Policy Report

Carers in Europe

Later-life caring in Europe

Findings from the Eurocare project

JPI MORE YEARS BETTER LIVES
a Joint Programming Initiative

Foreword

With expanding life expectancies and rapid medical improvements, many of us will live longer with medical conditions that require help and assistance from professionals, but also from our family and friends, - for those who got them. For the first time, NGOs and organizations that work for improving conditions for senior citizens are having two generations of members – the 70-year-old and their parents 90-95 years old.

This report is highlighting a development that is showing how caring for each other in later life will be and should on the agenda for the coming years.

First, the key findings show that **caring in later life is varying over Europe**. **More caring is done in countries with less support and long-term care solutions.** The pandemic revealed that LTC care in many parts of Europe was inadequate. The launch of a European Care Strategy for caregivers and care receivers in 2022 was highly needed. The findings in this report on later life caring makes it necessary for policymakers to revisit the strategy and follow up on the action points. This goes for both the countries that are lacking state support, as well as countries that are considered well developed, like in the Nordics. In the Nordics the policy is changing, from LTC to ageing at home due to intensive costs for LTC. That cannot be done without a plan on how to support the working carers in their senior years, helping their spouses and/or parents, while still in paid jobs, as well as to invest in better at-home services.

The second point that needs attention is the **gender** aspect. The older **women are doing more caring** in their later life, and they also have longer life expectancy. The risks are, that they will take the burden of caring for others, but when they themselves need care, there is little or no support for them in their last years, which they are facing alone.

Socioeconomic differences will be a matter arising. The differences will divide between those who can pay for help and professional care, and those who can’t. This should be addressed with special support to those who need public respite and affordable care.

I also want to stress the effect on **mental health** when caring for instance for someone with cognitive impairment like dementia. To be living with and caring for a person with this illness is a potential area where we are likely to get two patients from one diagnosis if we do not support the carers!

In the coming years, many parts of Europe will change demographically to a continent where we are selling more incontinence products than baby diapers. The need to support the later-life carers are urgent. This report is highlighting the challenges. I highly recommend that the evidence-based policy directions outlined in need to be put to action, in order to support later-life carers across Europe.

Anita Vatland
CEO Pårørendealliansen, Norwegian alliance for informal carers
22 May 2024

Key Findings

The proportion of people caring in later-life **varies dramatically across European countries,** from 5% in Romania to 34% in Denmark.

Carers in countries where **state support** is low (which tend to be Southern and Eastern European countries) spend much more time caring than carers in countries with more state support (‘Nordic’ countries and the Netherlands).

Gender inequalities in later-life care

- Across Europe, women are slightly more likely than men to provide care in later-life. Women tend to do personal care like bathing, dressing, and getting in and out of bed, and women care for slightly more hours than men. The gender difference in care hours is also slightly greater in countries with less state support for carers. However, the census in England & Wales suggests that the gender differences in later-life caring have decreased over the last twenty years.

Socioeconomic inequalities in later-life care

- The likelihood of being a carer in the 65+ age group increases slightly with household incomes. This contradicts what we have seen in younger age groups where caring was more common among disadvantaged households. However, among carers aged 65+, intense care (20+h p/w) was still more common among disadvantaged households.
- People with little wealth, not in paid work, with older parents and those living with adults in poor health are more likely to provide long care hours in later life.

Mental health and wellbeing of later-life carers

- Evidence from the UK shows that taking up intensive care (20+ hours/week) in later life is linked with deterioration in mental and physical health. In Norway, we found that becoming a carer in later life is linked with an increase in worry and a decline in life satisfaction.

- Older carers in Norway report a higher level of loneliness despite the fact that they are participating in social activities more frequently.
- During the peak of the pandemic, older carers in Norway reported higher levels of worry and anxiety than non-carers. Impacts were greater for carers who provided more intensive care and those with health problems or lacking access to social support. Similarly, in the UK, the health of older carers worsened more than non-carers in the first year of the pandemic, especially for those who cared for someone they lived with.

Policy Implications

- Providing **long hours of care** in later life results in **deteriorating health**. This highlights the importance of access to high-quality respite care and health checks for older carers.

- Our work shows that **state support** for carers– in terms of both care provision and financial support for carers – allows carers to care intensively, at levels that help to preserve their health. State support for older carers should be enhanced, including via increased funding for respite care, financial assistance and services to alleviate the burden on carers.

- **Women** continue to provide the bulk of personal care in later life. Initiatives should be developed to tackle remaining gender disparities in caring. This may include promoting gender-neutral caring policies, providing targeted support for male carers and conducting awareness campaigns to challenge stereotypes about caring roles.

- Providing long care hours throughout is more common in **disadvantaged households,** highlighting the need to tailor support measures to address socioeconomic inequalities in later-life caring. This might involve offering adequate financial assistance, improving access to healthcare services and providing employment support for carers from disadvantaged backgrounds.

- Our work also shows that older carers are more likely to report **loneliness**, so support should aim at supporting not only the quantity but also the quality of social connections for older carers. Strategies should be established to safeguard the mental health and well-being of late-life carers, including access to counselling services, community engagement, social support networks and mental health screening programmes.

- More research into which **interventions** are most effective in supporting those providing intensive care is needed.

