The Present and Future Dementia Burden in China: Kinship-Based Projections and Global Comparisons

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Abstract

China has the largest number of patients with dementia in the world, and the rate of growth is expected to escalate further as the population ages. The majority of dementia patients rely on their families for care and assistance. Using demographic models of kinship, we provide quantitative estimates of the burden of dementia, from 1990 up to 2050, by illustrating the number of kin accessible to dementia patients, the dementia prevalence among kinship networks, and the dependency ratio of kin with dementia to working-age kin without dementia. We then compare the estimates of dementia burden across 194 countries and territories, accounting for historical trends in and future projections of mortality, fertility, and dementia prevalence. Our findings suggest that, unlike other aging societies, China's aging crisis is exacerbated by the fact that, in addition to the alarming rise in the number of elderly in need of care, the number of possible family caregivers is also dropping at an unprecedented pace. The increase in dementia dependency ratio is expected to exceed the increases in most other countries across East Asia, Western Europe, and the United States. These findings have important implications for understanding the evolution of elderly care networks in China over time and from a cross-country comparative perspective.

Introduction

Alzheimer's disease and related dementias (hereafter referred to as dementia) constitute an enormous challenge for patients, their caregivers and family members, and society as a whole. At a population level, numerous studies have documented the causes and consequences of dementia, its variation across time and place, and its growing impact on the economy and healthcare systems (Baumgart et al. 2015; Nichols et al. 2022; Pedroza et al. 2022). Dementia profoundly changes the lives of patients and those of their families and relatives (Schulz and Martire 2004). Those effects depend, among other things, on the structure of kinship networks: the numbers, age distributions, and social roles of the relatives of a person with dementia.

Our goals in this paper are to analyze the demography of dementia within kinship networks, calculating values in the historical past and projecting them into the future. Our primary focus is on China, and we then extend our analysis to a global comparative study. China has the largest number of patients with dementia in the world, and the rate of growth of this number is expected to escalate in the coming years because the population is aging at an accelerating pace. The number of those living with dementia has increased over fourfold in the past three decades, from 3.68 million in 1990 to 15.33 million in 2019, and this number is expected to triple to 45.54 million in 2050 (Nichols et al. 2022). While a significant amount of research has documented the increased rate of dementia cases and the associated economic costs at the national level (Nichols et al. 2022; Chan et al. 2013; L. Jia et al. 2020; Nichols et al. 2019; Sohn 2023), the familial implications of dementia in kinship networks have yet to be fully explored.

Of particular importance is the number of possible family caregivers available to individuals with dementia, as well as the number and relations of one's family members who may potentially experience dementia throughout their lifetime. Thus, the burden of dementia (and many other diseases) in China, and in rapidly aging populations worldwide, is fundamentally a kinship problem. The kinship network determines the number of possible family caregivers, and how many families and relatives are affected by the occurrence of dementia among their kin. For example, an individual may, in young adulthood, have a grandmother with dementia, have a parent with dementia in middle age, and have a spouse or a sibling with dementia in their own older age. This age pattern may vary across population subgroups stratified by kin type, gender, race, socioeconomic status, and place of residence, and it will likely have significant consequences for social inequality (Alburez-Gutierrez et al. 2022; Chung and Hepburn 2018; Feng, Song, and Caswell 2024; Jiang 1995; Friedman, Freedman, and Patterson 2023; Song and Caswell 2022; Verdery and Margolis 2017; Zhou, Verdery, and Margolis 2019). While the availability of relatives does not solely determine the provision of care, which also depends on the health care system, the costs and access to institutional care facilities, and the cultural norms of family responsibilities, kinship networks play a crucial role in elderly care, consistently emphasized in previous demographic analyses.

The expected kinship network of a focal individual is an outcome of the mortality and fertility schedules to which the population is subject. The recent development of kinship models allows us to analyze these demographic trends and predict how kinship structures might evolve (Caswell 2019; Caswell and Song 2021). We use the time-varying version of this kinship model to project kinship structure based on observed and projected changes in mortality and fertility schedules from 1950 to 2050. China's rapidly changing demography makes this time-varying approach particularly useful (Wang 2011; Peng 2011).

By applying the age-specific dementia prevalence rates to the age distributions of various kin types, we calculate the burden of dementia care for individuals. This burden varies depending on a person's age, their kin's ages, and their relatedness to different kin types. In general, older cohorts will face a greater burden than younger ones. We introduce an index called the dementia dependency ratio (DDR), which calculates the ratio of the number of kin with dementia to the number of kin without dementia who are potential caregivers. The DDR is an individual property. To evaluate the burden of dementia at the population level, we average the age-specific DDR over the age distribution of the population. After computing results for China, we compare the index across a wide range of countries.

Our results suggest that China will experience among the fastest-growing dementia burdens in the world in the next three decades. In 2050, China's age-weighted DDR is projected to rise to approximately 18 times its 1990 level, marking one of the most rapid increases ever recorded, surpassed only by Singapore's expected climb of roughly 24 times. This trend is largely driven by rising numbers of dementia cases and shrinking kinship networks. Given China's immense population size and its relatively underdeveloped public health support system, the challenges faced by China will be substantially more formidable than those of many other countries. The results also underscore the need for future research to redirect its focus from merely the total count of dementia cases to a more comprehensive assessment of dementia burden from a demographic perspective. The kinship approach offers new insights into the economic and healthcare impacts of dementia in a rapidly aging context.

Background

Population Aging and Dementia in China

China's population is aging at an unprecedented rate. Its three-and-a-half decade long history of the One-Child Policy, along with its remarkable economic take-off following the 1978 economic reforms, has led to a sustained fertility decline and a rapid increase in life expectancy (Cai and Feng 2021; Wang 2011; Chen and Liu 2009). This ongoing demographic transition will eventually turn China's population pyramid upside-down. Even assuming, against the trend, a gradual and moderate recovery of fertility, the proportion of the population aged 65 years and above is expected to increase from 191 million in 2020 to 395 million in 2050, eventually accounting for 30.1% of the total population (United Nation 2022). This accelerated aging of the population will lead to substantial pressures on the fiscal capacity and the social welfare system in China. Cai, Wang, and Shen (2018) estimated that maintaining an average social welfare generosity at the 2014 level, public health spending will more than double and pension spending will more than triple from 2015 to 2050. Assuming that China manages to maintain its economy at the 2020 level, the spending on public health and pension alone would consume as much as 82.8% of the government revenue by 2050. The impact that the COVID-19 pandemic has had on China's birth rate and economy would only precipitate the tipping point of the potential fiscal crisis.

The increasing prevalence of dementia is among the greatest challenges that China's aging population may face. China has the largest population of dementia patients (L. Jia et al. 2020), with many of them undiagnosed (Lang et al. 2017), and this number is expected to climb as the population ages. In 2017, dementia became the fifth leading cause of death in China, following stroke, ischemic heart disease, chronic obstructive pulmonary disease, and lung cancer (Zhou et al. 2019). There is no effective cure for dementia, and sufferers eventually require assistance as the disease progresses. The disease thus poses a heavy economic and healthcare burden on patients and their families. A survey of 81 representative hospitals, nursing homes, and care facilities across 30 provinces in China in 2015 indicated that the average annual cost per patient of dementia was US $19,144.36, for an annual national total of US $167.74 billion (J. Jia et al. 2018). Indirect costs, such as financial loss sustained by patients themselves or their informal caregivers account for 51.9% of the total cost, while the direct medical costs (such as medication and hospitalization) and non-medical costs (such as costs of transportation and healthcare equipment) account for 32.5% and 15.6%, respectively.

The Demography of Dementia Caregiving

The burden of dementia on families will continue to grow due to China's changing family structure and shrinking kinship size. In addition to the financial burden, dementia places a significant caregiving strain on families, causing additional physical, psychological, and emotional stress for caregivers (Brodaty and Donkin 2009; Vicki A. Freedman et al. 2022; Ory et al. 1999; Patterson et al. 2023). The majority of people living with dementia in China rely on members of their family at home for care and assistance (L. Jia et al. 2020; J. Jia et al. 2016). About 84.9% of patients who have dementia were cared for by family members, 8.3% lived alone, 4.9% received care from hired nannies, and only 2% were undergoing formal care in nursing homes or hospitals (J. Jia et al. 2016).

