8 *Sharing the burden: the impact of long-term care on the financial situation of families in Europe*

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8.1 Introduction

Demographic ageing has increased the number of older people who find themselves in need of help and support with everyday activities, such as dressing or getting out of bed. As a result, public expenditure on long-term care in European countries is projected to almost double by 2070, according to projections from the European Commission, albeit in some cases from a very low base (ECOFIN/AWG, 2018). However these estimates do not consider the costs borne by users themselves or their families, nor is it clear that this increase in public expenditure will be sufficient to meet the needs of older people, or protect them from the risk of catastrophic expenditure arising from meeting those same needs. The need for long-term care tends to have a very high degree of uncertainty and the potential to be long-lasting (Forder & Fernández, 2009). Given the lack of individual private insurance schemes offered by the market and the actual costs of care, even middle-income groups would likely be unable to afford long-term care without the support of public welfare systems (Colombo et al., 2011, Oliveira Hashigushi & Llena-Nozal, 2020).

This chapter focuses on the costs of long-term care borne by users and their families and the related question of how much current systems protect individuals from the costs arising from care needs, and

what kind of policies are needed to insulate individuals from such costs. We focus on home care services – where the gap in the existing evidence on affordability of care is arguably greater – as it is widely acknowledged that persons in need of care overwhelmingly favour being cared for at home (Roy et al., 2018). Persons in need of care living at home also represent the majority of users of long-term care across Europe (Rodrigues et al., 2012). While decision making concerning the use of home care services is based on the users' wellbeing in the first instance, financial considerations also play a role and impact choices related to care arrangements.

Among the costs borne by users and their families are direct financial contributions to the costs of long-term care in the form of OOP payments. Across nearly all countries in Europe, some sort of OOP payments are required from users. These can correspond to the actual (or market) costs of long-term care for people who purchase services directly on the care market (e.g., because they do not meet the eligibility criteria for publicly funded long-term care). More commonly however, OOP payments refer to the contributions to the costs of public or subsidised long-term care that are required from users and are subject to varying rules and degrees of coverage for the actual costs of care (see Spasova et al., 2018; Oliveira Hashigushi & Llena-Nozal, 2020; and chapters 3 and 5 in this volume on eligibility and financing respectively).

OOP payments are often put in place with the goal of both increasing the financial resources for care and reducing moral hazard in the use of services (i.e. inefficient use of care services). An important consideration underlying such payments is that their amounts should be 'fair' by reflecting people's ability to pay across the income distribution. In most long-term care systems, OOP payments are regulated by the state and often vary with income or have exemptions for individuals with fewer financial resources, with only those with resources above a high threshold being required to pay the costs of long-term care fully out of their own pocket. This should make long-term care an eminently redistributive tool. However, despite some single-country studies which mostly focus on residential care costs, there is a dearth of information on the actual amounts of OOP payments and how they are distributed across population groups (see Hancock et al., 2013; Fernández & Forder, 2010; Rodrigues et al., 2022). The first section of this chapter provides a brief overview of the type of OOP payments that are in place for long-term care, distinguishing between income- and asset-based OOP payments as

well as those levied on family members, and existing evidence of their distributional impact. While the focus of the chapter is on home care, where relevant we also review evidence from residential care.

The lack of an internationally agreed definition for long-term care needs and diversity in long-term care systems (discussed in chapters 3 and 4 of this volume) have hampered comparability of OOP payments between countries, apart from a few existing international studies using hypothetical or stylised cases (i.e. examples of different types of representative users) (Oliveira Hashigushi & Llena-Nozal, 2020). To bridge this gap, the second section of this chapter uses data from SHARE to estimate amounts and distribution of OOP payments for home care services across the income distribution of a varied set of European countries. This provides a first measure of fairness or equity by analysing whether OOP payments are disproportionately concentrated among individuals with lower financial resources. To assess the degree of protection from excessive costs that is provided by different welfare systems and provide an additional measure of how equitable OOP payments are (i.e. whether they place a disproportionate financial burden on people with fewer financial resources), we use the concept of *catastrophic payments* – out-of-pocket spending by users of services which are purported to cause some degree of financial hardship (Cylus et al., 2018) – and estimate their distribution across income quartiles. By using survey data rather than stylised exemplary profiles of need and household composition, we ensure the findings reflect the distribution of needs and payments in a given country (i.e. its representativeness) as well as the actual amounts paid.