Introduction

The **Eurocare** project brings together researchers from the UK, Germany, Spain, and Norway to investigate inequalities in caring and the impact of caring across European countries from a life course perspective. This is because the nature and impact of providing care are likely to differ at different life stages. This report shares some of the Eurocare project's findings on caring in later-life.

What do we mean by 'care'?

We use the term 'care' to refer to help or assistance that is provided usually unpaid to family members or friends with mental and physical health conditions, disabilities, and addictions.

Understanding more about carers is important in the context of ageing populations, increasing levels of ill health and inequalities, combined with long-standing challenges in the delivery of formal social care in many countries. Unpaid carers play a key role in promoting the quality of life of those with care needs and their families, ensuring their needs are met and they are supported. Older carers often provide care to partners, but also adult disabled children, parents, in-laws, or other relatives. A key feature of care provision in later life is that many older carers have retired and provide long hours of care, while their own health and wellbeing deteriorate. While all countries rely on care provided by family or friends to some degree, this reliance varies fairly dramatically across European contexts. In this report, we look at how common caring is in later life in Europe across different levels of state support for carers and inequalities in who provides care by gender and socioeconomic position. We then look at caring in relation to health and well-being. We use a mixture of national survey and census data and longitudinal surveys that follow the same people over time where we can, to observe whether becoming a carer leads to changes in health and wellbeing.

How common is later-life caring in Europe?

The proportion of people caring in later life (aged 65+) varies substantially across countries, from 5% in Romania to 34% in Denmark (Figure 1). In Finland, France, Iceland, and Croatia, more than 20% of people aged 65+ are carers, while in the Czech Republic, Spain, Cyprus, Slovak Republic, and Romania, less than 10% of older people are carers.[1] One possible explanation for this pattern is differences in life expectancy - in Denmark, Finland, France and Iceland, more people live into older age[2]and thus there may be more people with care needs. When looking at care hours among carers, we see a different pattern. Carers in Spain, the Slovak Republic, Romania, Portugal, Ireland, and Italy are the most likely to provide intensive

care (20+ hours per week), although the proportion of people caring in these countries is relatively low. This might be explained by the different levels of state support for carers (see next section). It is also important to acknowledge that estimates of caring vary depending on the specific question asked and also may vary due to cultural and social differences in interpretation.