Several factors explain the low utilization of formal care in China. First, formal care that is provided by nursing homes or hospitals is often not covered by medical insurance in China, rendering it financially unfeasible for many families (Wang, Cheung, and Leung 2019). Second, the provision of dementia care services is often inadequate and fragmented, particularly in rural and underdeveloped areas, further restricting access to formal care options (Quail et al. 2020). Finally, the cultural influence of filial piety places a substantial burden of guilt on family members who consider placing older family members with dementia in nursing homes, as it is perceived as a deviation from the traditional familial caregiving arrangement (Chang, Schneider, and Sessanna 2011). These intertwined factors collectively contribute to the limited use of formal care services and the enduring significance of kinship in the context of dementia care in China.

The ongoing demographic and social changes have called the underpinning of traditional family arrangements into question. Despite the long history of preference for large families and intergenerational co-residence in China, the average household size has shrunk from 4.41 in 1982 to 3.44 in 2000 and 2.62 in 2020 (China National Bureau of Statistics 2021). Moreover, with a total fertility rate of 1.3 in 2020, China now has one of the lowest fertility rates, similar to its East Asian neighbors (China National Bureau of Statistics 2021). The three-and-a-half-decade-long strict One-Child Policy and the changing fertility preferences have significantly altered the kinship network (Bongaarts and Greenhalgh 1985; Wang, Cai, and Gu 2013; Wang, Gu, and Cai 2016). Critics warned that the One-Child Policy would severely weaken family and kin structures in Chinese families, resulting in the disappearance of many kin ties for the generations of children most affected. For example, an only child has no siblings, and the children of the two only-child parents have no aunts or uncles.

Microsimulation studies have predicted that the availability of kin will drop unavoidably (Jiang 1995; Verdery 2019; Hammel et al. 1991; Yang 1992). One recent estimate shows that China has reached an era of peak family, in which the number of extended family members remains high but is projected to drop in the coming years. By the year 2050, two-fifths of the population under 50 will be only children. The kinless population, defined as those without spouses or children, will reach around 25 million (Verdery 2019). Moreover, massive rural-to-urban migration has split families, as many adult children have migrated to metropolitan regions for better opportunities, leaving their elderly parents behind in rural villages (Liang 2016; Lin and Tang 2023; Wang and Mason 2007). The percentage of elderly people over 65 living alone is expected to increase to 14% in rural areas and 11% in urban areas in 2050 (Zeng et al. 2008). Overall, the number of dementia cases is expected to rise due to population aging, at the same time that the number of available family caregivers, particularly those who are not in old age themselves, decreases.

Projecting the Kinship Network and the Dementia Burden

Changes in kinship structures impact caregiving arrangements and the well-being of older adults (Vicki A Freedman et al. 2024; Murphy 2010; Wachter 1997; Wolf 1994; Schulz et al. 2016).

These shifts in family dynamics play a pivotal role in determining how older adults receive care and support as they age. To analyze the dementia burden, formal demographic models offer a valuable framework for quantifying the implications of these changes in terms of kinship networks. These models leverage data on mortality, fertility, and other demographic rates to calculate and understand the dynamics of kinship. Below we describe the analytical framework that characterizes the evolving landscape of caregiving for older adults.

The Kinship Network of Individuals

Notation The following notation is used throughout this paper. Matrices are denoted by upper case bold characters (e.g., $\mathbf{U}$) and vectors by lower case bold characters (e.g., $\mathbf{a}$). Vectors are column vectors by default; $\mathbf{x}^{\mathsf{T}}$ is the transpose of $\mathbf{x}$. The ith unit vector (a vector with a 1 in the ith location and zeros elsewhere) is $\mathbf{e}_i$. The vector $\mathbf{1}$ is a vector of ones, and the matrix $\mathbf{I}$ is the identity matrix. When necessary, subscripts are used to denote the size of a vector or matrix; e.g., $\mathbf{I}_\omega$ is an identity matrix of size $\omega \times \omega$. The symbol $\circ$ denotes the Hadamard, or element-by-element product.[1] The symbol $\otimes$ denotes the Kronecker product. The vec operator stacks the columns of a $m \times n$ matrix into a $mn \times 1$ column vector. The notation $\|\mathbf{x}\|$ denotes the 1-norm of $\mathbf{x}$.

The matrix kinship model on which we rely has been presented in a series of papers, each of which extends the demographic processes that can be incorporated (Caswell 2019, 2020, 2022; Caswell and Song 2021; Caswell, Margolis, and Verdery 2023). Because we are interested in *changes* in kinship, beginning in the past and continuing into the (projected) future, our analysis is based on the version of the model that incorporates time-varying demographic rates.

The model describes the kinship network of an individual, referred to as Focal. The model treats each type of kin as a population. As Focal ages, her kinship network develops through

1. The element-by-element product is implemented by $.*$ in MATLAB. and by $*$ in R

the births and deaths of each type of kin. Our one-sex definitions of kin include mother, grandmother, great-grandmother, daughter, granddaughter, great-granddaughter, sisters, cousins, aunts, and nieces.

The age structure of each type of kin is projected using the matrix formulation of rates of survival and fertility. The population of any type of kin is subsidized; that is, new members of the population of one type of kin come not from the reproduction of those kin, but from the reproduction of some other type of kin (e.g., new sisters of Focal arise not from the reproduction of her current sisters, but from the reproduction of her mother).

Let $\mathbf{k}(x,t)$ denote the age distribution for a generic type of kin:

$$\mathbf{k}(x,t) = \text{ kin of type } \mathbf{k} \text{ at age } x \text{ of Focal at time } t \tag{1}$$

The kin vector is projected using a survival matrix $\mathbf{U}_t$ and a fertility matrix $\mathbf{F}_t$, both of dimensions $\omega \times \omega$ (i.e., the number of age groups). The survival and fertility rates may vary with time. For example with $\omega = 3$, we have

$$\mathbf{U}_t = \begin{pmatrix} 0 & 0 & 0 \\ p_{1t} & 0 & 0 \\ 0 & p_{2t} & [p_{3t}] \end{pmatrix} \qquad \mathbf{F}_t = \begin{pmatrix} f_{1t} & f_{2t} & f_{3t} \\ 0 & 0 & 0 \\ 0 & 0 & 0 \end{pmatrix} \tag{2}$$

where p_{it} is the survival probability and f_{it} the fertility rate of age class i at time t.[2]

The kin at age $x+1$ of Focal at time $t+1$ include the survivors of the kin of age x at time t. These survivors are obtained by multiplying the age distribution $\mathbf{k}(x,t)$ by the survival matrix $\mathbf{U}_t$. New individuals are produced according to a recruitment vector $\boldsymbol{\beta}(x,t)$ such that

$$\mathbf{k}(x+1,t+1) = \mathbf{U}_t\mathbf{k}(x,t) + \boldsymbol{\beta}(x,t) \qquad x = 0,\ldots,\omega \quad t = 0,\ldots,T \tag{3}$$

The recruitment vector $\boldsymbol{\beta}(x,t)$ has one of two forms. For some kin (e.g., older sisters of Focal), there is no recruitment of new members after the birth of Focal, so that

$$\boldsymbol{\beta}(x,t) = \mathbf{0}. \tag{4}$$

2. The optional (ω, ω) cell in $\mathbf{U}_t$ describes an open final age interval.

For some types of kin,

$$\boldsymbol{\beta}(x,t) = \mathbf{F}_t \mathbf{k}^*(x,t) \tag{5}$$

which applies the fertility at time t to the age structure vector of the kin $\mathbf{k}^*$ that provides the subsidy. For example, younger sisters ($\mathbf{n}$) of Focal are produced by reproduction of the mothers ($\mathbf{d}$) of Focal, so

$$\mathbf{n}(x+1,t+1) = \mathbf{U}_t \mathbf{n}(x,t) + \mathbf{F}_t \mathbf{d}(x,t) \tag{6}$$

The model must specify a set of boundary conditions that give the kinship network of Focal at her birth and at the earliest time t included. For some kin this is zero (e.g., Focal has no children at birth), for others, it is not (e.g., Focal may have older sisters at birth). For details see Caswell and Song (2021).

