Caregiving and Cognitive Impairment Around the World

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Introduction: Populations around the world are aging rapidly and providing care for elderly individuals is becoming an increasingly difficult task. The cost of formal care is extremely high, whether borne directly by families themselves or paid for through public insurance programs and formal caregivers are often in short supply. Perhaps as a result, regardless of the mechanism used to finance care and/or determine eligibility for public benefits, in country after country, families provide the majority of care (Gruber, McGarry, & Hanzel, 2025).

In recognition of the challenges facing societies and the growing need to plan for the future, in 2020, the National Bureau of Economic Research launched the International Long-term Care project. The project draws on an international group of distinguished researchers, all experts in the topic of long-term care, to examine how care is provided in different countries. The long-term goal of the project is to leverage differences across countries in policies and populations to learn how those countries, and others similarly situated, can best provide care going forward. It is hoped that through continued analyses and discussions on various issues regarding the provision of care, important information can be gleaned about what works and what doesn't.

In the first volume (Gruber and McGarry 2025), chapters were contributed by 10 countries with each chapter documenting the landscape for providing long-term care in that nation, the structure of public insurance programs, the role of the family and informal caregivers, and the cost of this care shouldered by public and private entities. The countries contributing to the volume were selected because despite having similarly well-developed economies and aging populations, they differ substantially in how long-term care is provided and in how it is funded.

Several themes emerged from that first volume. First, regardless of the structure of the long-term care system, governments fund the majority of formal care, typically close to two-thirds of care. This pattern holds even in countries such as the United States and England that do not have national long-term care insurance programs. Second, despite the sizable public contributions towards formal care, families shoulder much of the burden; in every country included in the study, including those with generous public long-term care insurance programs, the majority of care is provided informally by family and friends. Finally, the total costs of care, and those of informal care in particular, are extremely large relative to GDP and likely to grow over time.

Cognitive Impairments: As we look to the future, in terms of the demands these long-term care needs will place the public health care infrastructure and on families, one of the largest challenges will be the prospect of caring for the growing number of individuals with cognitive impairments. Between 2019 and 2050, the number of individuals living with dementia globally is expected to more than double from 57 million to over 150 million (Nichols et al., 2022). And although there is evidence that the fraction of individuals with Alzheimer's disease and Alzheimer's disease related dementias (AD/ADRD) at a given age is declining, the dramatic growth in the sheer number of elderly foretells a significant increase in the number of individuals with cognitive difficulties.

In this second volume of the International Long-term Care project, we therefore turn our focus to examining the provision of care for individuals with cognitive limitations and how this care compares to that for the elderly who suffer solely from physical limitations. We look at these differences both within and across our set of countries. We include nine of the 10 countries participating in the inaugural volume: Denmark, England, Italy, Germany, Japan, the Netherlands, Spain, Singapore and the United States.[1]

Because we are using survey data in most cases, we do not have medical diagnoses of dementia or cognitive impairment. We therefore want to be clear that what we are studying is care for those with cognitive limitations. We classify individuals as having cognitive limitations or impairments (and we use the terms interchangeably) based on their performance on sets of questions contained in the population-based surveys employed here. These questions ask the respondent to perform tasks such as counting backwards, remembering a list of words, doing simple subtraction, and naming the calendar day and date. Individuals who perform exceptionally poorly relative to others in the sample are classified as having cognitive limitations.

While we endeavor to standardize measures of both cognitive and physical impairments across countries to the extent possible, there remain differences in the specific questions asked, in which individuals are included in the survey framework, and in underlying educational levels, all of which make a "one-size-fits-all" approach to designating a cognitive limitation impractical. As such, researchers from each country use their discretion in how best to define cognitive impairment based on the distribution of cognitive performance scores in their country. Thus,

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[1] The researchers from Canada lacked the necessary data to undertake the analyses in this chapter.

rather than examining care for those with dementia, we are examining the care provided to those in the population with extremely low scores on cognitive tests.[2]

We define physical impairment based on standard measures indicating whether the respondent (or their proxy) reports that they have difficulty performing two or more activities of daily living (ADLs). This measure is comparable across countries for the most part with exceptions in only a few cases.[3]

In terms of care, we examine three types of care: home care provided by a family member or friend which we term informal care, although we recognize that such care is clearly often crucial and provided on a regular, ongoing basis. We also include formal care which we define as care as paid care provided by a health care worker in one's home. And finally, nursing home care for care provided in an institution.[4]

Although much of the focus of the chapters is on comparisons between care for the cognitively and physically impaired *within* country, we find remarkably consistent patterns *across* most countries in the relative treatment of the cognitively and physically impaired. First, in the majority of settings, individuals with cognitive limitations, regardless of their physical capacities, are *less* likely to receive formal care than individuals with physical impairments alone. We speculate that this pattern arises in part because the criteria used to determine eligibility for formal care in many cases, criteria which focus on the presence of physical limitations. In the United States, for example, most private long-term care insurance policies require individuals to have an inability to perform two or more ADLs—such as bathing, dressing, toileting, getting in and out of bed, walking across a room or eating—to qualify for benefits. Individuals with cognitive impairments or dementia may be able to perform these tasks but may still require substantial supervision (such as with bathing), or may simply be unable to be left alone for extended periods of time. The omission of this more supervisory role when determining care needs, likely adds substantially to the burden families face. Absent eligibility for paid care, such

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[2] Allowances are also made in most cases for the classification of individuals whose surveys are completed by proxy respondents.

[3] Activities of daily living include dressing, bathing, eating, toileting, getting in and out of bed, and walking across a room.

[4] While there are a variety of assisted living options in many countries, we endeavor to limit this category to skilled nursing facilities.

individuals may be forced to rely on families for the needed support, creating a difficult situation for many families.

Notably, changes are rapidly beginning to take place in this regard. Japan now has an extensive program for cognitively impaired individuals including specialized day care services with staff trained to work with this population and “structured social interactions” all designed to allow cognitively impaired individuals to remain in the community. Germany too has expanded coverage of cognitive impairments, with the most recent expansion in 2017, and similar programs exist or are being developed in other countries. Also receiving a great deal of attention in the popular press are the “dementia villages” in the Netherlands (Plockova, 2023). The individual country chapters contain more detailed discussions of the assessment of need with respect to cognitive limitations as well as programs for assistance to this group.

The second pattern that regularly appears is that while those with cognitive limitations are less likely to receive care, those who *are* receiving assistance receive *far more* hours of care and incur far greater costs of care than those with physical limitations alone. The differences in the per capita cost of care are large enough that in many cases, the aggregate costs of care for the smaller cognitively impaired population is actually larger than the aggregate costs for those with physical limitations alone.

Finally, while not brought out in the statistics that address solely the current situation, the impending rise of the elderly population portends increases in both types of care and the need for countries to prepare to address these needs.

In the remainder of this introductory chapter, we highlight some of the results across countries drawing comparisons in the caregiving patterns and focusing on common themes. Each chapter in this volume provides much more detail and delves into nuances that there is little space for here; we encourage the interested reader to explore the rest of the volume. Finally, we note instances in which data limitations restrict our ability to make inferences regarding certain aspects of care or to draw comparisons across countries when similar statistics or information do not exist. We view this component as an important contribution and hope it receives attention from those charged with collecting data on the needs of our elderly populations.

Defining Cognitive impairment:

As noted above, countries differ slightly in their definitions of cognitive impairment, but all except Japan use responses to sets of survey questions designed to assess cognitive capacity. [5] Individuals are defined as cognitively impaired if they score in the lower tail of the distribution of scores for that country. Most countries place this cut-off point at approximately the sixth percentile of the distribution. Individuals with these low cognitive scores are considered cognitively impaired regardless of whether they also have physical impairments, thus some in this group report physical limitations and some do not. We thus use a lexicographic definition of needs with cognitive impairment defined first (irrespective of physical impairments), then physically impaired, and then no impairment.

Because the chapters rely almost exclusively on survey-based measures of cognition, an important consideration is how best to capture individuals with cognitive limitations severe enough to prevent them from responding to a survey. In most cases, the surveys used in this volume address this issue through the use of proxy respondents rather than omitting these intended respondents entirely. The extent to which proxy responses are solicited and the questions that are asked of them differs across countries. Researchers from each country chose how best to incorporate proxy responses in their analyses, but typically information from the proxy respondent regarding the cognitive fitness of the sample person is used to provide a classification. Where information is available, the vast majority of those individuals with proxy responses do not complete the survey themselves because of a cognitive impairment. This pattern points strongly to the central role that the inclusion of proxy responses can play in understanding the distribution of impairments in a population. Surveys that do not invest in obtaining proxy responses likely miss a large fraction of the impaired population. Because those with proxy responses are also shown to be far more likely to be receiving care, estimates of the provision of care are also underestimated when failing to include those unable to respond to the survey themselves.

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[5] Japan uses diagnoses from medical records to classify an individual as cognitively impaired or not. We note also that the Netherlands uses the Mini-Mental State Exam (MMSE) the questions of which differ from those used by the other seven countries and are geared more towards severe cognitive limitations. As illustrated later, the distribution of scores for the Netherlands thus differs sharply from those for the other countries.

Figure 1 showcases the distribution of cognition scores across countries by age group. The blue bars illustrate the scores for those ages 65-84 and the red bars illustrate the distribution for those ages 85 or older. For the majority of countries, the total possible score is 29, but the maximum score may be higher or lower as is apparent from the horizontal axis in the figure and described in more detail in the individual country chapters. While the point totals differ across countries, with the exception of the Netherlands which uses a different set of questions (see footnote 5) the relative distributions by age are remarkably similar.[6] The dramatic decline in cognitive performance with age is striking—with the distribution of scores for the 85+ population shifted substantially to the left in all countries. This pattern is consistent with evidence from the medical literature regarding the increase in dementia with age (e.g. Olfson, et al., 2021). We note this strong pattern exists despite the expectation of selective mortality with those who survive to older ages typically having greater levels of education, income and wealth, all of which are associated with better cognitive performance.[7]

For individuals with a proxy response, no cognitive score is available, so they cannot contribute to the distribution of scores. However, the prevalence of proxy responses is of interest, and we denote the fraction of such response in the left-most sides of the figures, again differentiating by age category. Not only is there a strong relationship between age and cognitive performance as seen with the mostly bell-shaped curves, but there is also a strong positive relationship between age and the probability of a proxy response, a pattern apparent in the relative heights of the pair of bars leftmost in the figures. This pattern is consistent with cognitive and/or health issues necessitating the use of a proxy respondent and hints at the potential needs of those with proxy responses, and the importance of their inclusion in the study.