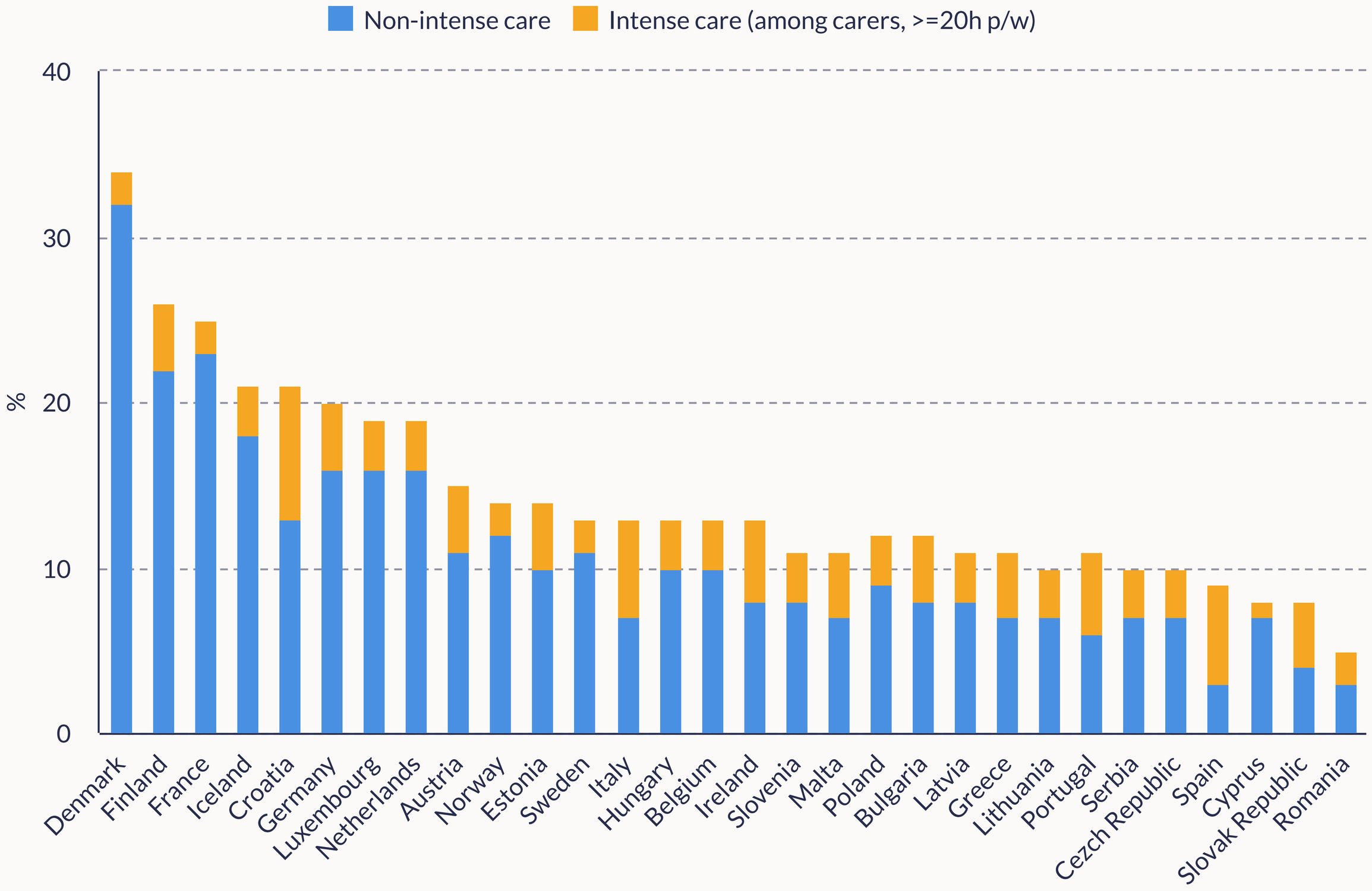

Fig. 1 Percentage of aged 65+ providing care by country, 2019
Source: European Health Interview Survey in 2019 (EHIS 3)

Differences by levels of state support for carers

We have grouped 24 European countries into high, mid, and low levels of state support for carers based on: expenditure on long-term care services as a share of GDP, the number of long-term care beds per 1,000 people aged 65+, the number of long-term care workers per 100 people aged 65+, carers leave provision, and financial support for carers.[3] As shown in Figure 2, the high-support countries include the 'Nordic' countries and the Netherlands. The mid-support countries include North-West European countries, and the low-support countries are generally in Southern and Eastern Europe.

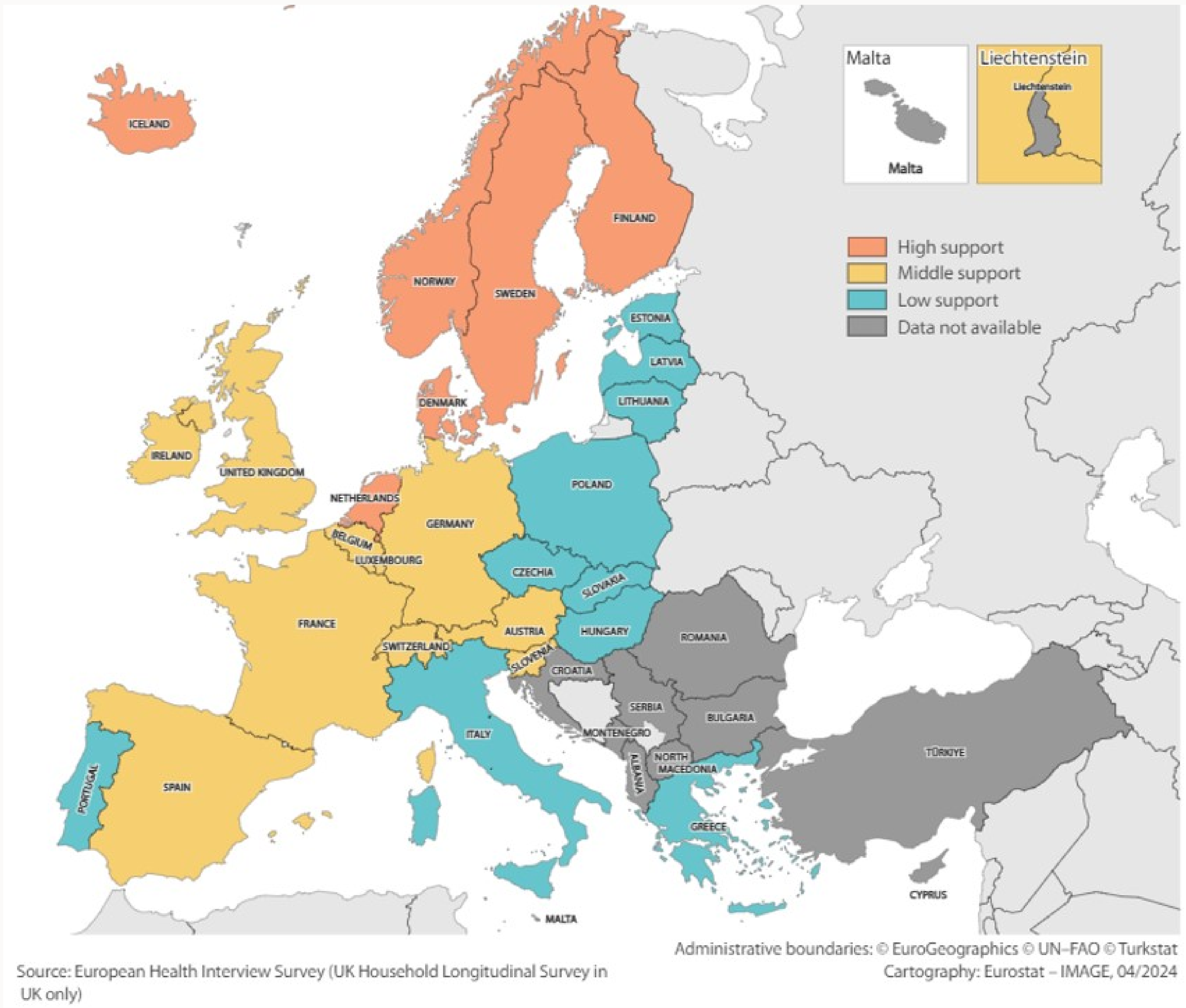

Fig 2. Map of countries grouped by levels of state support for carers, 2019

State support is based on expenditure on long-term care services as a share of GDP, # of long-term care beds per 1,000 people aged 65+, # long-term care workers per 100 people aged 65+, carers leave provision and financial support for carers.