Total Numbers of Kin. The vector $\mathbf{k}(x,t)$ gives the age structure of female kin in maternal lines of descent. To compute the total numbers of kin, both male and female, through all lines of descent, would require a two-sex model incorporating both male and female mortality and fertility schedules (Caswell 2022). However, approximate results for total numbers of kin, assuming that males and females are identical, can be obtained by multiplying the kin vectors by a set of factors suggested by Goodman, Keyfitz, and Pullum (Goodman, Keyfitz, and Pullum 1974), called the 'GKP factors' (Caswell 2022): twice as many children as daughters, four times as many grandchildren as granddaughters, twice as many parents as mothers, four times as many grandparents as grandmothers, twice as many siblings as sisters, four times as many nieces and nephews as nieces, and so on.

The Dementia Dependency Ratio of Individuals

We calculate several measures of the burden of dementia for an individual Focal. If $\boldsymbol{\Psi}$ is a vector containing age-specific prevalences of dementia (or any other condition), then the expected number of kin with dementia at age x of Focal at time t is

$$y(x,t) = \mathbf{\Psi}^{\mathsf{T}}(t)\,\mathbf{k}(x,t). \tag{7}$$

The number of kin with dementia within a specified age range (e.g., kin in the post-retirement ages 60 and above) would be given by restricting $\mathbf{\Psi}$ to those ages; e.g., $\mathbf{\Psi}_{16-64}$ denotes the prevalence vector with all entries except those from 16 to 64 set to zero.

From the numbers of kin with dementia, we calculate the probability that Focal, at age x and time t, has at least one relative with dementia, using a Poisson approximation, as in Song and Mare (2019) and Song, Campbell, and Lee (2015). If the expected number of kin with dementia at time t is $y(t)$, under the Poisson assumption the probability of having at least one such kin is

$$P(\text{at least one kin with dementia}) = 1 - e^{-y(t)}. \tag{8}$$

The burden of dementia experienced by Focal is measured by a dependency ratio. The familiar demographic dependency ratio is calculated as the ratio of those not considered part of the labor force (younger than 15 or older than 65) relative to those considered to be part of the labor force (16–64) and thus supporting the dependant ages. Here we calculate a corresponding dementia dependency ratio for each type of kin:

$$\text{DDR}(x,t) = \frac{\text{kin with dementia}}{\text{kin without dementia aged 16–64}} = \frac{y(x,t)}{(\mathbf{1} - \mathbf{\Psi}_{16-64})^{\mathsf{T}}\mathbf{k}(x,t)}. \tag{9}$$

The dementia dependency ratio can be interpreted as a measure of the burden that kin with dementia place on kin without dementia in working ages.[3]

The Dementia Burden of a Population

The kinship network and the DDR are expected properties of an individual of a given age x. A population is a collection of individuals of different ages, with an age structure given by, say,

3. Chung and Alexander (2019) proposed a similar Kin Dependency Ratio (KDR) index, which is defined as the ratio of the number of plausibly dependent kin at Focal age x to the number of plausibly non-dependent kin at Focal age x.

$\mathbf{n}(t)$. The population kinship structure is obtained by averaging the individual values over the age distribution. Define the proportional age distribution as

$$\mathbf{w}(t) = \frac{\mathbf{n}(t)}{\|\mathbf{n}(t)\|} \tag{10}$$

Then the age-weighted, population dependency ratio is

$$\text{DDR(pop)} = \sum_x w_x(t)\text{DDR}(x,t). \tag{11}$$

This quantity is the expected dementia dependency ratio of an individual selected at random from the population.

The calculation can focus on a subset of ages by including only those ages in $\mathbf{n}$ (e.g., calculating the age-weighted kin structure of that part of the population over 65 years of age). The DDR(pop) describes the expected dementia burden of the population and permits comparison across populations of different countries and at different times. As is done with standardized mortality calculations, a standard age distribution could be used for all countries. We do not explore this here.

Data Sources and Estimation

Our analyses are based on mortality and fertility schedules from the 2022 Revision of the United Nations World Population Prospects (UNWPP) (United Nation 2022), starting in the year 1950 and continuing from the year 2021 to 2050 as a projection of future rates. The time-zero boundary condition $\mathbf{k}(x,0)$ was obtained by a time-invariant calculation using the rates of 1950 and the distribution of ages at maternity in 1950 based on the UN's estimate of births by age of the mother. The age-zero boundary condition specifies $\mathbf{k}(0,t)$ for each year; it was calculated from the appropriate kin at time $t-1$ (see Table 1 of Caswell and Song 2021). Thus, when we report kinship results for a particular year (e.g., 1990), the results reflect the changing mortality and fertility schedules in China from 1950 up to that year.

We draw on period fertility and mortality estimates for China and 194 other countries from the year 1950 to 2021 documented in the 2022 UNWPP. The 2022 UNWPP provides age-specific fertility and mortality estimates for each single-year age group. For projected estimates up to the year 2050, we choose the medium-variant projections of fertility and mortality rates provided by the UN. The medium-variant projection refers to the median of several thousand distinct trajectories of each demographic component derived using the probabilistic model that takes into account the historical variability in fertility and mortality of each country (United Nation 2022). According to the medium fertility scenario, China's fertility is expected to rebound gradually and moderately to 1.4 from 2022 to 2050 after reaching a historical low of 1.2 in 2021.

To estimate the prevalence of dementia, we draw on data from the 2019 Global Burden of Disease (GBD 2019), which provide estimates of the prevalence rate of Alzheimer's disease and other types of dementia by age and year. The Global Burden of Disease uses a Bayesian meta-regression model to estimate age-specific prevalence rates and provides the mean value out of 1,000 draws from their model. The Bayesian models provide a meta-analysis of 43 published studies on dementia in China. These data can be downloaded through GBD's Data Input Sources Tool. We did not use the public version of the GBD data as the data exclude dementia induced by other clinical disorders, including Down syndrome, Parkinson's disease, clinical stroke, and traumatic brain injury. Instead, we use updated dementia prevalence rates provided in Nichols et al. (Nichols et al. 2022) that include all forms of dementia. We use the mean-value dementia prevalence estimates throughout our analyses. Because the dementia prevalence rates were estimated in the five-year age group, we used linear interpolation to impute single-year age-specific prevalence rates. Table S1 in the online appendix summarizes sources, data types, time coverage, and age ranges for data used in our analyses.

We carried out our calculations using the `R` package `DemoKin` (Williams et al. 2022). This package implements the calculations developed in Caswell (2019, 2020, 2022) and Caswell and Song (2021), which are presented in those papers as MATLAB programs.

Results

Changing Kinship in China

We begin with estimates of changing kinship structures in China using 1990, 2019, and 2050 as exemplary years.[4] Figure 1 provides a full picture of the expected numbers of kin of various types by Focal's ages in three selected years[5]. Compared to 1990, Chinese people in 2019 have fewer grandchildren and great-grandchildren but are more likely to have living parents, grandparents, and great-grandparents. For instance, the average number of children for Focal aged 30 has decreased from 1.78 in 1990, to 1.20 in 2019, and is projected to be 0.58 by 2050. In contrast, the estimated average number of grandparents for Focal age 30 has risen from 0.69 in 1990, to 1.70 in 2019, and is expected to reach 2.33 by 2050.

*** Figure 1 About Here ***

However, the change in number of kin between 1990, 2019, and 2050 does not follow a linear trend for certain kin types, especially among older individuals. For example, Focal at 80 years old has 3.71 children in 1990, 3.96 children in 2019, and 1.79 children in 2050. This nonlinear pattern is largely the result of the rise and fall of fertility and mortality rates since the 1950s: the immediate fertility drop following the Great Leap Forward Famine (1959–1961), the baby boomers born from 1962 to 1964, the subsequent long-running fertility decline following the Later-Longer-Fewer family planning campaign in the 1970s, and the more stringent One-Child Policy between 1980 and 2016 (Cai 2010, 2008; Feeney and Feng 1993; Peng 1987;

4. We have also estimated kinship structure in years between these three anchoring years. More detailed results are available upon request.

5. We show the total number of kin across all ages of kin, but the calculation can be limited to a subset of ages of kin (e.g. only kin aged between 16 to 64).