Great care was taken in our analyses to evaluate both the physical and cognitive status of those individuals with proxy responses for whom such information is available and to classify the individual accordingly as impaired or not impaired. Where proxy responses are obtained, it is typical for the proxy respondent to be asked the reason that the intended respondent was unable

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[6] The distributions for Japan are not shown because the Japan analysis does not use survey data / cognition scores to identify cognitive impairment, instead using medical diagnoses. The Netherlands uses a different set of cognitive performance questions (the MMSE) and while the shape of distribution differs, the age pattern still holds.

[7] Operating the opposite direction is the rise in educational levels over time, particularly in countries such as Singapore that have had rapid economic growth. This increase in education across cohorts suggest that younger cohorts will have higher levels of schooling, offsetting the selective mortality.

to complete the interview; cognitive difficulties are consistently the most popular answer. In addition (or alternatively) in some cases, proxy respondents are asked to assess the cognitive abilities of the intended respondent. Countries make use of this information to classify proxy responses as cognitively impaired when appropriate. Proxy respondents are also typically asked about physical limitations of the intended respondent, so physical limitations can be assessed as well.

We also note the difference in the use of proxy interviews across countries. In the sample used in the Netherlands there are no proxy responses, while the number in Germany, even among the oldest group is low, approximately 5 percent. In contrast, for the oldest age group in Denmark, over 25 percent of the responses are completed by proxy. Most countries, England, Italy, Singapore, and the United States, are around 15 percent. These differences are important when we assess the fraction with cognitive impairments and the fraction using nursing homes, and we encourage the reader to keep these differences in mind.

We also suggest that our results in the various chapters pointing to the use of home care and nursing home care by those with proxy responses attest to the need for surveys to work to include an option for proxy responses when individuals are unable or unwilling to complete a survey themselves.

While we define a set of individuals in each country as “cognitively impaired,” cognitive scores are strongly associated with the receipt of personal care even for those whose scores place them well above the cutoff for impairment. Figures 2a-2c illustrate this point by examining the use of care across cognitive score quintiles for each of the three types of care: informal home care from a family member or friend in figure 2a, formal (paid) home care in figure 2b, and nursing home / institutional care in figure 2c. Proxy responses that are considered to be indicative of cognitive impairment are included in the lowest quintile of cognitive scores.[8] Unsurprisingly, those in the lowest 20th percentile, with respect to cognitive score (or determined to be impaired by a proxy), denoted by the dark blue bars, are substantially more likely to be receiving care than those in four upper quintiles. For example, in Figure 2a, illustrating the receipt of informal care, the

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[8] Breakpoints for the quintiles are determined for the portion of the sample that have cognitive scores (the non-proxy respondents) thus this lowest quantile actually has more than 20 percent of the full sample, albeit just 20 percent of those with cognitive scores.

United States, 32 percent of those in the lowest quintile receive informal care compared to approximately 9 percent in the two upper quintiles combined. Interestingly, the pattern exhibits a nearly linear decline in care usage across the quintiles. Continuing with the example of informal care in the United States, the fraction of those receiving care in the four higher quintiles is 15, 9, 6, and 3 percent. This pattern holds across all countries and all types of care, with only minor deviation from linear declines due to sample sizes.[9]

Figure 2b repeats this exercise for formal home care; the patterns are the same, although there are lower frequencies of care throughout. Consider again the case of the United States. The probability of receiving formal home care falls from 11 percent in the lowest quintile to just 1 percent in the highest. Similar patterns exist across countries. For example, the probabilities of care across quintiles in Spain are 21, 13, 11, 8, and 7 percent. Only Germany and Italy exhibit non-monotonic declines, but even in these cases the pattern is clear.

We also note the large variation across countries in the fraction of the sample receiving care. We do not make too much of these differences because of differences in the sampling frames for surveys. However, the relatively low use of formal care in England and the United States (figure 2b) across all quintiles when compared to countries like Germany and the Netherlands is noteworthy, and consistent with the lack of a national long-term care insurance program in England or the United States, both providing only means-tested benefits in most cases. Somewhat more surprising is the similarly low use in Denmark among all but those in the lowest cognitive quintile, despite the well-developed and relatively generous system of long-term care that exists in Denmark.

Because of differences in survey sampling frames and the availability of other data, not all countries have information on nursing home residents. Figure 2c illustrates nursing home use by cognitive quintile for the smaller subset of countries for which such data are available. Nursing home use is extremely rare outside the lowest quintile, but the pattern continues to hold, although the probabilities of nursing home care outside of the lowest quintile are vanishingly small.

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[9] Samples in some countries can be small, and when divided into quintiles and focusing on those needing care, the numbers are indeed tiny. For example, the total sample size in the Netherlands is xxxx

Also of note are the relative fractions of individuals receiving each type of care as illustrated on the vertical axis in figures 2a-2c. With the exception of the Netherlands and somewhat less so, Germany, informal care is the dominant mode of care.

While individuals who were reported by proxy to be cognitively impaired were included in the lowest cognitive score quintile, if we examine the use of care for those sample individuals with proxy interviews who were *not* reported to have cognitive difficulties (i.e. the "not cognitively impaired" proxy interviews) their use of care is also at a far greater rate than respondents in the second through fifth quintiles and often at a greater rate than those non-proxy respondents in the lowest cognitive quintile. Thus, even those with proxy interviews who are not cognitively impaired, are intensive users of care. This result (not shown) holds across countries and highlights again the importance of obtaining proxy interviews in population-based surveys if we are to understand more generally the needs of the elderly population. We return to this point in the section below.

Cognitive Impairment and Type of Care

Perhaps it is not too surprising that those with limited cognitive abilities need a great deal of care. A key component of this volume is thus examining how care received by these cognitively impaired individuals compares with care for those with physical limitations, but who are not cognitively impaired.[10] Figure 3 provides this comparison showing the fraction of those with cognitive impairments and those with only physical impairments who receive care, by country. We also include here the fraction of those whom we classify as not impaired. Because we defined physically impaired as reporting difficulty with *two* or more activities of daily living (ADLs) some of these individuals have difficulty with a single ADL are receiving assistance in that sphere.

In all countries except the United States (and Japan which employs a different sampling mechanism), the likelihood of receiving care is somewhat larger for those with physical impairments than cognitive impairments, although the probabilities are similar for the two types of impairments. Where there are larger differences (e.g. Singapore, Spain, and perhaps Italy),

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[10] Recall that cognitively impaired individuals may or may not report physical limitations as well.

those with physical limitations are more likely to receive care than those with cognitive limitations. The one country that stands out as different in this regard is Japan in which those with cognitive impairments are 50 percent more likely to receive care than those with physical impairments (75 versus 50 percent). However, this difference is an artifact of the sample and the definition of cognitive impairment used by Japan in this volume, which defines cognitively impaired based on a medical diagnosis obtained from administrative records. The cognitively impaired group in Japan thus consists of those with sufficient impairments that they have received medical care and are thus also likely to be benefiting from Japan's generous long-term care insurance system—one that has built in specialized programs to provide care for the cognitively impaired. While Singapore does make extensive use of migrant domestic workers (MDW) to provide care, the 100 percent assistance rate for those with physical impairments in Singapore is a simple artifact of the data in which information on physical limitations is obtained only for those receiving care.[11]

Another striking result from Figure 3 is that if we imagine turning the chart upside down to examine at the fraction *not receiving care*, many individuals with physical or cognitive impairments appear to have unmet needs. While the bars rise above 50 percent in most cases, indicating that more than half of those needing care are receiving it; the bars rarely even reach 75 percent so more than a quarter of the impaired populations are not getting any help, not even informal assistance from a family member. Perhaps optimistically, one might posit that some fraction of those designated as impaired may be sufficiently mildly impaired such that they do not require assistance. However, in most countries the survey questions used to identify physical impairments first ask if an individual (or proxy) reports that they have difficulty performing an activity of daily living, meaning that the definition of impairment and the need for assistance are mechanically linked.[12] As a result, it is likely that there are unmet care needs resulting from a combination of gaps in the formal care system, limits on capacity or staffing shortages, and a

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[11] The Singaporean government facilitates the use of migrant domestic workers (MDW) for caregiving in that government levies for MDW caring for the elderly are only 20 percent of those levies for MDW assisting the non-elderly.

[12] In the US Health and Retirement Study, the questions are of the form: "Because of a health or memory problem do you have any difficulty with (bathing or showering)?" The English Longitudinal Study of Ageing, the questions are of the form, "Please tell me if you have any difficulty with these [activities] because of a physical, mental, emotional or memory problem." And then lists the activities. For the Survey of Health Ageing and Retirement in Europe the questions are similar. "Please tell me if you have any difficulty with these activities because of a physical, mental, emotional or memory problem."

lack of informal caregivers. Such unmet needs may place older adults at risk of adverse health events like falls, malnutrition, pressure sores, and even death. Almost certainly, unmet personal care needs adversely affect quality of life.

While many of those with impairments do not receive assistance, a fraction of those classified as having *no impairments* are reported to be receiving care. Because our definition of physically impaired is needing help with two or more ALDs, these individuals may have a single impairment and receive help with that activity. In the remaining figures, we exclude this unimpaired group to focus more clearly on the difference between cognitively and physically impaired.

A key difference across these countries that was highlighted in the earlier volume (Gruber and McGarry, 2025), is the location where care is delivered, particularly in the use of nursing homes. In Figures 4a-4c we break down the care receipt patterns from Figure 3 by type of care, to illustrate the use of different modes of care by type of impairment and by country. Figure 4a reports the usage rates for informal care. Because, as we have seen, informal care is the primary mode of assistance, the patterns for informal care in figure 4a follow those for the overall provision of care in figure 3. Excluding Japan which has different patterns due to the sample used, there appears to be a greater use of informal care among those with physical impairments rather than cognitive impairments. Only the Netherlands differs from this pattern. This result may indicate the better ability of families to provide care for those with physical impairments than to care for those with dementia who may need much greater levels of assistance.