Figure 3 shows that caring in later-life is less common in countries where state support for carers is lowest, but carers in those countries with less state support are much more likely to care for 20+ hours per week than carers in countries with more state support.[1,3] For example, amongst those aged 65+, 39% of carers cared for 20+ hours per week in countries with low levels of state support for carers, compared with 20% in countries with medium levels and 12% in countries with high levels of state support for carers. This pattern is in line with previous work showing that family members are more likely to take up care, but less intensively, where the state provides much of the more demanding personal care tasks.[4]

Carers in countries with less **state support** spend more time caring.

In countries with low state support, 39% of carers aged 65+ provide **20+ hours** of care weekly, versus 12% in countries with high support

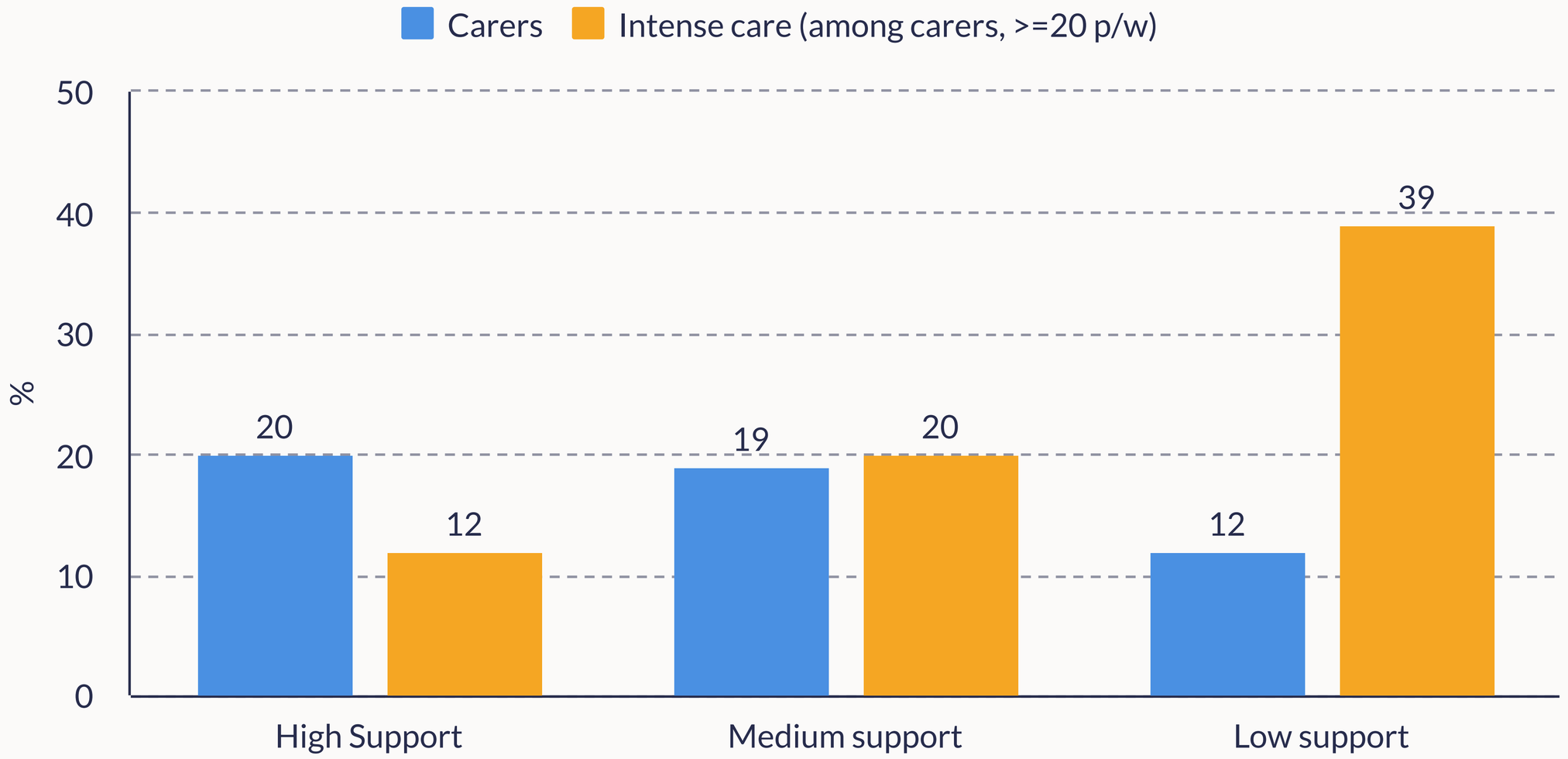

Fig 3. Percentage of aged 65+ providing care by state support, 2019
***Source: European Health Interview Survey in 2019 (EHIS 3)**

State support is based on expenditure on long-term care services as a share of GDP, # of long-term care beds per 1,000 people aged 65+, # long-term care workers per 100 people aged 65+, carers leave provision and financial support for carers.

In England & Wales

The % of carers **caring for 50+** hours per week rose from 36% in 2001 to 47% in 2021

Looking at England & Wales, the census data shows that levels of caring in later-life have remained similar over the past twenty years, between 11% and 14%. Figure 4 shows that, amongst carers aged 65+ in England & Wales, the proportion of caring for 50+ hours per week increased from 36% in 2001 to 39% in 2011 and then 47% in 2021. It should be noted that the 2021 census was collected during the COVID-19 pandemic, which may contribute to these differences.