Whyte, Feng, and Cai 2015). Nevertheless, as Focal at the age of 40 in 2019 reaches 80, they will have fewer accessible kin of various types, such as children or grandchildren, than Focal at age 80 in 2019. This pattern reflects the long-term trend in declining fertility, such that generations born earlier had a higher level of fertility.

These estimates of kinship structure are important as they reveal not only the number of specific kin types Focal has across various life stages during different periods but also the maximum number of available kin of specific types that could potentially provide care when Focal develops dementia or other illnesses. We also present a table that shows the number of kin of Focal at different ages in the online appendix Table S2. In the following section, we employ the projected dementia prevalence rates from the Global Burden of Disease (GBD) study to estimate the prevalence of dementia in Focal's kinship network.

Dementia Prevalence among Kinship Network

Figure 2 depicts age-specific dementia prevalence rates in 1990, 2019, and 2050 estimated by the Dementia Forecasting collaborators in the Global Burden of Disease Study (Nichols et al. 2022). Figures 2B and 2C display the projected number of dementia cases by age, as well as the total count of dementia cases for the years 1990, 2019, and 2050. The sources of data are described in the Methods section and Table S1 in the online appendix. Per age, dementia prevalence grew considerably between 1990 and 2019. For example, 7 out of 100 people aged 80 had dementia in 1990, and this number increased to 10 out of 100 in 2019. The rise in dementia prevalence in China over the last three decades has been well reported, reflecting increased longevity and improved diagnostic criteria (Chan et al. 2013; L. Jia et al. 2020). Between 2019 and 2050, the projected age-specific dementia prevalence rate shows only a small increase. However, the proportion of people with dementia in the population is expected to increase dramatically by 2050, because the population as a whole is expected to be much older.

*** Figure 2 About Here ***

Combining the prevalence and kin age distributions we obtain the expected number of kin with dementia. Figure 3A presents the expected number of kin with dementia as a function of Focal's age in 1990, 2019, and 2050. These results suggest that the number of kin with dementia has increased substantially between 1990 and 2019 and is expected to further increase over the next three decades. Over time, individuals will tend to have more grandparents and great-grandparents with dementia at younger ages, parents and aunts/uncles with dementia at middle age, and children, siblings, nieces/nephews, and cousins with dementia at older ages. As individuals live longer and have older kin, they will not only tend to experience dementia themselves but also become subject to the ripple effect of dementia within their kinship networks.

The probability of having at least one relative of each type with dementia, as a function of the age of Focal is shown in Figure 3B. Nearly half of individuals born in 2050 can expect to have at least one great-grandparent with dementia at birth. Among individuals at age 30 in 2050, 28% are expected to have at least one grandparent with dementia; among those at age 60, 18% will have parents with dementia; and among those aged 75, 17% of them will have siblings with dementia, 25% will have aunts and uncles with dementia, and more than 70% will be expected to have cousins with dementia. Given the elevated prevalence of dementia within kinship networks, it is highly possible that the majority of the population will experience its direct or indirect consequences at some point in their lives.

*** Figure 3 About Here ***

The increase in the number of kin with dementia is a result of both the rising prevalence of dementia and population aging. We use the Kitagawa method (Kitagawa 1955) to decompose the change in the number of kin with dementia into contributions from changing prevalences (rate effect) and changing age distributions. Figures 4*A* and 4*B* present the results for different types of kin for two time periods. Between 1990 and 2019, the rate and the age effects jointly determine the increase in dementia cases. Between 2019 and 2050, the age effect is expected to dominate the increase in kin with dementia.

*** Figure 4 About Here ***

Dementia Burden in China and Globally

The components of the Dementia Dependency Ratio DDR(x), and the DDR itself, are shown in Figure 5 for the years 1990, 2019, and 2050. The age-specific DDR(x) values presented in Figure 5*C* indicate that individuals tend to have a higher DDR before the age of 25 and after the age of 60. Age-specific DDR values are expected to skyrocket by 2050. The dramatic increase in DDR is driven by two factors: the increase in the number of kin who have dementia (Figure 5*A*) and the decline in kinship size over time (Figure 5*B*).

*** Figure 5 About Here ***

To situate China in a global context, we repeat the calculations for 194 countries. We base the comparison on the population-level dementia burden index DDR(pop). We use available dementia estimates in the Global Burden of Disease database and demographic rates from the United Nations (Nichols et al. 2022; United Nation 2022). Table S3 in the online appendix displays the expected age-weighted DDR(pop) for 194 countries and territories in 1990, 2019, 2030, 2040, and 2050.

Figure 6 shows the heat maps of age-weighted DDR(pop) by countries in 1990, 2019, 2030, 2040, and 2050. In 1990, DDR(pop) was high in Europe and North America, with the highest values appearing in Sweden, with a level of 2.0. China had one of the lowest levels of age-weighted DDR(pop) at the time, with 0.5, similar to Mexico and Libya in that year. In 2019, the global ranking of DDR(pop) shifted, and Japan was in the lead, with a DDR(pop) level of

6.8. The age-weighted DDR(pop) of China was 1.9, similar to Ireland and Chile in that year. In 2050, the DDR(pop) of China is projected to be among the highest around the world at 8.2, above many well-known aging societies such as Germany and France.

*** Figure 6 About Here ***

Figure 7 depicts the projected change in the age-weighted DDR(pop) from 1990 to 2050. China's age-weighted DDR(pop) in 2050 will be approximately 18 times higher than it was in 1990, making its increase one of the fastest ever observed, following only Singapore's, which will climb roughly 24 times. However, due to China's massive population size and underdeveloped public health support system, the challenges it faces will be far greater than those of other countries.

*** Figure 7 About Here ***

Discussion

China has the highest number of people living with dementia in the world. As China's population continues to age, dementia is expected to remain a significant social and public health concern for the foreseeable future. While the majority of elderly with dementia are cared for by family members, shrinking family size and changing kinship structures are undermining the traditional family care arrangements. Furthermore, a recent study has revealed that the unit cost of dementia care in China has doubled from 2000 to 2019 and is predicted to double again within the next two decades (Pedroza et al. 2022). The compound effects of increasing dementia cases, smaller families, and rising costs may exacerbate the impact on individuals, families, and the wider society. With the rising demand for dementia care in China, the present study illustrates the evolving accessibility of care provided by family members, who offer an alternative care source to professional providers and healthcare institutions.

Using demographic models of kinship, we estimate kin availability and prevalence of dementia among individuals' kinship networks. We find the probability that an individual has a close family member with dementia rises significantly. For example, among people aged 30, the likelihood of having at least one living grandparent with dementia grew from 5% in 1990 to nearly 30% in 2050, whereas among those aged 50, the likelihood of having at least one living parent with dementia climbed from 3% to 11%. Furthermore, the number of kin available to elderly persons for caregiving will plummet over the next three decades.

Factoring in changing kinship sizes and structures, our kin-based DDR indices shed more light on the impact of demographic change on the dementia caregiving demand. Our results suggest that the dementia caregiving burden in China is expected to climb 18-fold, one of the most dramatic changes around the world. For example, in 1990, a Focal individual of age 80 would have had 0.4 kin with dementia (considering all types of kin and kin of different ages) and 35.1 working-age, dementia-free kin (defined as kin aged 16 to 64 without dementia). In 2019, an 80-year-old Focal would have had 1.2 kin with dementia and 29.9 kin who were dementia-free and could have been care providers. Looking ahead to 2050, these figures are expected to change to 2.2 kin with dementia but only 11.6 dementia-free kin. However, it is also worth noting that because kinship models are projections of the consequences of the demographic rates conditional on these hypotheses, they are not expected to duplicate the results found from empirical censuses of kin (as noted explicitly by Goodman, Keyfitz, and Pullum (1974)). Rather, they capture the main effects of the demographic structure against which the effects of violations of these assumptions can be evaluated.

This study highlights important directions for future research. First, our study treats the population as a homogeneous group, with a single set of demographic rates and dementia prevalences. However, fertility and mortality rates and dementia prevalences vary significantly across education, income, *hukou* status, place of residence, and other sociodemographic indicators

(Crimmins et al. 2018; Jiang 1995; Yang 1992). These factors would lead to variations in the estimates of kinship structure and dementia burden that are overlooked in the current study. For example, in rural-to-urban migration in China, the working-age rural population tends to move to large cities in response to growing labor demand and economic opportunities, which has resulted in millions of elderly people left behind in rural areas (Chen and Liu 2009). Although rural older adults have larger kinship networks than their urban counterparts, they are in poorer health and often have no primary family members nearby who can provide dementia care (Lin and Tang 2023). Future research should investigate the complex interaction between kinship and other social factors to identify the most vulnerable, hard-to-reach groups that have limited access to health coverage. Extending our approach using multistate matrix kinship models (Caswell 2020) is a promising approach.