While we might have expected greater informal care usage in countries that lack a comprehensive long-term care insurance system relative to those countries which provide for paid care, this does not appear to be the case. Germany has an extensive national long-term care insurance program and the United States primarily provides only means tested care, but the use of informal care for those with cognitive impairments (the red bars) is identical in the two countries and the use of informal care for the physically impaired is actually lower in the United States that Germany—suggesting that informal care is not substituting for the lack of insurance to cover formal paid care in the United States. Similarly, Denmark, with its generous public coverage of long-term care, has a greater use of informal care than England, which like the United States, means-tests long-term care benefits. The small fraction of either group receiving informal care in the Netherlands is consistent with its extensive (and expensive) system of formal care which comprises over 4 percent of its GDP (Bakx, et al., 2025).

In Figure 4b, examining the receipt of formal home care, the pattern is similar; in most countries (six out of the nine shown) those with physical impairments are more likely to receive care than those with cognitive difficulties. Here we do see something of a correlation between the public provision of long-term care and the likelihood of receipt. England and the United States, both of which have means tested public long-term care insurance, have the lowest use of formal care while Japan and Germany, with long-established national long-term care programs, have among the highest.

Some of the greater likelihood of care receipt among the physically impaired may stem from eligibility requirements in publicly or privately funded long-term care insurance programs that were constructed initially to deal with physical needs. In the United States, for example, cognitive impairments typically do not trigger eligibility for Medicaid or most private insurance policies unless they are also associated with the inability to perform (usually two or more) physical tasks such as dressing, bathing, or eating. Other countries do, however, include specific eligibility requirements surrounding cognitive impairments (e.g. Germany, Japan, the Netherlands and Spain). Similarly, physical impairments may be more noticeable to potential family caregivers and prompt immediate assistance, while cognitive issues may be harder to discern, particularly for non-coresident family members. The importance of the lack of recognition of cognitive decline has been highlighted in several recent articles that note the likelihood of financial mistakes for those who are eventually diagnosed with dementia (Nicholas et al., 2021; Li et al., forthcoming), thus suggesting that individuals could benefit from earlier recognition of cognitive decline.

Perhaps unfortunately, part of the difference across countries may be in the structure of the surveys employed as well. Surveys such as the Health and Retirement Study (HRS) in the United States and the Survey of Health Ageing and Retirement in Europe (SHARE) ask about assistance with an ADL only when an individual reports having difficulty with a task (see footnote 11). In these surveys, if respondents do have difficulty with something like dressing themselves, they are then asked if they get help, and other follow-up questions such as the amount of help. If an individual has cognitive difficulties, their needed help may come mostly in the form of supervision; assistance that may not be captured by the surveys if they are able to carry out the tasks, and yet could impose a substantial burden, particularly for family members who acknowledge that the individual cannot be left unsupervised.

Another factor contributing to the greater use of formal home care by those with physical impairments compared to those with cognitive impairments is that those with cognitive impairments who are most in need of care are more likely to receive nursing home care. This institutional care is not included in figure 4b which features formal home care. We thus turn to figure 4c which shows the difference in nursing home use by impairment type for those countries that have data on nursing home residents. Because individuals with cognitive impairments, and in more severe cases, dementia, often require 24-hour care—a need likely far too great for home care, particularly from informal caregivers—we see far higher levels of institutionalization for those with cognitive impairments.[13] We note the extremely high nursing home use in Denmark for both types of impairments, but particularly for those with cognitive impairments wherein almost 50 percent of cognitively impaired individuals are in a nursing home. Not only is this large, but recall that we are not measuring dementia, but simply low cognitive scores, and is consistent with the generous coverage of long-term care provided in Denmark. Also of note is the very large difference in nursing home use across the two impairment types in England and the United States, the two countries with only means-tested long-term care benefits. Given the cost of nursing homes, they may be relied on less frequently than in other countries and thus used primarily when families cannot manage the individuals' needs at home.

While nursing home care is provided around the clock and can thus meet the needs of those with several cognitive or physical impairments, care at home, whether formal or informal, can be of varying intensity. In Figures 5a and 5b, we examine the number of hours of informal and formal care, conditional on care being received. When looking at the number of hours of informal care in Figure 5a, what stands out is the extremely high 214 mean hours of informal care in the United States received by those with cognitive impairment. Only England, which also does not have a national long-term care program comes close to matching that level. Even Japan, which is using a formal medical diagnosis of cognitive impairment and thus has a more stringent

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[13] An Alzheimer's Association report (Alzheimer's Association 2024) note that at age 80, 75 percent of those with ADRD live in nursing homes in the United States compared to just 4 percent of the non-ADRD population and approximately 60% of long-term residents (100 days or more) have ADRD.

definition of cognitive impairment, has fewer hours of informal care, conditional on use, for the cognitively impaired. This result will be a factor below when we examine the cost of care.

We caution, however, that hours of informal care are difficult to measure, particularly for those with cognitive impairment for whom a caregiver may feel "on call" 24 hours a day, ready to help and / or providing supervision, while only providing "hands on" care some of that time. Indeed, survey responses of caregivers do occasionally report levels of care equivalent to 24-hour days.

In contrast, the average number of hours of informal care for those with physical impairments in the United States is on par with those of most other all countries. The relatively high number of hours of informal care for the physically impaired in Germany comes as a surprise given its long-standing public long-term care insurance program and generous benefits. Despite this, the average number of hours of informal care provided in Germany is nearly identical to that in England and the United States, neither of which have national long-term care insurance programs.

When turning to formal care, there is a consistent pattern of more hours for the cognitively impaired everywhere except Spain and Singapore (Figure 5b). The differences in most countries are large in percentage terms, up to 90 percent in Italy and almost 100 percent more in the United States. This result attests to the intensity of care for those with severe cognitive impairment and is similar to their greater use of nursing homes, which represent the most intensive form of care. We do note that the low number of hours for Denmark and Germany are surprising given their generous provision of long-term care and the absence of above average hours of informal care.

Costs

The somewhat lower likelihood of receiving any care among the cognitively impaired relative to those with only physical impairments, accompanied by more intensive care when care is received, leaves open the question of how the aggregate cost of care for the elderly cognitively impaired compares to the cost of care for those with solely physical impairments.

To address that question, each country imputed total care costs by impairment type. These cost calculations rely on a number of assumptions including the price of a night in a nursing home, the hourly wage for home care workers and the number of hours of such care, and importantly, the imputed price of an hour of an informal caregiver's time. In all cases the cost of care was assumed to be the same for cognitively and physically impaired. If care for a cognitively impaired individual were greater than that for the physically impaired (consider the cost of a memory care wing at a nursing home, or specially trained home care workers), then the results are biased against greater costs for the cognitively impaired, conversely, if custodial care for patients with cognitive impairments costs less than care for those with physical difficulties who may need more hands on assistance, then the bias is in the opposite direction.

The individual chapters detail the source of the price of a night in a nursing home and an hour of formal care. For the more difficult imputation of the value of an hour of informal care, we followed the methodology of Gruber and McGarry (2025) which uses demographic characteristics of the caregiver to impute an hourly wage as well as to estimate the probability the caregiver would be working in the formal sector absent caregiving duties.

The total cost of an hour of informal caregiving time is then constructed as:

(the probability of working) x (hours of care x imputed hourly wage) + (probability of not working) x (hours of care) x (mean wage of formal care workers).

This method uses the individual's opportunity cost of time (the imputed wage rate) for any caregiving hours they would likely have spent in the labor market absent the need to provide care and the "replacement" cost (the mean wage of formal care workers) of an hour of care for foregone hours of likely non-work / leisure. This latter component, the recognition that not all caregiving comes at the cost of time in the workforce is important in this situation because many caregivers are spouses who are elderly themselves and who might be retired and would not have been earning a wage had they not provided care. Nonetheless, the value of their non-work time has value as it may come at the cost of household production, investments in health capital, or time with grandchildren.

Table 1 shows the cost of care for each impairment type inflated to the national population of each country. Amounts are reported in US dollars, adjusted for purchasing power parity. When looking across countries, a comparison of total costs is of less interest in that total costs primarily represent population size. We therefore also report the ratio of total costs for care for the physically impaired to that for the cognitively impaired.

The ratio of care for the cognitively impaired to the physically impaired is greater than one in all countries except Germany, Japan, and the Netherlands. These are three of the countries that did not have measures of nursing home care for the cognitively impaired and are thus missing an important component of costs. In all other countries, the cost of care for the cognitively impaired, despite the smaller number of individuals with such limitations, is much larger than the cost for the physically impaired.

We note that these figures are underestimates of the true cost of care. Because we define physical impairment as difficulty with 2 or more activities of daily living, we are missing that portion of care to those with a limitation in just one sphere. Also missing for many countries is an accurate measure of the total costs of nursing homes because of the limitations of the survey frame used in the respective studies, as well as care for the non-elderly. Finally, the text in this chapter noted other shortcomings of the data (e.g. the exclusion of proxy interviews and caregiving questions that focus on help with activities of daily living rather than supervisory care). Nonetheless, we find these numbers to be of interest.

In Figure 6a we examine the cost per impaired individual, with the denominator being the number of individuals in that country's sample with the particular impairment type. The high use of nursing homes for the cognitively impaired and their associated cost, as well as the larger number of care hours, leads to a higher average cost of care for the cognitively impaired in the majority of countries. The relatively low cost for the cognitively impaired in Germany is due to their lack of nursing home residents in their sample and similarly for Singapore.

Personal Cost: Missing from these estimates of the cost of care is the toll caregiving takes on the caregivers and their families. While we have included an imputed cost of a caregiver's labor market time, (and a value for leisure time), the true cost of lost employment will be much greater if there are long-term impacts on wages / wage growth (Skira, 2015; Fahle and McGarry, 2022; McGarry 2025) or similarly, if an individual leaves a job to provide care and has difficulty finding a job when the spell of caregiving has ended.