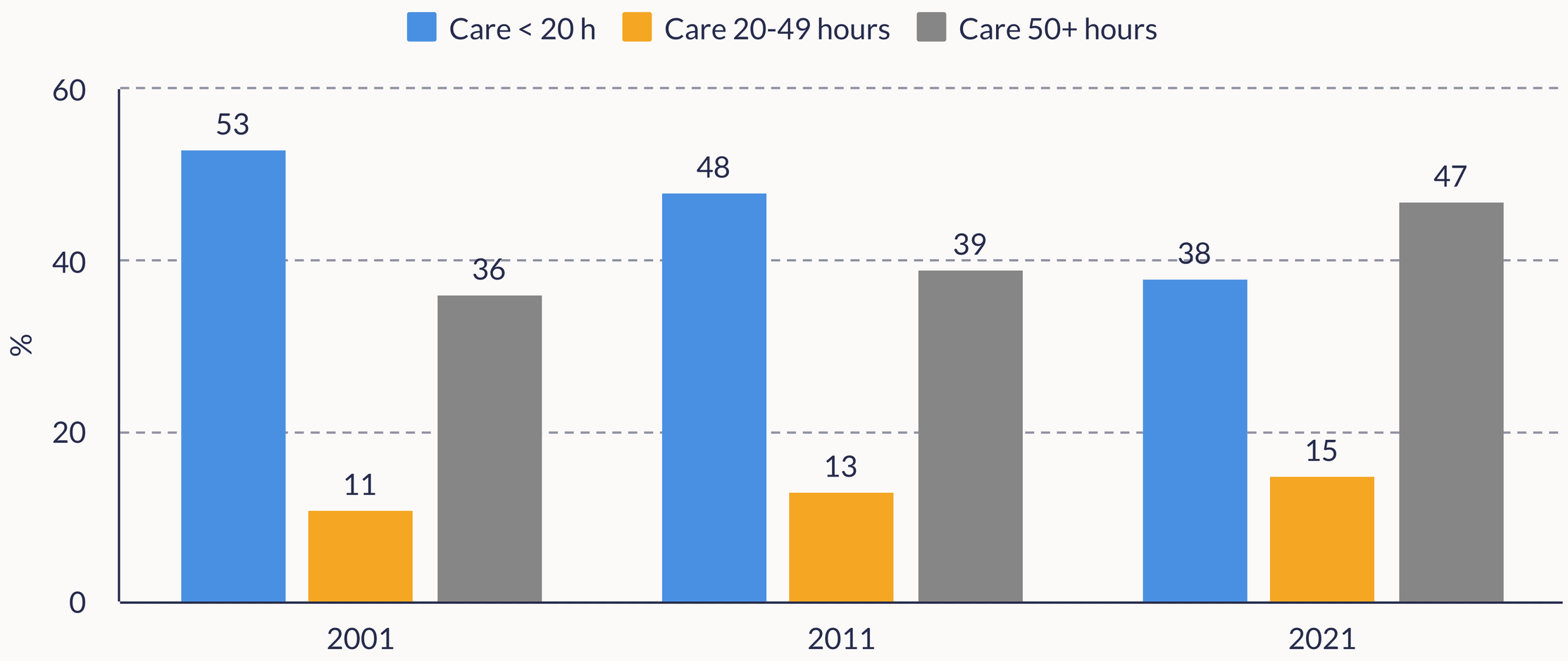

Fig. 4 Weekly care hours for carers aged 65+ in England & Wales at 2001, 2011, 2021
Source: Census in England & Wales in 2001, 2011, 2021

Are there inequalities in later-life caring in Europe?

Gender

In this report, we refer to gender as a binary categorisation to reflect traditional norms considering care to be a feminine labour form. Looking across Europe, women are slightly more likely than men to provide care in later-life and women care for slightly more hours than men.

Women are more likely to care for longer hours in later-life

In 2019, 13% of men aged 65+ provided care compared with 15% of women. As Figure 5 shows, amongst carers aged 65+, 26% of women cared more than 20 hours per week compared to 22% of men.[1]

Women were more likely to do personal care like bathing, dressing, and getting in and out of bed whereas males were more likely to take over practical household help like home repairs or gardening.[5]