Researchers should also pay attention to whether the increasing prevalence of dementia among kinship networks will produce new social inequalities for those providing care and those at risk of having kin with dementia. From a life course perspective, having grandparents or parents with dementia at younger ages may temporarily disrupt an individual's work as he or she takes time off or adjusts work schedules to provide care for family members, or even lead to long-term consequences for reduced work performance, diminished career prospects, and financial strain. Another limitation of our findings is that we omitted spouses as potential caregivers in the calculation of DDR. Spouses are more likely than children and other biological kin to live with the person with dementia and are often better equipped to provide care due to their closer emotional bond with the dementia patient. Yet, because of the dynamic nature of marriage and cohabitation relationships, we are unable to incorporate estimates of spouses into the kinship and DDR calculations. Future research with family- and household-level microdata may provide valuable insights into the impact of dementia on spouses. Finally, we offer a broad definition of kin availability, which includes not only close family such as children and siblings, but also extended kin, such as cousins and nieces/nephews. While contact and care support are common among extended family members in China, the extent to which this tradition will continue, after decades of profound demographic and economic transformations, is unknown. An additional analysis that limits the types of kin to only children, siblings, and parents shows a similar significant rise of DDR in China when compared to other countries as those presented in Figure 5 (see results in online appendix Figure S2 and S3).

Our findings have policy implications for national healthcare systems and family well-being. Although China is not the only country anticipated to see a rapid increase in the DDR, the challenge it faces is formidable given the sheer size of its elderly population and inadequate health capacity. According to the OECD Health Statistics (OECD 2023), there were 12.1 practicing nurses per 1,000 people in Japan, 8.4 in Korea, and only 3.3 in China in 2020 (China National Bureau of Statistics 2021). Our findings suggest an urgent need for China to expand its healthcare infrastructure, increase the size of the professional, community, and public health workforce, and improve early dementia diagnosis and intervention for the middle-aged and elderly, as well as risk reduction programs targeted at younger age groups. In addition, future policies should strengthen social and governmental support for family caregivers, who will soon find that there are fewer family members to share the mounting financial, physical, and emotional responsibility as more of their close relatives develop dementia in the coming decades.

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Figures

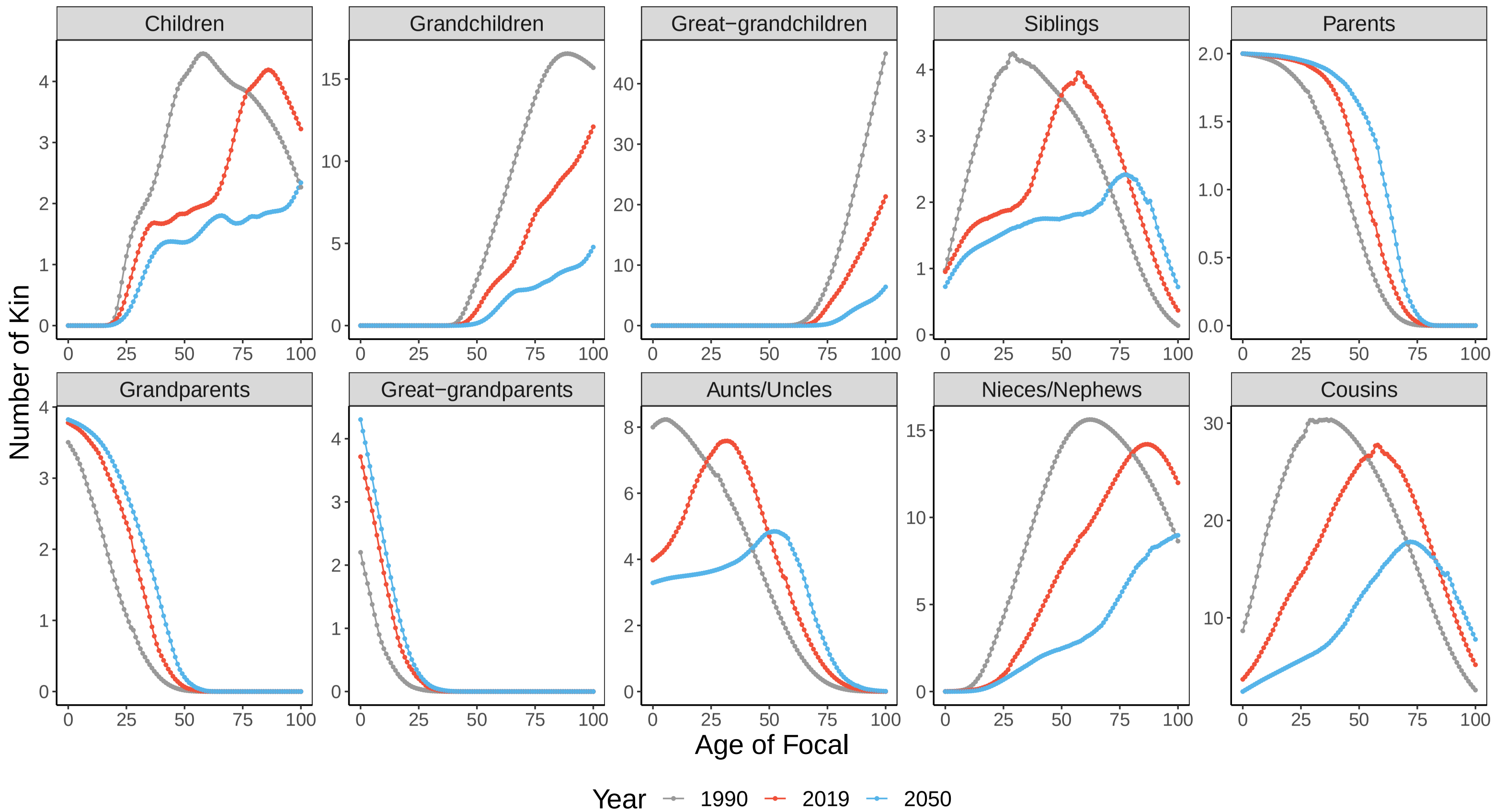


Fig. 1. Expected Numbers of Kin of Various Kinds as a Function of the Age of Focal in 1990, 2019, and 2050

Data sources: Institute for Health Metrics and Evaluation (IHME). Findings from the Global Burden of Disease (GBD) Study 2019. Seattle, WA: IHME, 2021; United Nations, Department of Economic and Social Affairs, Population Division (2022). World Population Prospects 2022 Revision, Online Edition; GDB 2019 Dementia Forecasting Collaborators Nichols et al. 2022.

Notes: The figure presents the expected numbers of living kin of various types as a function of the age of Focal in 1990, 2019, and 2050, respectively. The living kin are estimated from the time-varying kinship model using period age-specific fertility and mortality rates from 1950 to 2050 from the UN's 2022 Revision of World Population Prospects United Nation 2022. The results in a particular year reflect the changing mortality and fertility schedules in China from 1950 up to that year. The methodology is described in the Materials and Methods section. To estimate the number of all kinds of kin from both paternal and maternal ancestry, we assume that the demographic rates of female and male kin are equal.