However, in addition to the time costs of care, numerous studies have found significant effects on emotional well-being including increases in rates of depression and declines in self-reported health among caregivers (e.g. de Zwart et al., 2017; Bom et al, 2019a, 2019b).[14] When comparing the stress and mental health effects of caregivers for those with and without dementia, the literature shows that the negative effects of caregiving for an individual with dementia are far larger (Gonzalez-Salvador, 1999; Ory, 1999). Brodaty and Donkin (2009) refers to these family caregivers as "the invisible second patient". While it is beyond the scope of this study to examine the psychological cost to caregivers and differences in that cost by type of impairment, we want to highlight that this too is an important part of the cost of care. Increases in the need to care for patients with cognitive limitations will present a growing burden on families, not only in the monetary cost of care and time costs of care, but in the emotional costs as well.

Discussion

Our analysis in this introductory chapter and the detailed work in each of the subsequent chapters highlight the importance of understanding care for the cognitively impaired, its growing need, and the costs it entails, and provides several important lessons for survey methodology in analyzing the population with cognitive impairments.

First, as one might expect, individuals who have cognitive limitations are often unable to answer questions posed by an interviewer. In many studies, proxy respondents are thus queried to obtain the relevant information pertaining to the intended respondent. As the evidence from the United States and English chapters demonstrate, these proxy interviews provide important information that might otherwise be lost. We encourage surveys to make (or continue to make) the effort to interview proxy respondents when a respondent cannot or will not participate in the interview and, in addition, to report the reason for the proxy (e.g. the intended respondent is too busy, physically unable to participate, or cognitively unable). This information is crucial to learning about this important and exceptionally vulnerable population.

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[14] While there is consistent evidence that both mental health and self-reported health declines, there is much weaker evidence on the effect on diagnosed outcomes (Schulz et al., 1995; Coe and Van Houtven, 2009).

There also exist gaps in the sample frame. Many surveys are designed to be representative of the non-institutionalized population and thus may omit the population residing in nursing homes. However, this population is critical in assessing the care provided to those with cognitive limitations, as well as to the volume of care in general, and results in a bias in terms of capturing more of the care provided to the physically impaired relative to those with cognitive impairments. In the United States, over 50 percent of those in nursing homes suffer from some form of dementia (Alzheimer's Association, 2024),[15] and a larger share likely has a milder form of cognitive impairment. Thus, surveys that do not include those in nursing homes are disproportionately missing those with cognitive limitations. While some statistics can certainly be obtained from administrative data sources, many key items of interest cannot. For instance, by neglecting to survey the nursing home population, we also lose information about family members who may provide assistance, financial or otherwise, to a relative in a nursing home, or simply understand how the family situation, the availability of kin, and the availability of financial support vary for those receiving are at home and those in an institution.

Finally, distinguishing between the reasons an individual is experiencing difficulties performing activities of daily living, or why they are receiving care in a survey context could provide valuable insights. Many surveys ask a question with the form, "Because of a health or memory problem do you have any difficulty with…." If the respondent gets any help with the activity, the survey goes on to ask who provides the help, and how much. However, it is not possible to distinguish whether the difficulty is due to a physical or cognitive limitation. In forecasting the need for care based on trends in cognitive decline and morbidity, it is important to understand the difference.

Moreover, survey questions of this type, which begin a caregiving sequence of questions by asking about physical limitation, will likely miss any care provided to individuals who do not have limitations with respect to ADLs, but who, for example, cannot be left alone and need custodial care. The omission of this type of care can result in an incomplete understanding of informal caregiving for this population, care which may be more stressful and time-consuming in this context than caring for those who need help solely due to physical limitations.

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[15] See Mukamel et al. (2024) for the distribution of cognitively impaired individuals across types of nursing homes.

While none of these comments are meant to diminish the difficulty of caring for those with physical impairments, they do underscore the need for more complete measurement of caregiving and the need for assistance.

Conclusion

Collectively, the results of the chapters and inter-country comparisons lead us to draw several conclusions: First, cognitive impairment is a key driver of long-term care. The presence of cognitive impairments is positively associated with more intensive use of personal care services. In particular, the presence of cognitive difficulties appears to be a key determinant of whether institutional care, as typically provided in a nursing home, is needed or whether care needs can be met at home or in the community. As countries endeavor to rely to a greater extent on home care, careful consideration is needed about the appropriateness of this setting for individuals with cognitive impairment who may require 24-hour supervision (Mollica & Reinhard, 2005).

Second, care for those with cognitive impairments is a significant component of the overall cost of long-term care globally. The more intensive care needs of individuals with cognitive involvement result in more care hours overall, as well as greater likelihood of receiving care in a more expensive institutional setting.

Third, the need to care for those with cognitive impairment places significant burdens on family caregivers. With the need for more intensive care that appears to come with cognitive impairment, families may struggle to meet the demands. Furthermore, analyses done outside this volume suggest that caring for those with cognitive impairments may be especially taxing emotionally.

Fourth, virtually all countries appear to have impaired older adults with unmet care needs. We found that large fractions of those with reported impairments were not receiving any care. Further research is needed to determine whether cognitive impairment increases one's risk for unmet care needs due to restrictions on eligibility or difficulties identifying limitations. Also unknown are the long-term health consequences of these unmet needs regardless of impairment type.

Finally, while home care is almost uniformly preferred to institutionalization among both patients and their families, efforts need to be undertaken to ease the burden borne by informal caregivers.

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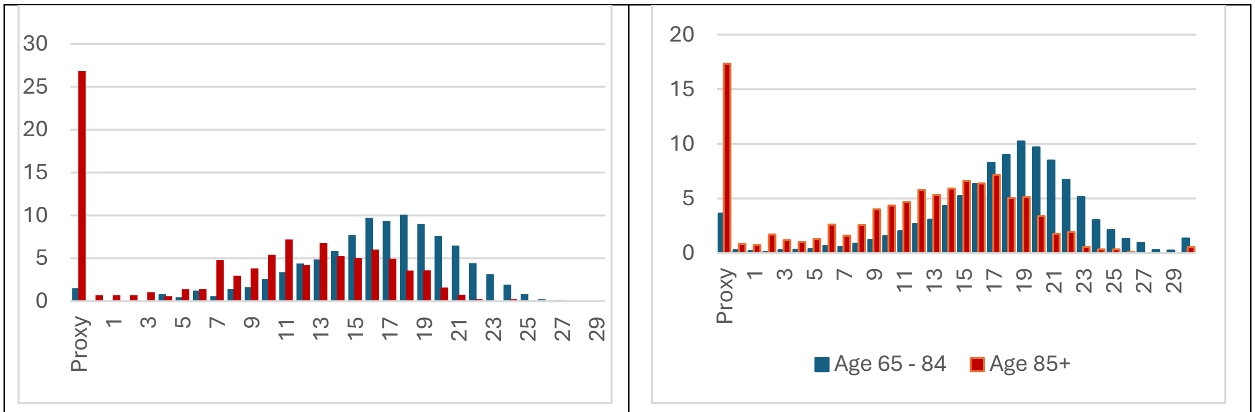
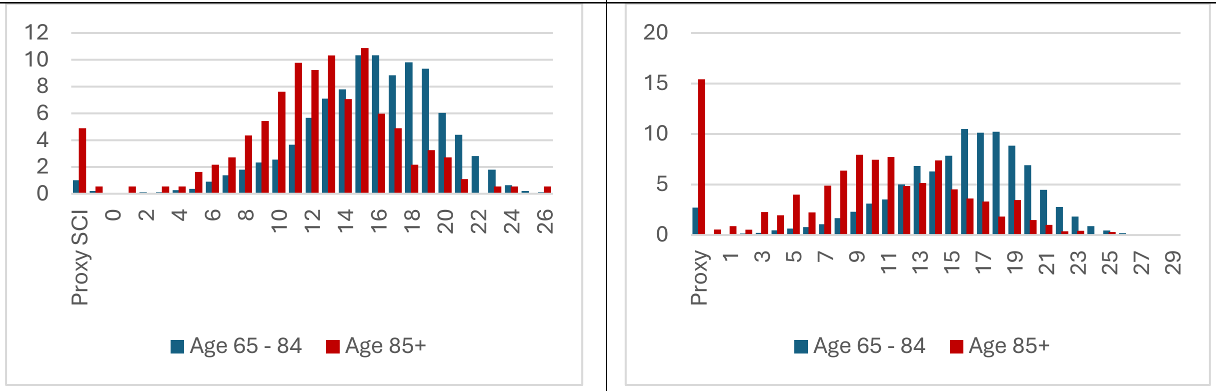
Figure 1: Distribution of Cognitive Scores, by Age Group and Country