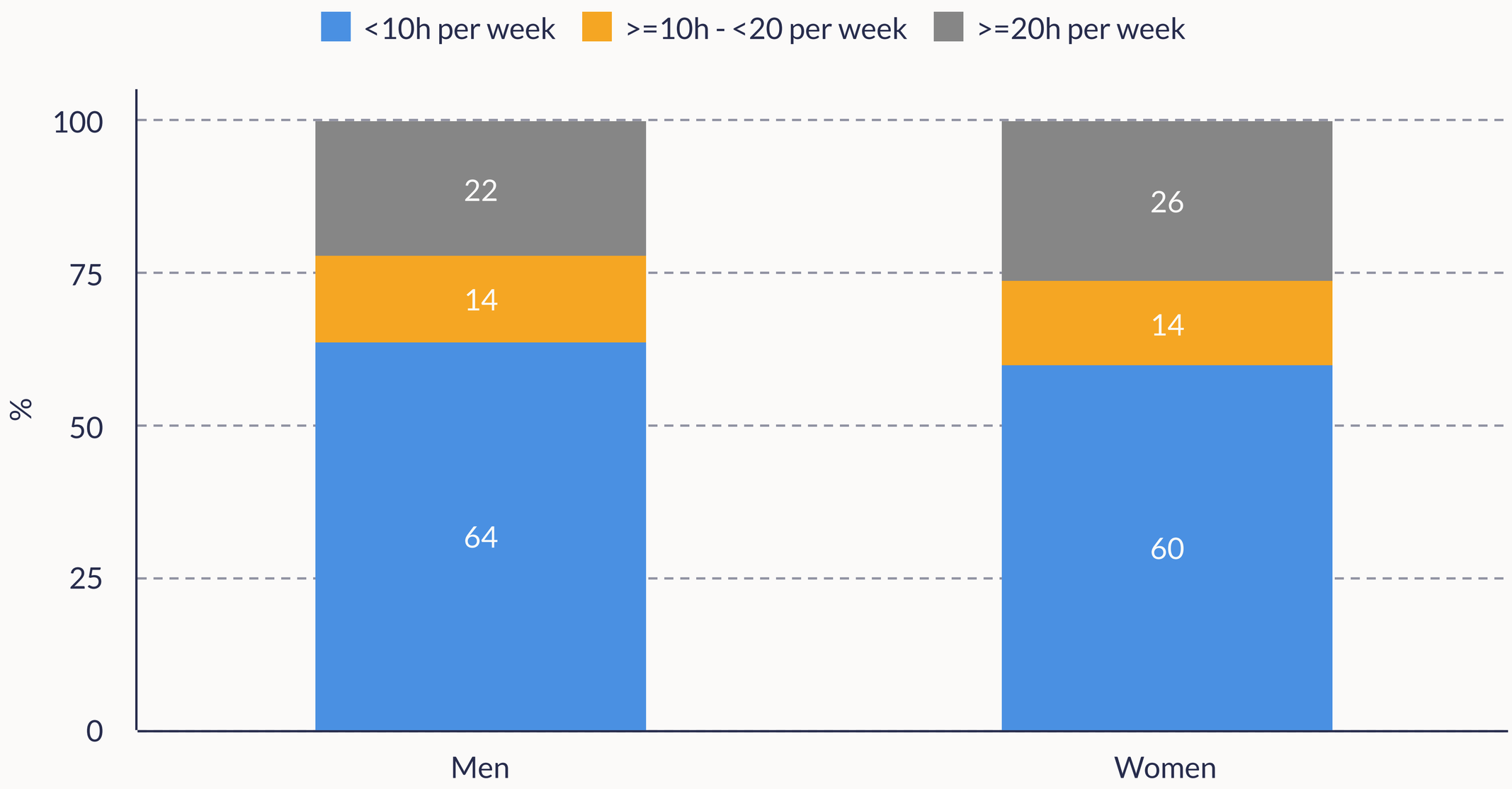

Fig. 5 Care hours among aged 65+ carers by gender, 2019
Source: European Health Interview Survey in 2019 (EHIS 3)

However, Census for England & Wales shows that the gender differences in later-life caring have decreased over the last twenty years in this age group, and there was not much gender difference in the proportion of men and carers or in care hours in 2021.

Gender, care hours and state support

Figure 6 shows that the gender difference in care hours is slightly greater in countries with less state support. In countries with low state support, the percentage of women who provide care for 20+ hours per week is 7 percentage points higher than among men whereas gender differences are negligible in countries with higher levels of state support.[1,3]

In countries with low state support, female carers are about **7% more likely** than male to care for 20+ hrs/week