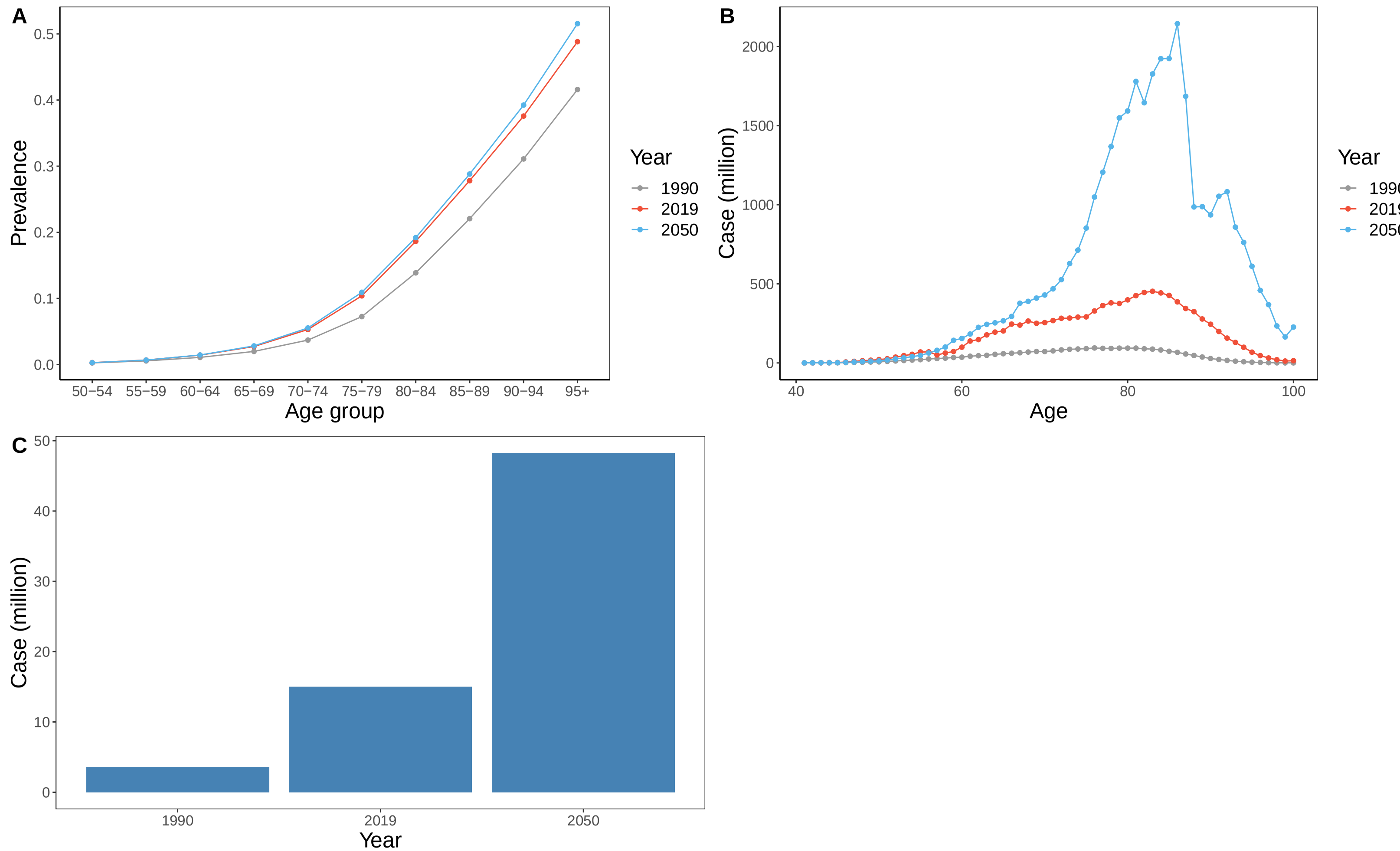


Fig. 2. (A) Projected Age-Specific Dementia Prevalence Rate and the Number of Dementia cases in 1990 and 2019, and 2050 (B) Projected Number of Dementia Cases by Age in 1990, 2019, and 2050. (C) Projected Total Number of Dementia Cases (in million) in 1990, 2019, and 2050.

Data sources: Institute for Health Metrics and Evaluation (IHME). Findings from the Global Burden of Disease (GBD) Study 2019. Seattle, WA: IHME, 2021. GDB 2019 Dementia Forecasting Nichols et al. 2022.

Notes: Panel A shows the age-specific prevalence rate of dementia in 1990, 2019, and 2050; Panel B shows the number of dementia cases (in million) in 1990, 2019, and 2050; and Panel C shows the total number of dementia cases (in million) in 1990, 2019, and 2050. These numbers are calculated using dementia prevalence estimates from the GDB 2019 Dementia Forecasting Collaborators Nichols et al. 2022

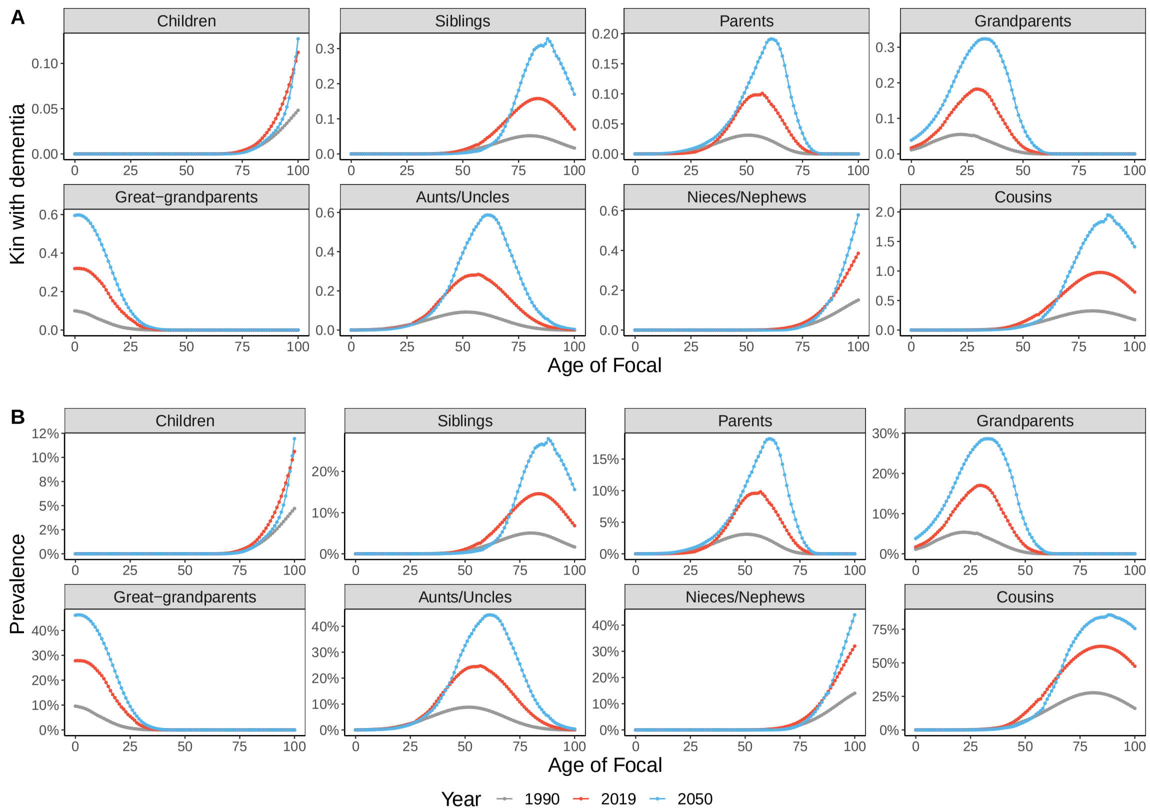


Fig. 3. (A) Estimated Number of Kin with Dementia as a Function of the Age of Focal in 1990, 2019, and 2050. (B) Estimated Probabilities of Having at Least One Kin with Dementia as a Function of the Age of Focal in 1990, 2019, and 2050.

Data sources: Institute for Health Metrics and Evaluation (IHME). Findings from the Global Burden of Disease Study 2019. Seattle, WA: IHME, 2021; United Nations, Department of Economic and Social Affairs, Population Division (2022). World Population Prospects 2022 Revision, Online Edition.

Notes: Section A presents the count of kin, categorized by kin type, with dementia for an individual by the age of that individual in the years 1990, 2019, and 2050. Section B shows the probability that an individual has a certain type of kin with dementia by the age of the individual in 1990, 2019, and 2050. These numbers are estimated from time-varying age-specific fertility, mortality, and prevalence of dementia in the population. The estimation details are described in the Methods section.