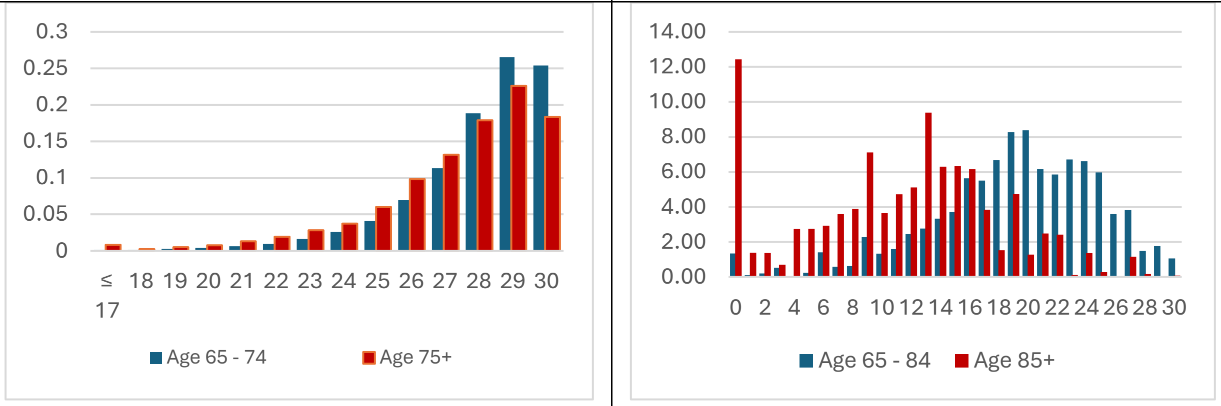
Denmark

England



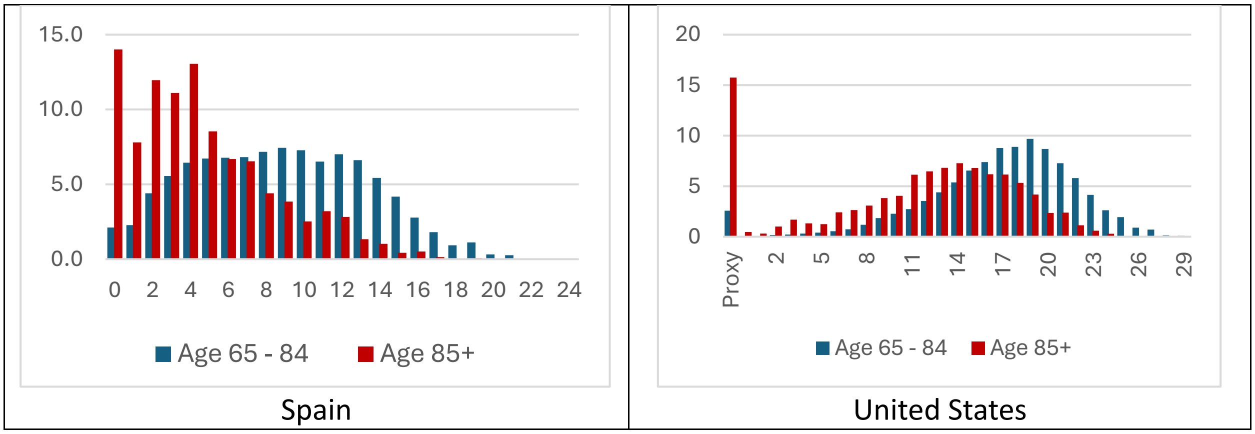
Germany

Italy



Netherlands

Singapore

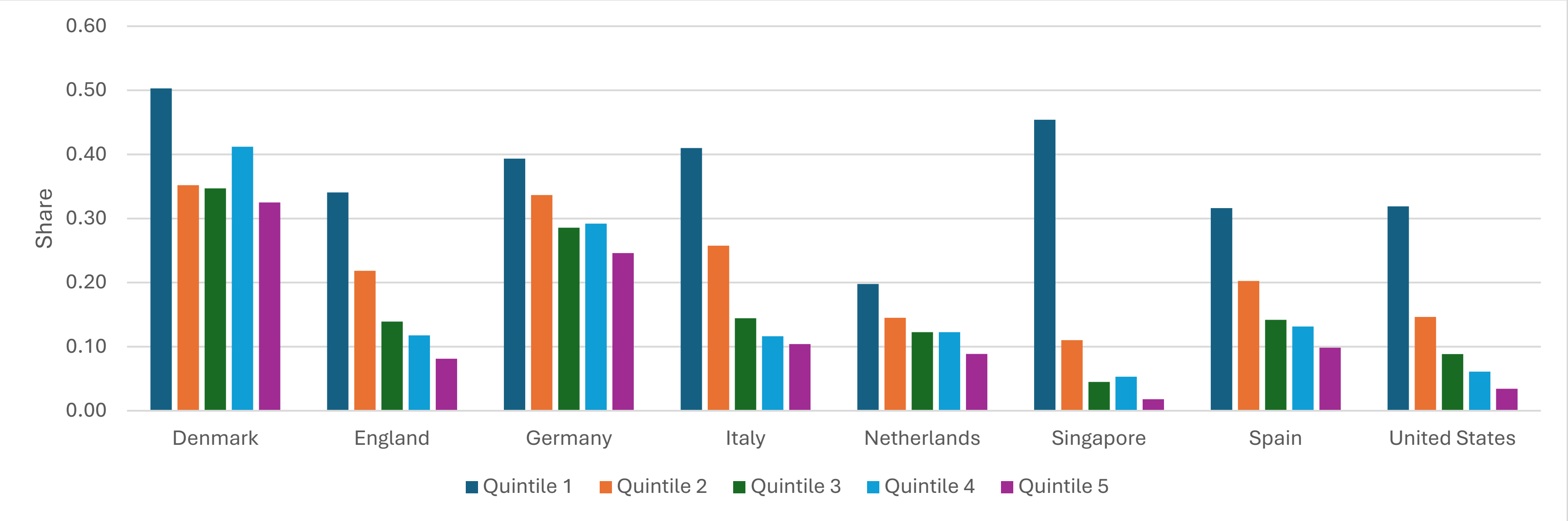


Spain

United States

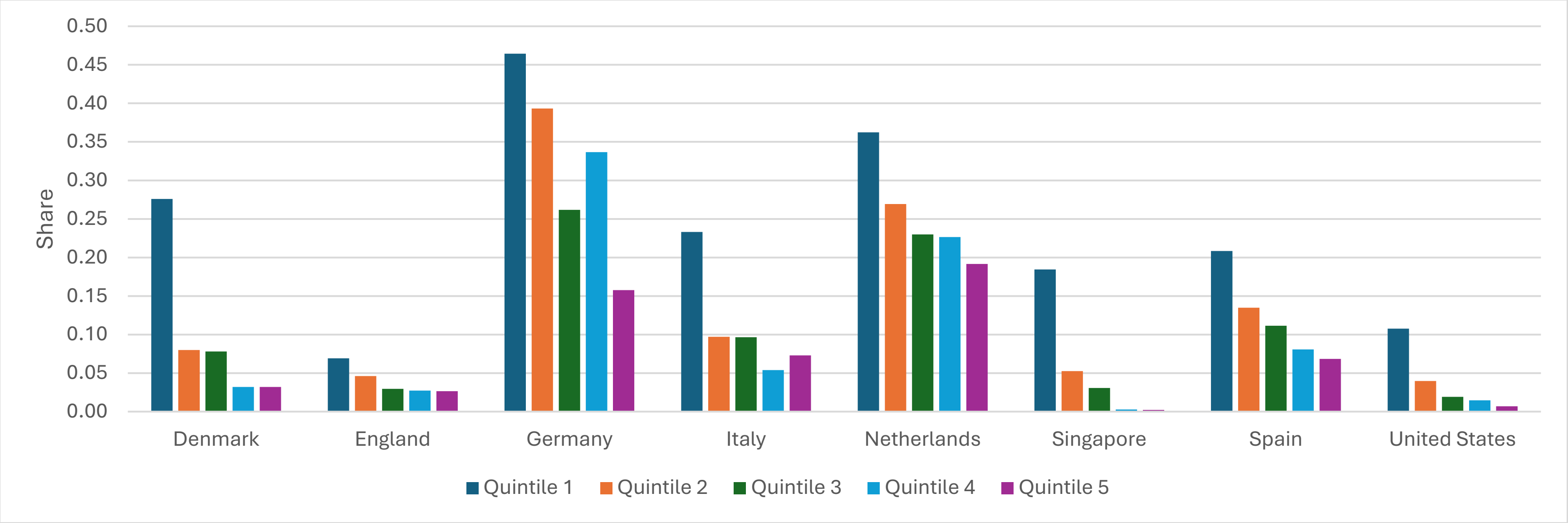
Note: Most countries use survey responses to questions asking the respondent to repeat a list of 10 words immediately and with a delayed, counting backwards from 100 by 7, and naming the month, day, date, and year or similar. The Netherlands uses the Mini-mental state examination (MMSA) designed to screen for dementia and scores thus skew higher.

Figure 2a: Share Receiving Informal Care, By Cognition Quintile



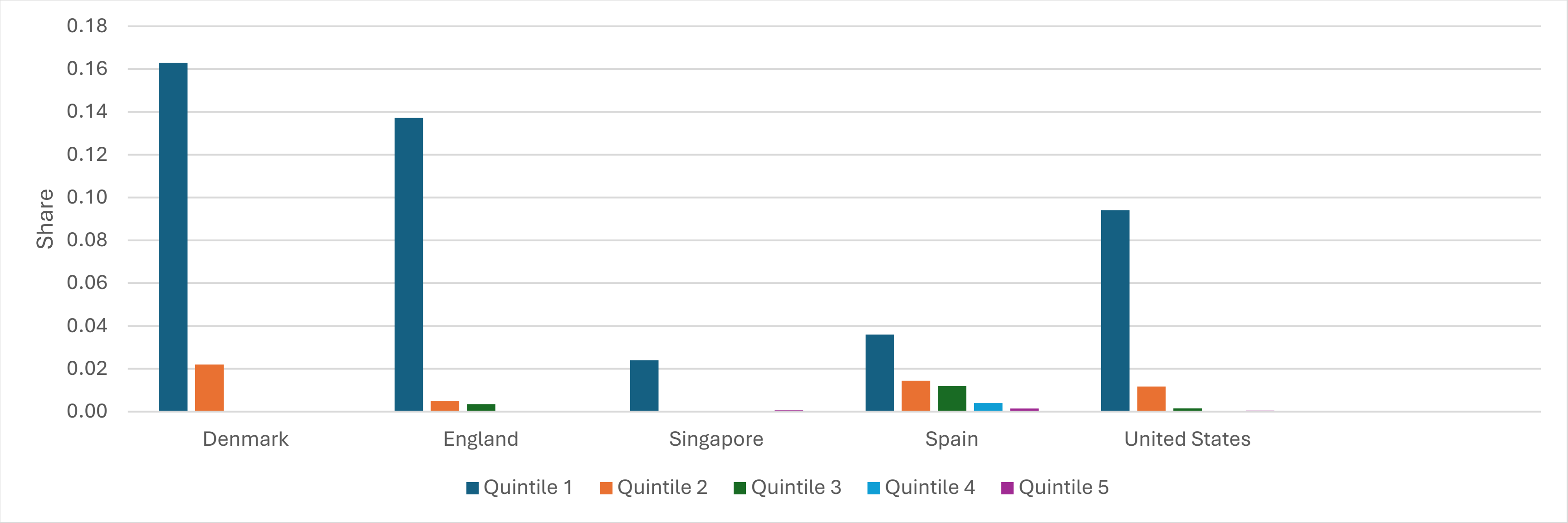
Notes: Figure 2a displays share receiving informal care grouped by quintiles. The first quintile includes individuals with proxy responses whom the proxy identified as cognitively impaired, as well as respondents with cognitive scores in the bottom 20 percent of the distribution. The other quintiles include 20 percent of those with cognitive scores in the survey data.