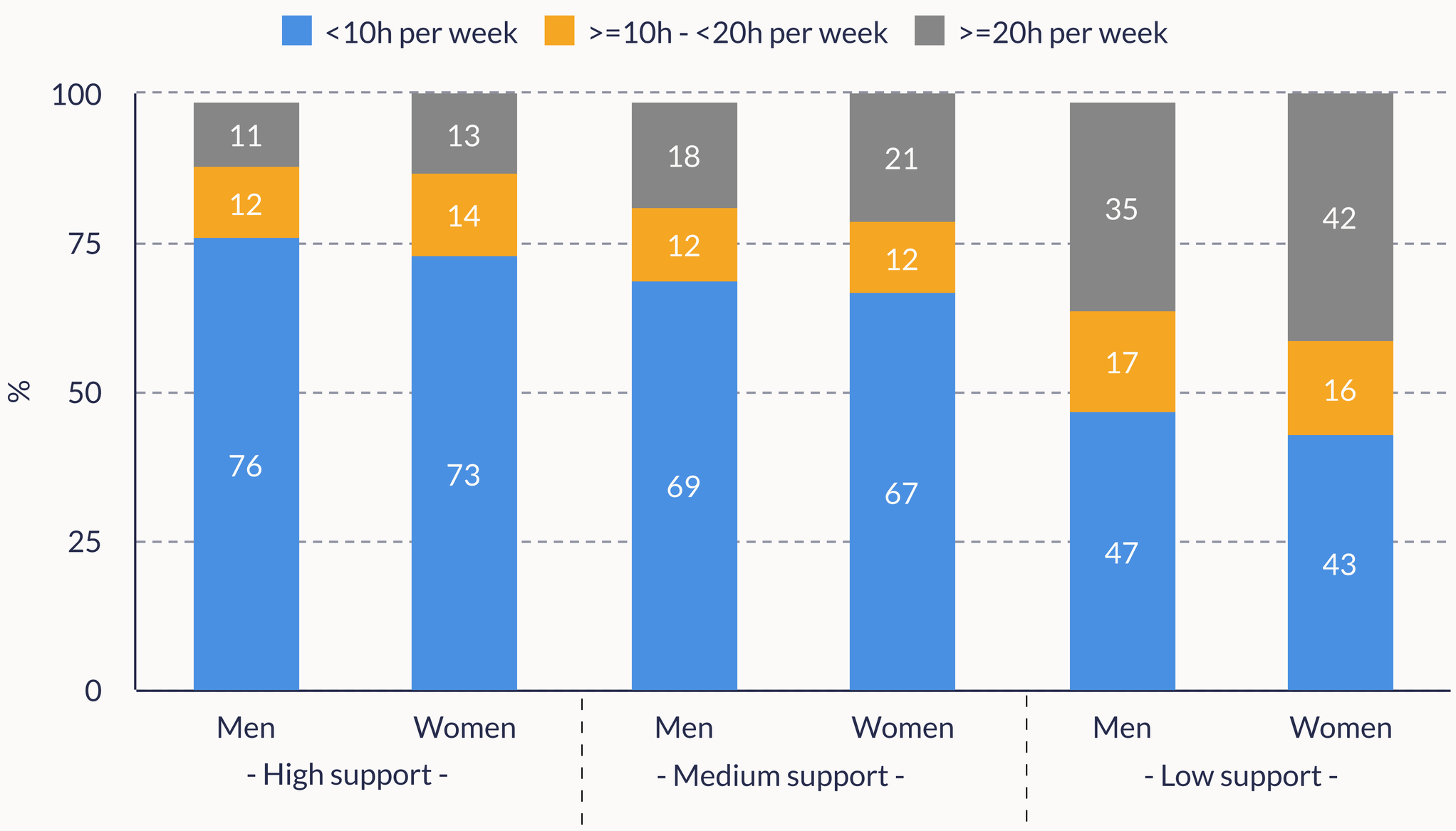

Fig. 6 Percentage of aged 65+ providing care by state support, 2019
Source: European Health Interview Survey in 2019 (EHIS 3)

State support is based on expenditure on long-term care services as a share of GDP, # of long-term care beds per 1,000 people aged 65+, # long-term care workers per 100 people aged 65+, carers leave provision and financial support for carers.

Income

Figure 7 shows that the likelihood of being a carer in the 65+ age group increases slightly with household income.[1] For example, 14% of older people in the poorest fifth of household incomes were carers compared to 18% of the richest fifth of household incomes. This contradicts what we have seen in younger age groups where caring was more common in disadvantaged households.[1] One possible explanation is that older people with higher incomes are more likely to have living parents who need care,[6] or that the reported findings are based on a rather broad definition of care that does not differentiate which type of care is provided or where it is provided (inside or outside the household). However, when looking at care hours, we find that those with poorer household incomes are more likely to provide intense care.

Carers from **lower-income households** are more likely to provide intensive care.

20% of carers from the richest household **care for 20+h/w** compared to 24% to 26% of the rest groups.