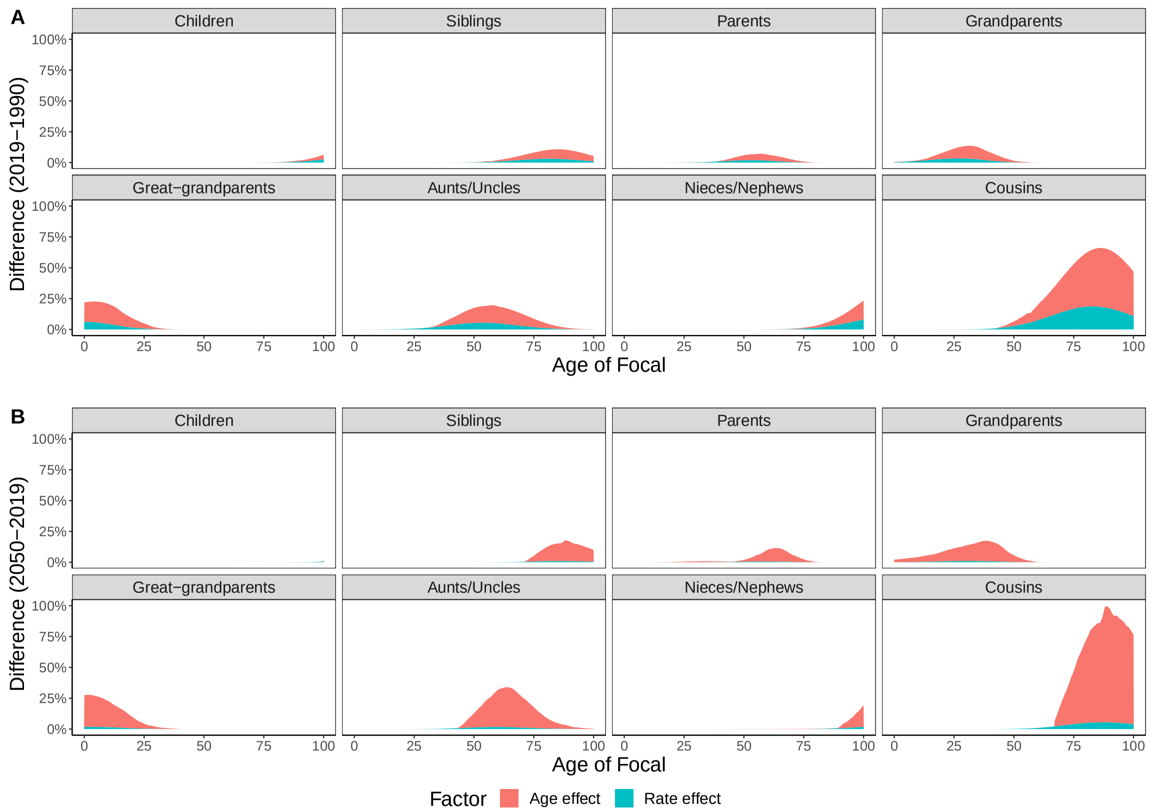


Fig. 4. (A) Decomposition of the Difference in the Number of Kin with Dementia between 1990 and 2019. (B) Decomposition of the Difference in the Number of Kin with Dementia between 2019 and 2050.

Data sources: Institute for Health Metrics and Evaluation (IHME). Findings from the Global Burden of Disease Study 2019. Seattle, WA: IHME, 2021; United Nations, Department of Economic and Social Affairs, Population Division (2022). World Population Prospects 2022 Revision, Online Edition.

Notes: Sections A and B present the Kitagawa's decomposition results. The total area of each graph gives the difference in the number of kin with dementia between 1990 and 2019 (A), 2019 and 2050 (B), partitioned into contributions from the difference in age structure of kin and the difference in age-specific dementia rate.

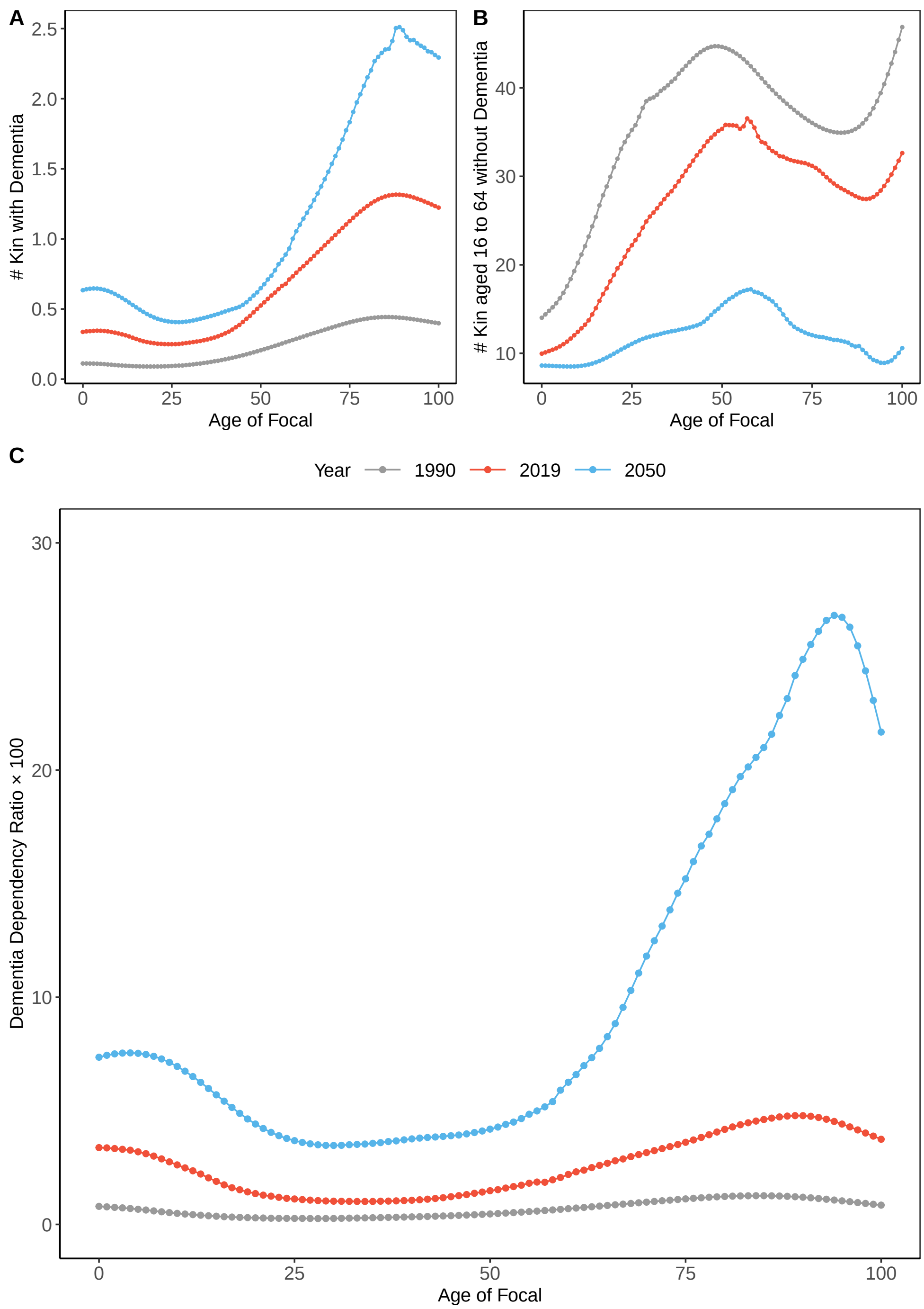
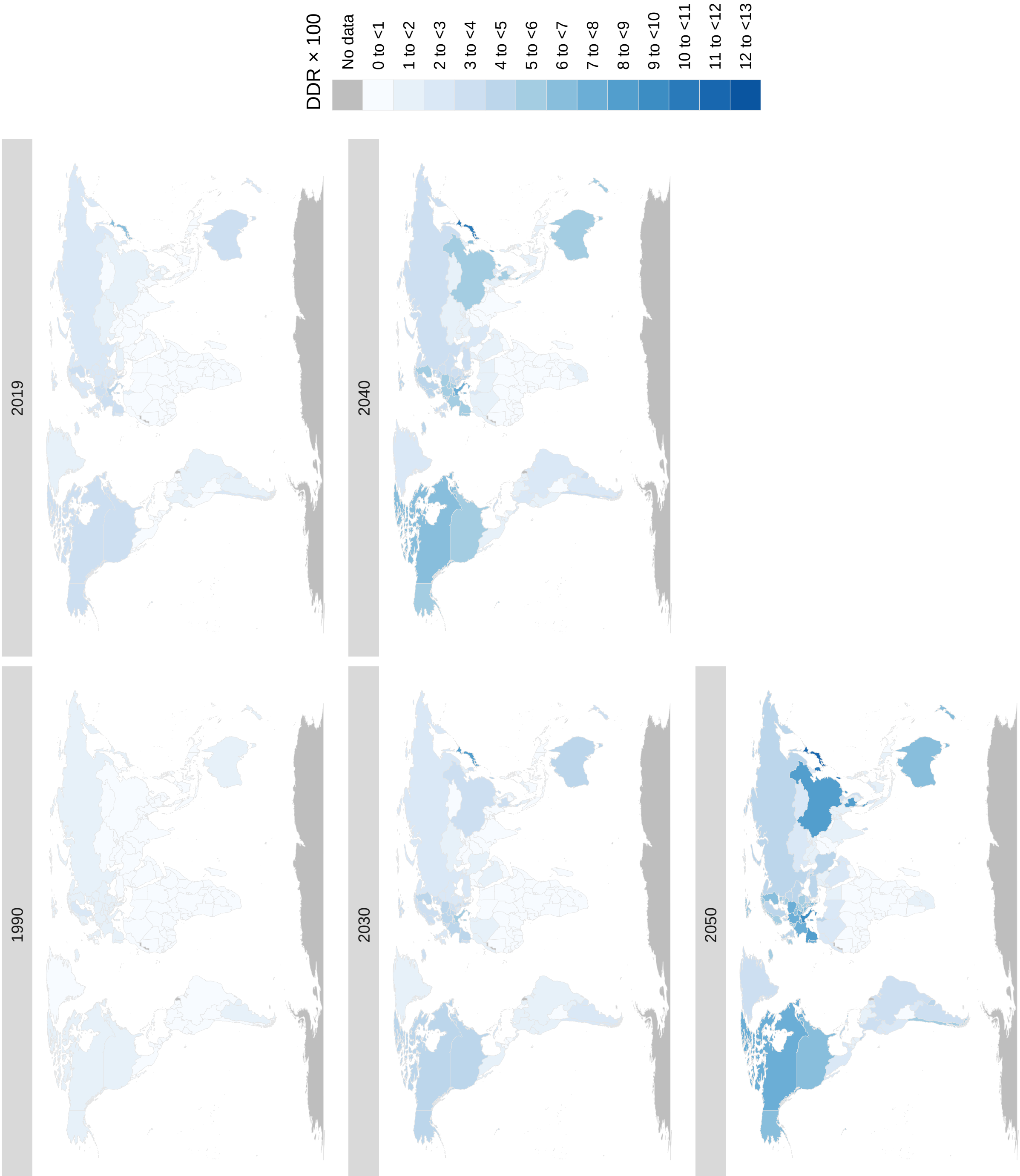