Figure 2b: Share Receiving Formal Home Care, By Cognition Quintile



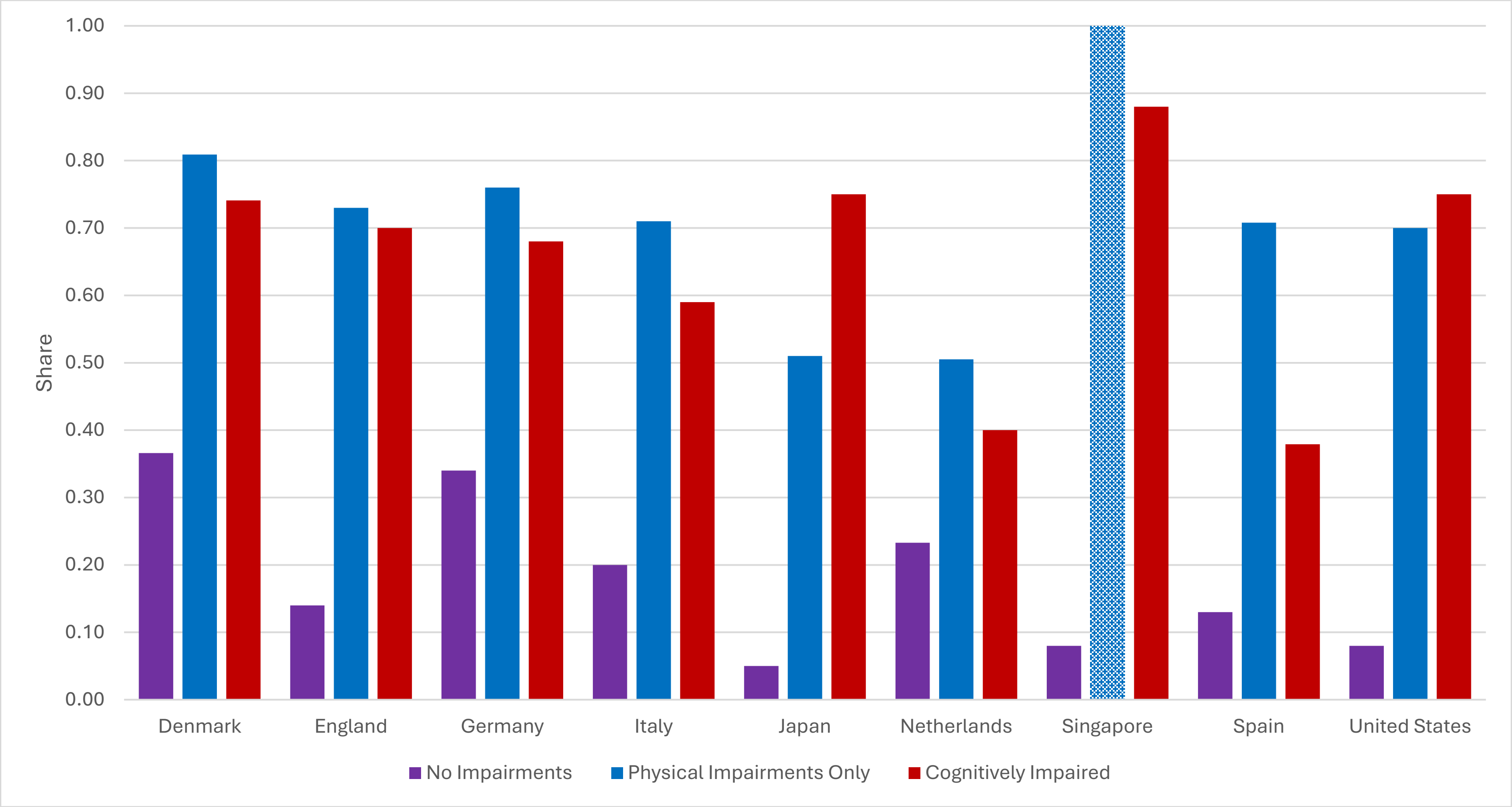
Notes: Figure 2b displays share receiving formal home care by quintile of cognitive score. The first quintile includes individuals with proxy responses whom the proxy identified as cognitively impaired as well as respondents with cognitive scores in the bottom 20 percent of the distribution. The other quintiles include 20 percent of those with cognitive scores in the survey data.

Figure 2c: Share Receiving Nursing Home Care, By Cognition Quintile



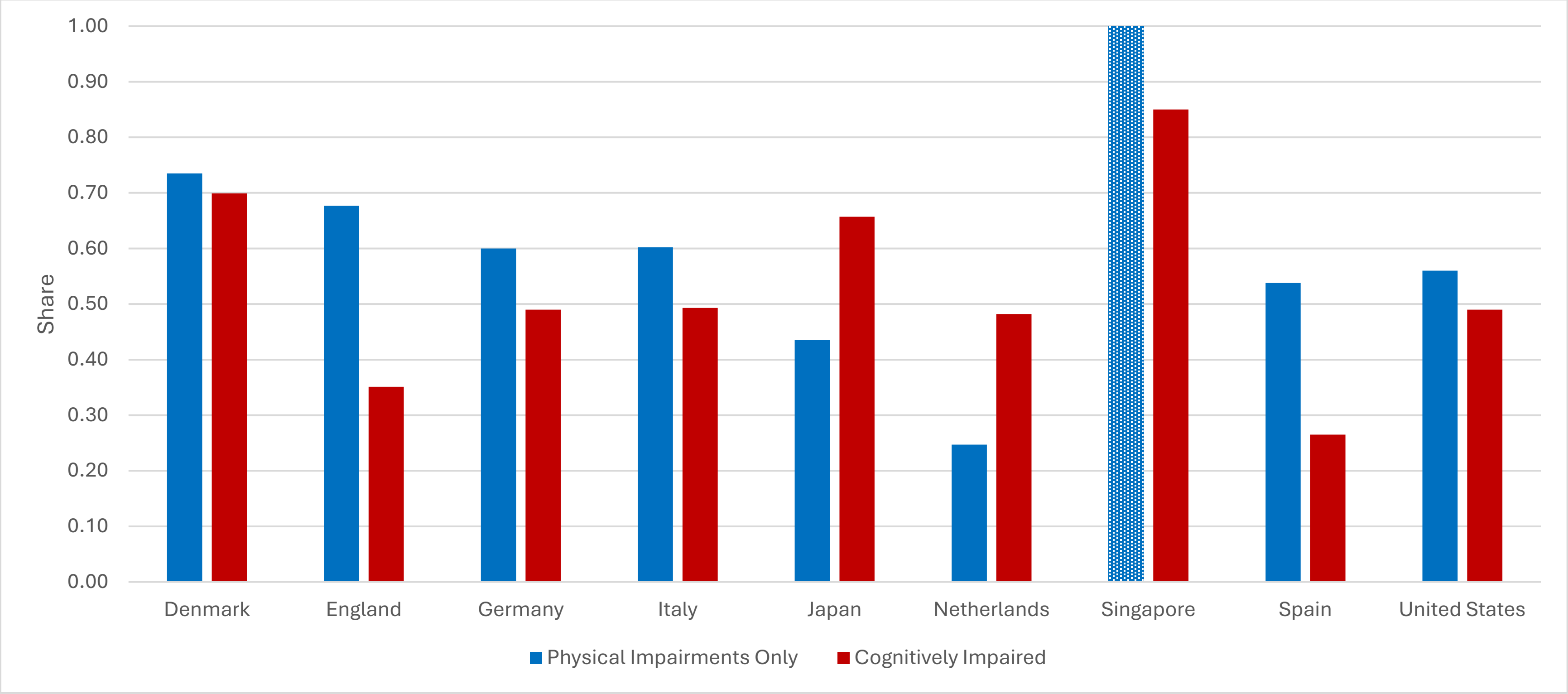
Notes: Figure 2c displays share receiving nursing home care by country and quintile of cognitive score. The first quintile includes individuals with proxy responses whom the proxy identified as cognitively impaired as well as respondents with cognitive scores in the bottom 20 percent of the distribution. Germany, Italy, Japan and the Netherlands do not have complete data on respondent use of nursing home and are excluded from the table.