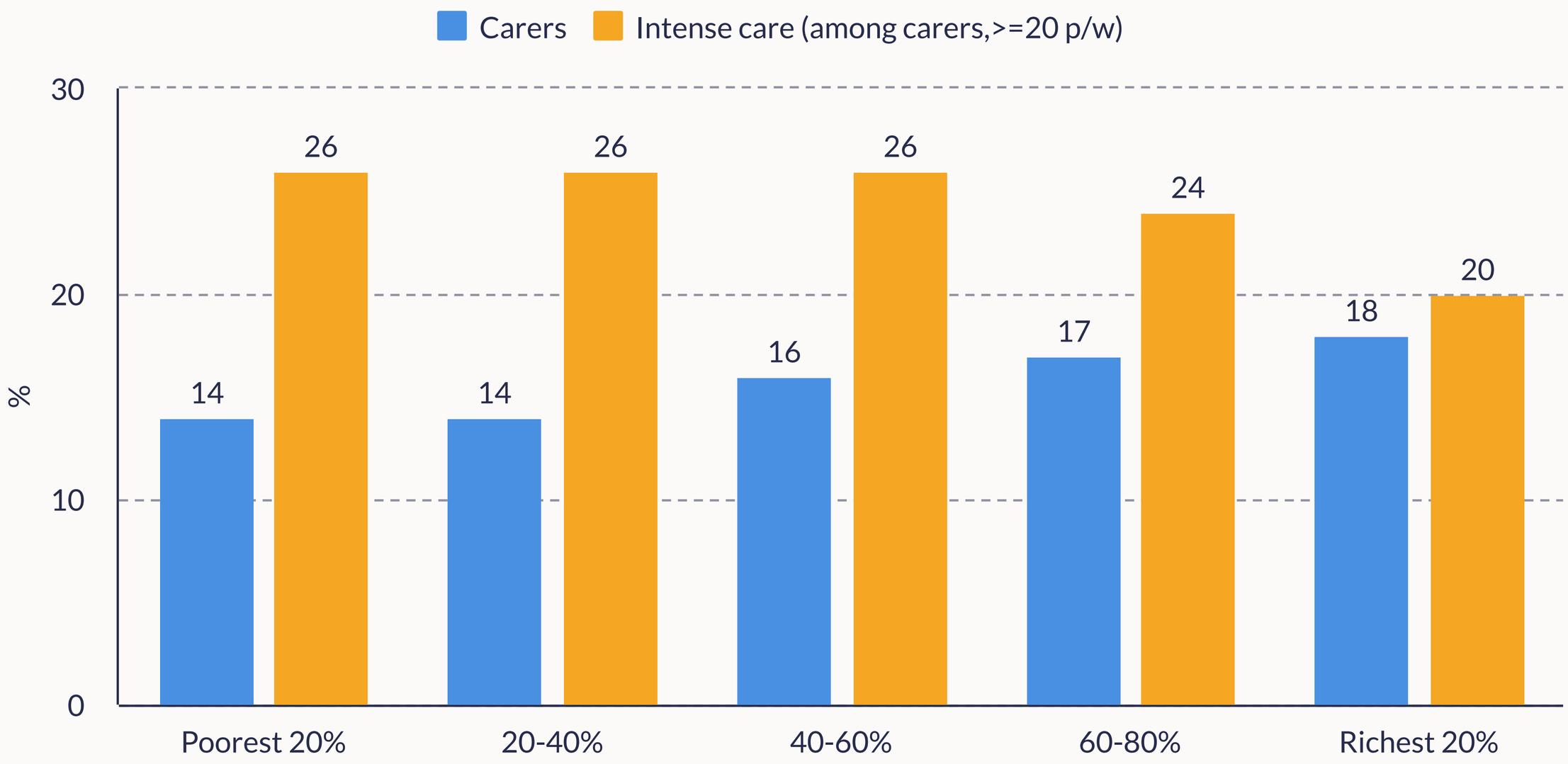

Fig 7 Percentage of aged 65+ providing care by household income, 2019
Source: European Health Interview Survey in 2019 (EHIS)

Later life care over time & who becomes a carer in later life

In addition to looking at the snapshots of caring at a single point in time, we looked at how care changed over 6 years for people aged 50+ in England. We found that two-thirds of people never provided care over 6 years, 5% provided intensive care throughout, 23% decreased the care hours they provided over time and there were 7% whose care hours increased over time. Women and those in good health were generally more likely to provide care over time.[7]People with little wealth, not in paid work, with older parents and those living with adults in poor health are more likely to provide long care hours in later life.[7]

How does later-life caring affect older people's health and wellbeing?

Data from people aged 50+ across European countries shows that, for both men and women, personal care provided inside the household was associated with increased depressive symptoms.[5]

In the UK, we also found that becoming a carer in later life and caring for 20 hours or more per week was linked with deterioration in mental and physical health.[8]

In Norway, we found that becoming a carer in later life was linked with an increase in worry and a decline in happiness and life satisfaction.[9]

By comparing carers with and without migrant backgrounds, we found that the patterns were quite similar for the two groups.[10]

Care and well-being during the Covid-19 pandemic

During the peak of the pandemic, older carers in Norway reported higher levels of worry and anxiety than non-carers. Impacts were greater for carers who provided more intensive care and those with health problems or little access to social support.[11] Similarly, in the UK, the physical and mental health of older carers worsened more than non-carers in the first year of the pandemic, especially for those who cared for someone they lived with.[12]

Care and participation in social activities in Europe

Looking across Europe, we found that becoming a carer in later life increased the frequency of volunteering activities and group membership in both the short and long term, particularly among individuals providing fewer care hours.[13] This suggests that care is not necessarily associated with worse outcomes, but rather the strain and burden resulting from increased care hours that impact the carer's time and energy to participate in these social activities.[14]

In Norway, we also found that older carers reported a higher number of social activities, such as volunteering activities and group membership. However, older carers were also more likely to report loneliness.[15] This may be because some older carers are active in social activities, yet still feel lonely due to the stress of caring.

Alec

Alec is in his early 70s. He lives in Glasgow and he is retired. Alec lives with his wife Paula, who has arthritis and dementia, and his 12 year old grandson Kye. Kye has autism and lives with his grandparents under special guardianship after his parents weren't able to care for him due to their substance misuse.

Alec is trying to get a place in a special school for Kye but there is a waiting list and the nearest available provision is over an hour's drive away. Paula's behaviour is erratic and can be aggressive. Kye is upset by this and his grandmother's behaviour triggers his own challenging behaviour. Alec has to manage Paula's personal care, including continence and personal hygiene, and all the cleaning and cooking. He has to manage both Paula and Kye's challenging behaviour. He feels it is impossible to have both Paula and Kye under the same roof for much longer.

Alec and his family live in a housing association flat. Their only income is a state pension. Because Kye lives with his grandparents under special guardianship, they only get child benefit for him and can't claim any additional money as they would be able to do if they had fostered him. Alec feels that he had no choice but to take in his grandson to keep him in the family, as the alternative was to place him into the care system. However, Alec feels bitterness and anger that the full situation was not explained to him and Paula when they were encouraged to agree to this arrangement and feels that long-term fostering would at least have given them additional income and access to support.

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Find out more:

https://www.ucl.ac.uk/epidemiology-health-care/research/epidemiology-and-public-health/research/eurocare-inequalities-informal-caregiving-over-1

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