2018), ELSA (2012-2018), SHARE (2013-2017), CHARLS (2013)
Absence of Care for Sample with Any IADL Limitation	
G. No care for IADL	HRS (2012-2018), ELSA (2012-2018), CHARLS (2013-2018)
H. No informal care for IADL	HRS (2012-2018), ELSA (2012-2018), CHARLS (2013)
I. No formal care for IADL	HRS (2012-2018), ELSA (2012-2018), SHARE (2013-2017), CHARLS (2013)

Notes: HRS = Health and Retirement Study; ELSA = English Longitudinal Study on Ageing; SHARE = Survey of Health, Ageing and Retirement in Europe; CHARLS = China Health and Retirement Longitudinal Study; ADL/IADL= basic or instrumental activities of daily living; ADL = basic activities of daily living; IADL = instrumental activities of daily living.

Supplementary Table 6. Missingness of variables, n (%), among all eligible samples (person-waves) who were asked the survey questions (*Dementia Sample*, 2012-2018)

Variables	HRS (United States) n (%)	HRS (United States) Total Eligible	ELSA (England) n (%)	ELSA (England) Total Eligible	SHARE (19 Countries) n (%)	SHARE (19 Countries) Total Eligible	CHARLS (China) n (%)	CHARLS (China) Total Eligible
Disabilities								
Number of ADL/IADL limitations	2 (0)	2717	0 (0)	1125	0 (0)	5128	1 (0.05)	2067
Number of ADL limitations	0 (0)	2717	0 (0)	1125	0 (0)	5128	1 (0.05)	2067
Number of IADL limitations	2 (0.07)	2717	0 (0)	1125	0 (0)	5128	0 (0)	2067
Absence of Care for Sample with Any ADL/IADL Limitation								
No care for ADL/IADL	1 (0.04)	2717	23 (2.0)	1125	NA	NA†	1 (0.05)	2067
No informal care for ADL/IADL	11 (0.40)	2717	46 (4.1)	1125	NA	NA†	1 (0.05)	2067
No formal care for ADL/IADL	20 (0.74)	2717	47 (4.2)	1125	7 (0.14)	5128	1 (0.05)	2067
Absence of Care for Sample with Any ADL Limitation								
No care for ADL	3 (0.15)	2043	0 (0)	922	46 (2.4)	1890†	0 (0)	1294
No informal care for ADL	9 (0.44)	2043	0 (0)	922	44 (2.3)	1890†	0 (0)	347†
No formal care for ADL	27 (1.3)	2043	0 (0)	922	4 (0.10)	3842	0 (0)	347†
Absence of Care for Sample with Any IADL Limitation								
No care for IADL	1 (0.05)	2198	32 (4.3)	739	NA	NA†	4 (0.23)	1714
No informal care for IADL	14 (0.64)	2198	49 (6.6)	739	NA	NA†	1 (0.19)	519†
No formal care for IADL	14 (0.64)	2198	50 (6.8)	739	6 (0.15)	3958	1 (0.19)	519†

Notes: *Dementia Sample* represents samples (person-waves) with disabilities who developed dementia during the study periods, who were included in the analyses. The missingness were estimated for total eligible sample (person-waves) for each measure. The eligible samples could be different across measures depending on variable definitions and included survey waves. Supplementary Table S4 lists the included survey waves, while this table details the eligible sample for each measure along with the extent of missing data among those eligible.

Abbreviations: HRS = Health and Retirement Study; ELSA = English Longitudinal Study on Ageing; SHARE = Survey of Health, Ageing and Retirement in Europe; CHARLS = China Health and Retirement Longitudinal Study; ADL/IADL= basic or instrumental activities of daily living; ADL = basic activities of daily living; IADL = instrumental activities of daily living.

† The sample size in these cells was relatively smaller because the relevant survey questions were included only in specific survey waves. For details on the waves included for each measure, see Supplementary Table S4. “NA” indicates that the measure was not collected in any of the survey waves.

Supplementary Table 7. Estimated correlation (ρ) between pairs of observations within a person in the GEE model (*Dementia Sample*, 2012-2018)

Variables	HRS (United States)	ELSA (England)	SHARE (19 Countries)	CHARLS (China)
Absence of Care for Sample with Any ADL/IADL Limitation				
No care for ADL/IADL	0.213	0.173	NA	0.161
No informal care for ADL/IADL	0.156	0.307	NA	0.194
No formal care for ADL/IADL	0.474	0.362	0.484	0.041
Absence of Care for Sample with Any ADL Limitation				
No care for ADL	0.364	0.446	0.196	0.384
No informal care for ADL	0.313	0.448	0.435	NA
No formal care for ADL	0.582	0.434	0.495	NA
Absence of Care for Sample with Any IADL Limitation				
No care for IADL	0.353	0.187	NA	0.211
No informal care for IADL	0.290	0.256	NA	NA
No formal care for IADL	0.419	0.323	0.381	NA

Notes: *Dementia Sample* represents samples (person-waves) with disabilities who developed dementia during the study periods, who were included in the analyses. Generalized Estimating Equations (GEE) models were used to estimate wave-specific longitudinal trends in the absence of care for each study, accounting for within-person correlation. Each GEE model employed a binomial family with a logit link and specified an exchangeable correlation structure, which fit the data better than other correlation structures, such as first-order autoregressive (AR-1) and unstructured. The AR-1 structure would drop dementia samples with only one observation, and the unstructured correlation reached similar results as the exchangeable structure although some models failed to converge with more parameters to estimate. This table provides the estimated correlation (ρ) between pairs of observations for each outcome with exchangeable correlation structure in each GEE model (i.e., the main setting).

Abbreviations: HRS = Health and Retirement Study; ELSA = English Longitudinal Study on Ageing; SHARE = Survey of Health, Ageing and Retirement in Europe; CHARLS = China Health and Retirement Longitudinal Study; ADL/IADL= basic or instrumental activities of daily living; ADL = basic activities of daily living; IADL = instrumental activities of daily living.