Figure 3: Share of Any Care Use



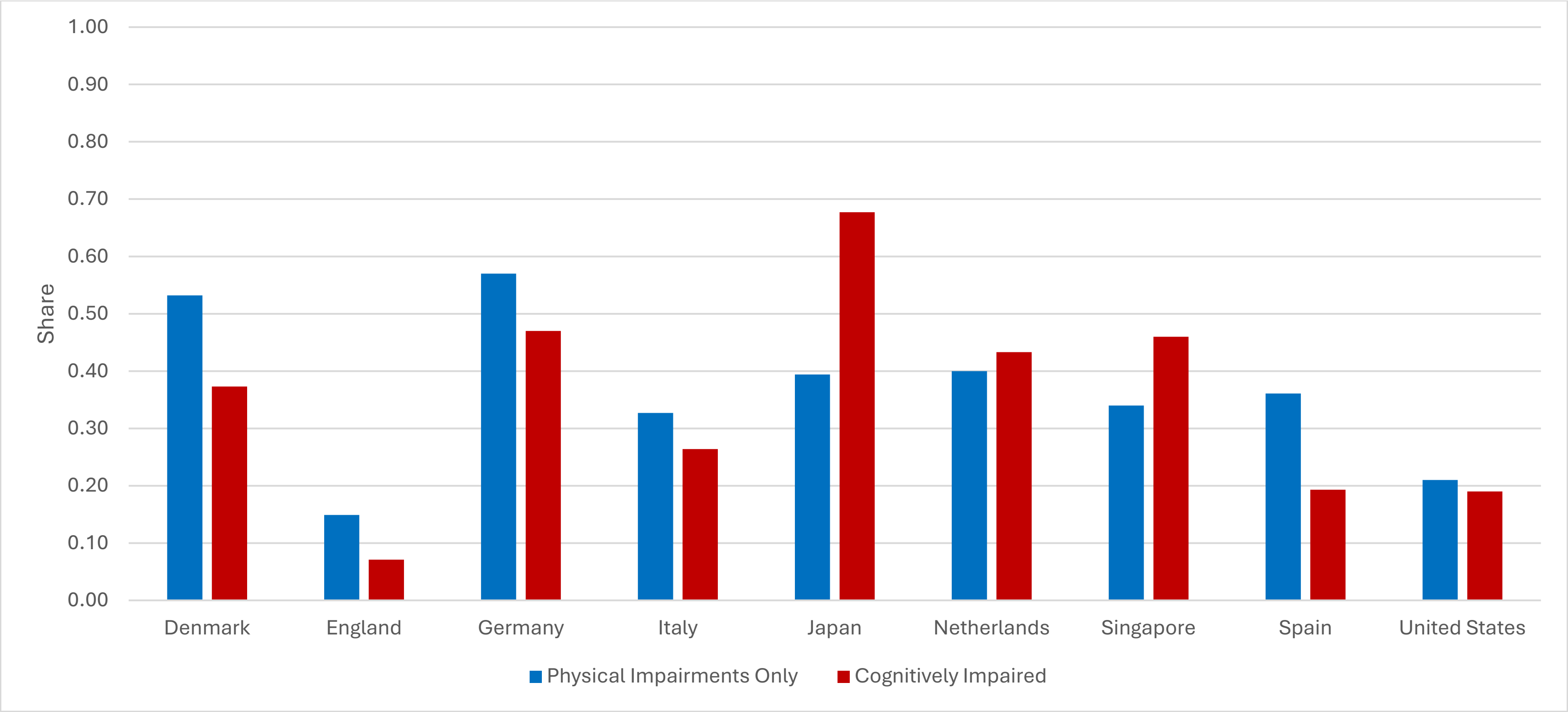
Notes: Figure shows the share of individuals using at any care (formal, informal, or nursing home), conditional on impairment type. Germany, Italy, Japan and the Netherlands do not have complete data on nursing home use, so the total use of care is lower than if the nursing home population were included. Formal home care received in the Netherlands includes only that formal care financed through the social health insurance program. Physical impairments in Singapore are only measured for those receiving some care, so the value, by definition, equals 100 percent.

Figure 4a: Share of Informal Care Use



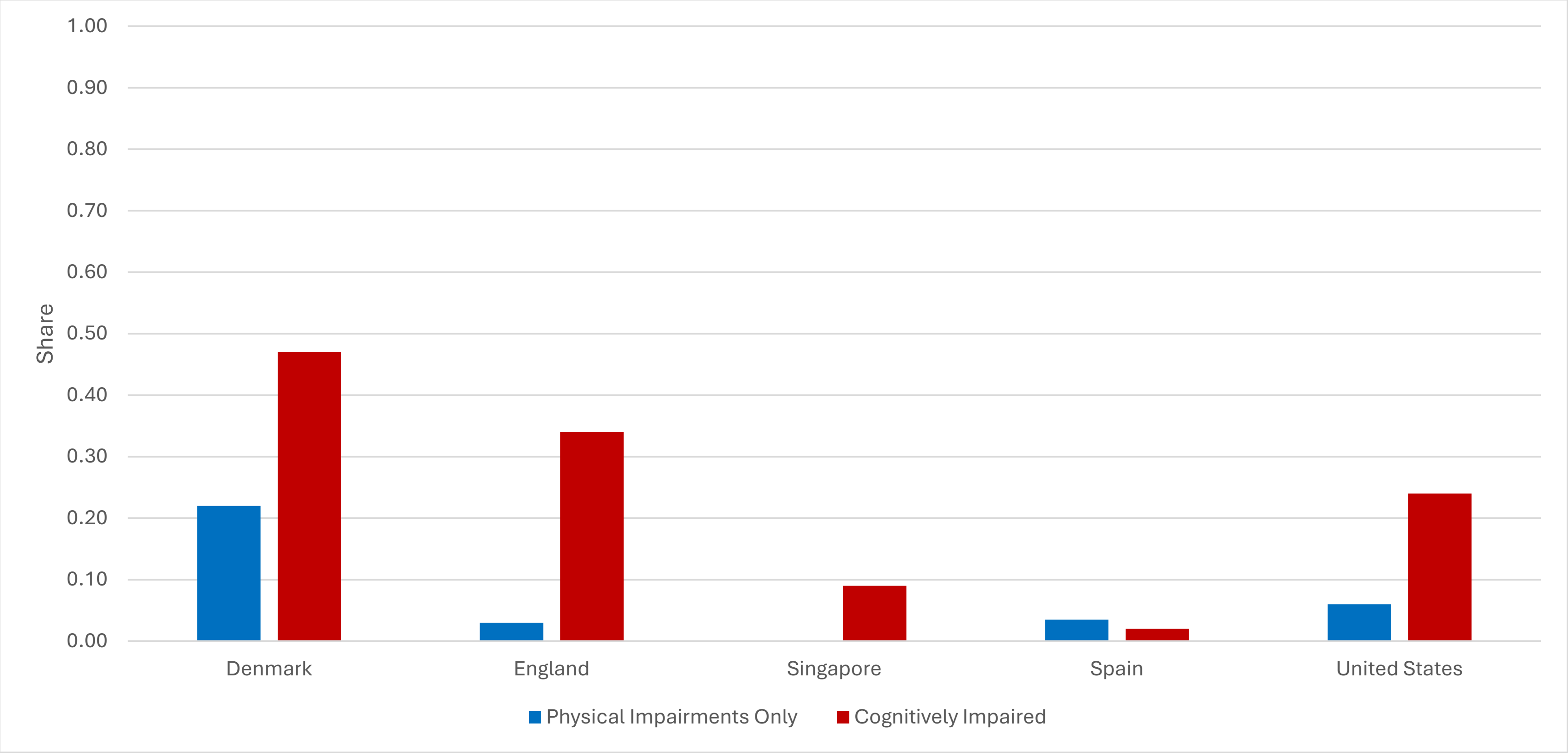
Notes: Figure shows the share of individuals using at any informal care. Physical impairments in Singapore are only measured for those receiving some care, so the value, by definition, equals 100 percent.

Figure 4b: Share of Formal Care Use



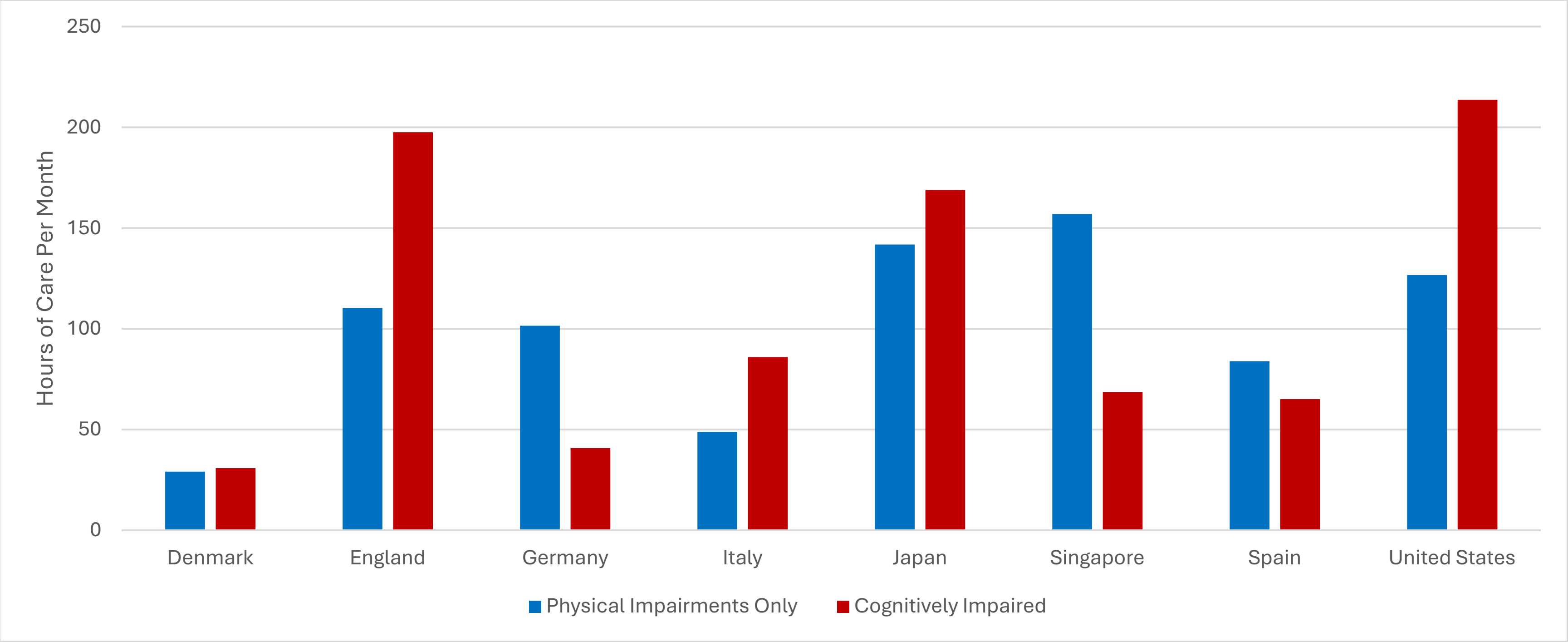
Notes: Figure shows the share of individuals using at any care (formal, informal, or nursing home), conditional on impairment type. Formal home care received in the Netherlands includes only that formal care financed through the social health insurance program. Physical impairments in Singapore are only measured for those receiving some care, so the value, by definition, equals 100 percent.