Fig. 5. (A) The Number of Kin with Dementia. (B) The Number of Kin Aged 16–64 without Dementia. (C) The Dementia Dependency Ratio (DDR(x)) as a Function of the Age of Focal in 1990, 2019, and 2050.

Data sources: Institute for Health Metrics and Evaluation (IHME). Findings from the Global Burden of Disease Study 2019. Seattle, WA: IHME, 2021; United Nations, Department of Economic and Social Affairs, Population Division (2022). World Population Prospects 2022 Revision, Online Edition.

Notes: These figures show the estimated number of kin with dementia, the number of kin aged 16-64 without dementia, and the estimated dementia dependency ratio (DDR) by age of individuals in 1990, 2019, and 2050. DDR refers to the proportion of family members with dementia to family members without dementia who are at risk for providing family care. The mathematical definition of DDR is discussed in the Methods section.



DDR × 100
No data
0 to <1
1 to <2
2 to <3
3 to <4
4 to <5
5 to <6
6 to <7
7 to <8
8 to <9
9 to <10
10 to <11
11 to <12
12 to <13
1990
2019
2030
2040
2050

Fig. 6. Population-Averaged Dementia Dependency Ratio DDR(pop) by Country and Region in 1990, 2019, 2030, 2040, and 2050

Data sources: Institute for Health Metrics and Evaluation (IHME). Findings from the Global Burden of Disease (GBD) Study 2019. Seattle, WA: IHME, 2021; United Nations, Department of Economic and Social Affairs, Population Division (2022). World Population Prospects 2022 Revision, Online Edition; GDB 2019 Dementia Forecasting Collaborators Nichols et al. 2022.

Notes: This figure presents five heat maps of DDR(pop) for countries of the world in 1990, 2019, and 2050. We apply the method used for estimating the DDR index for China to other countries. The indexes draw on dementia data from GDB 2019 Dementia Forecasting Collaborators and data of fertility and mortality rates in the UN's 2022 Revision of World Population Prospects United Nation 2022. A darker blue color indicates a higher caregiving burden caused by dementia on kinship groups, whereas a lighter blue color indicates a lower caregiving burden caused by dementia on kinship groups. The detailed DDR estimates are presented in Appendix Table S3.

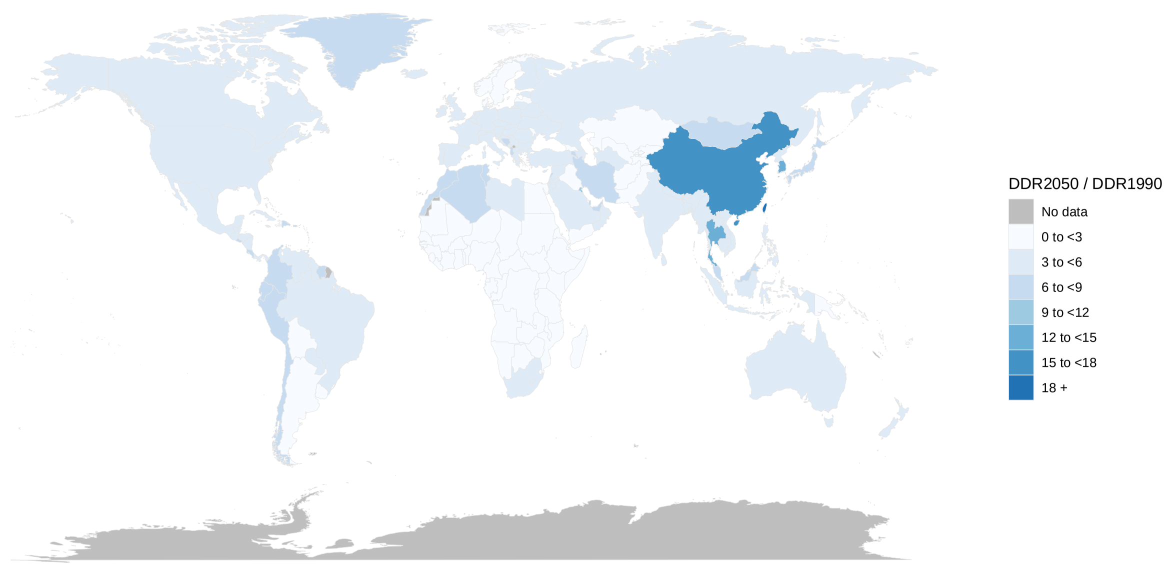


Fig. 7. Change in the Age-Avereaged Dementia Dependency Ratio DDR(pop) by Country and Region from 1990 to 2050

Data sources: Institute for Health Metrics and Evaluation (IHME). Findings from the Global Burden of Disease Study 2019. Seattle, WA: IHME, 2021; United Nations, Department of Economic and Social Affairs, Population Division (2022). World Population Prospects 2022 Revision, Online Edition.

Notes: This figure presents a heat map of changes in the age-weighted Dementia Dependency Ratio from 1990 to 2050 for countries of the world. We apply the method used for estimates for China to other countries with dementia data available in the Global Burden of Disease database and demographic rates estimated by the United Nations. A dark blue color indicates a rapidly increasing dementia burden on kin, whereas a light blue color indicates a slowly increasing burden caused by dementia on kin over time.