Figure 4c: Share of Nursing Home Use



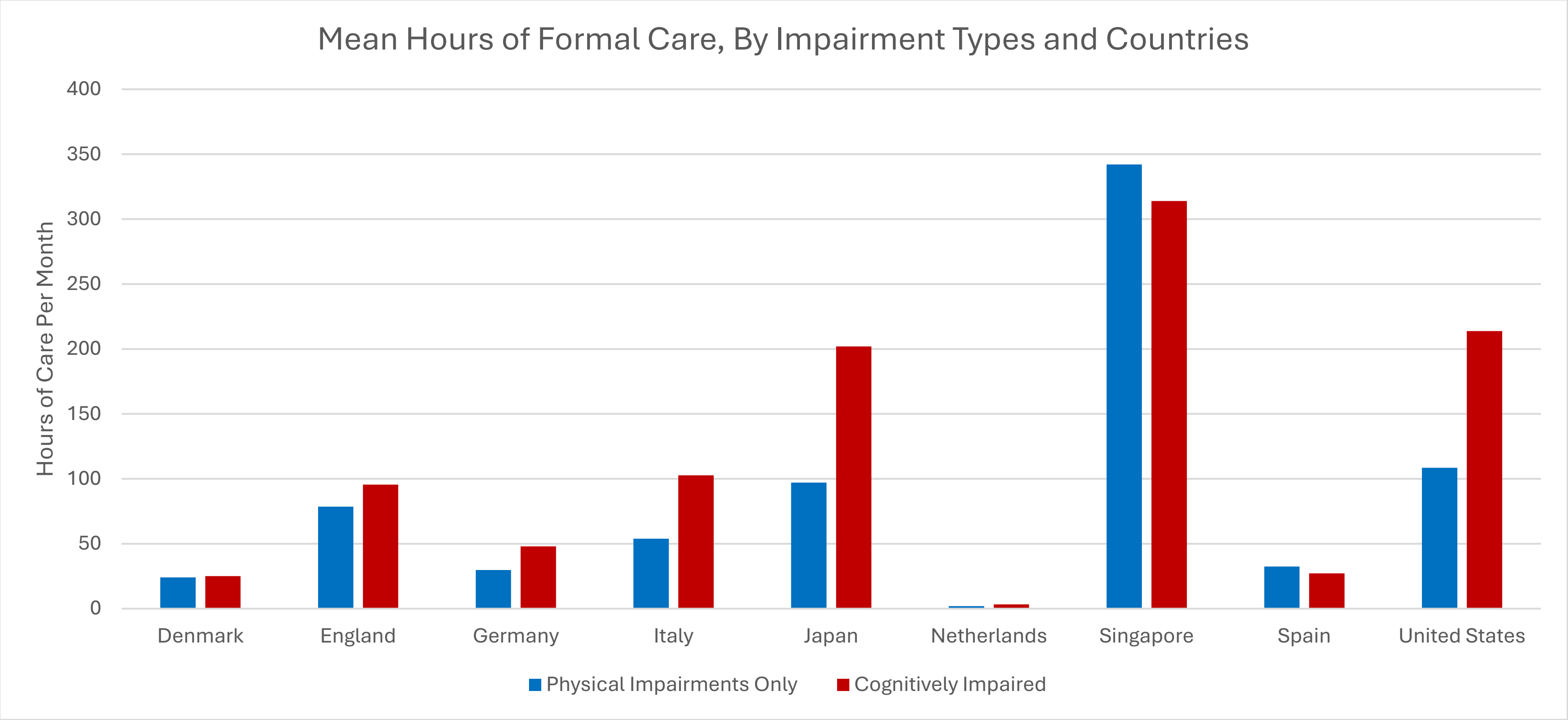
Note: Germany, Italy, Japan and the Netherlands do not have complete data on respondent use of nursing home and are excluded from the table.

Figure 5a: Total Hours of Informal Care



Notes: Figure shows mean monthly hours of informal care use conditional on informal care use. The Netherlands is excluded because the data provide information on whether an individual uses informal care but not the number of hours.

Figure 5b: Total Hours of Formal Care



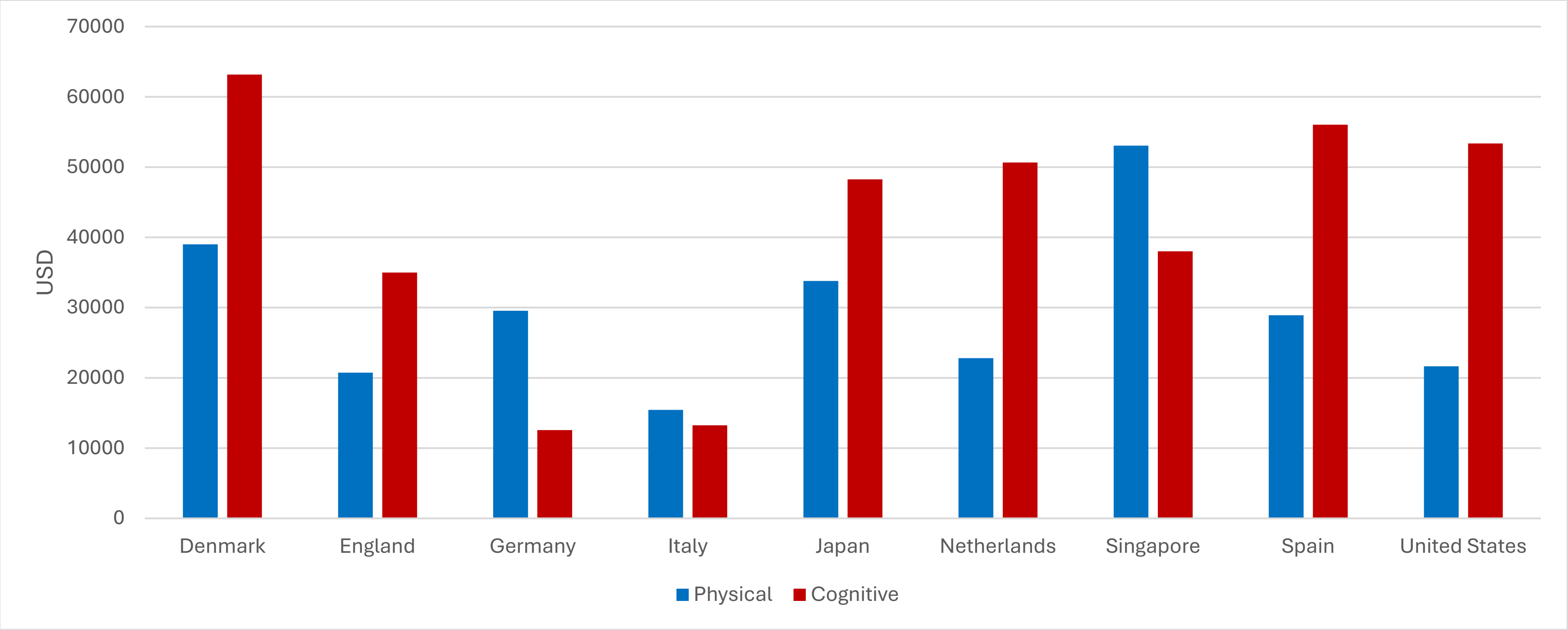
Notes: Figure shows mean monthly hours of formal care use conditional on formal care use. The Netherlands is excluded because its home care measure includes only services covered by social health insurance, which represent a subset of total home care use and the values are thus not comparable to other countries.

Table 1: Total Cost of Care

	Total Cost			
	Impairment type			
Country	Physical	Cognitive	Ratio	All
Denmark	2.3	3.2	1.4	11.0
England	20.7	31.5	1.5	65.3
Germany	33.5	8.1	0.2	125.8
Italy	8.3	15.9	1.9	38.5
Japan	51.4	24.6	0.5	102.7
The Netherlands	20.5	15.2	0.7	47.8
Singapore	0.9	1.5	1.6	2.9
Spain	4.7	12.9	2.7	27.2
United States	86.6	160.1	1.8	349.5

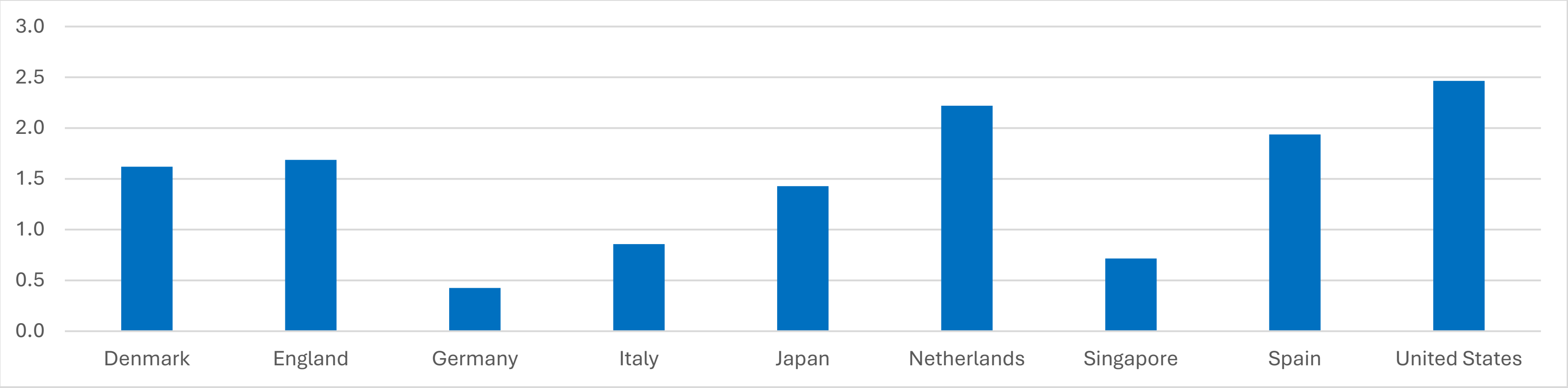
Note: The values in the table should be used to discern the relative importance of care for those with physical impairments only and those with some cognitive impairment (regardless of whether they have a physical limitation).

Figure 6: Per Capita Costs Across Impairment Types



Notes: Figure 6 shows costs per capita costs of care (i.e. per impaired individual) by impairment type. Cost of care for Denmark, England, Italy, Netherlands, Singapore, Spain and the United States include formal care, informal care and nursing homes. Cost of care for Germany and Japan include formal care and informal care. Monetary values are measured in USD using purchasing power parity.

Figure 7b: Ratio of Per Capita Costs between Individuals with Cognitive Impairments and Physical Impairments



Notes: Figure 7b shows the ratio of per capita cost of care (i.e. per impaired individual) for cognitively impaired and physically impaired. Cost of care for Denmark, England, Italy, Netherlands, Singapore, Spain and the United States include formal care, informal care and nursing homes. Cost of care for Germany and Japan include formal care and informal care. Monetary values are measured in USD using purchasing power parity.