As highlighted in chapter 5 in this volume, the main source of care and support for a significant share of older people is not formal care providers but rather relatives or friends acting as informal carers (Suanet et al., 2013). This is particularly relevant for lower-income groups (Rodrigues et al., 2018). A significant share of families' contributions to the costs of long-term care therefore takes the form of *time* rather than OOP payments. A number of studies have attempted to attribute a value to this time or *in-kind* contribution from families (see Ekman et al., 2021; Del Pozo-Rubio et al., 2020), concluding that the value of informal care is at least as high as public expenditure on long-term care, even in relatively high-spending countries. While attributing a value to time spent caring, these studies often overlook the material consequences of informal care provision – in other words, they fail to consider the

financial impact of care provision on families, even if informal carers may draw on specific benefits in a number of countries. In the third section of this chapter, we therefore provide estimates of the additional financial impact for families arising from informal caregiving by applying the concept of *impoverishment*. The concept refers to the onset of poverty as a consequence of informal caregiving. We also present figures for carers that are *further impoverished*, which captures those families that are already below the poverty line and whose distance to the poverty threshold increases after taking up caregiving – i.e. families that become even poorer as a consequence of caring. We further estimate the impact on carers' employment and income resulting from transitions into informal caregiving.

Finally, a concluding section summarises policy implications from the findings, drawing on the institutional differences between systems and what these might reveal in terms of their influence on the financial impact of long-term care on users and their families (including carers).

8.2 Evidence of the impact of OOP payments on the financial resources of care users and their families

OOP payments are meant to contribute to the fiscal sustainability of long-term care while keeping demand in check, or at least curbing frivolous demand (moral hazard). Moreover, they may contribute to enhancing fairness, by making sure the contributions to costs reflect people's ability to pay, and equity, by ensuring that people with fewer financial resources do not contribute to a disproportionate share of costs (Mayhew et al., 2010; Colombo et al., 2011). However, both care needs and equity are concepts that suffer from the lack of a fundamental definition and measurability, so that thresholds and eligibility criteria in the context of long-term care always contain a discretionary aspect. The challenge is to find a balance between setting the amount of OOP payments too high, which would lead to a high lack of take-up by certain groups in spite of their care needs, and having free long-term care at the point of delivery, which might lead to an extent of demand that cannot be satisfied by the system (Ikegami & Campbell, 2002; Ilinca et al., 2017; see also chapter 5 in this volume). However, as financing patterns of long-term care have developed in the context of different welfare regimes, related characteristics have shaped the extent and scope of OOP payments. In general, it could be assumed that the

more universalist a welfare regime, the more 'socialised' financing of long-term care would be (i.e. financing will be spread across society rather than concentrated on users). This would mean that in Nordic welfare regimes, where there has always been a rather universalist access approach to care services, public financing based on progressive taxes would contribute to funding the largest degree of care costs, with OOP payments playing only a limited role even for those with higher resources. Likewise, the more familialist a care regime (i.e. more reliant on the family for the satisfaction of needs) (Saraceno, 2016), the more liability would be expected to be placed on the nuclear family, based on the principles of subsidiarity (i.e. that the state should intervene only after family support is exhausted) and social assistance (i.e. needs and means testing). In an ideal example of a familialist care regime, the state would only contribute to care costs if family members were neither able to provide care nor to pay for external services. These features are likely to underpin the specific rules governing OOP payments in each country. As a first step, governments define criteria for access and eligibility for public or subsidised services, including setting the income or wealth threshold beyond which users are expected to pay fully for their costs of care. Most countries have built their long-term care systems around this logic rather than on eligibility and access criteria that are needs-based only, such as in universal health care systems. OOP payments are therefore used in practice as a key mechanism to steer access and eligibility under the assumption that persons in need should contribute their fair share to their costs. Funding of long-term care is thus generally based on the principle of subsidiarity, where the state only steps in as a last resort (Morel, 2007).

Taking a broad definition of OOP payments to include those payments that contribute to the full costs of care, three non-mutually exclusive types can be distinguished:

- income-related OOP payments
- asset-based OOP payments, and
- OOP payments required from partners, adult children or other family members and heirs.

This section presents information on these several types of payments, how they are defined and applied in various countries, and the evidence of their impact on the financial situation of individuals and their families. Throughout, the focus is on care at home, supplemented by

information on residential care. The information presented here refers mostly to OOP payments for public or subsidised long-term care, while the reader should refer to the eligibility chapter for a discussion on access to such long-term care services.

Income-related OOP payments

Income-related OOP payments are intended to ensure that the individual user pays a proportional amount of their income towards the costs of long-term care; the general aim is to ensure that people pay an amount that is not in excess of what they can afford, since the amount varies according to income. In residential care, income-related OOP payments generally consider the individual's income (pension plus any other cash benefits such as cash for care allowances – see chapter 3 on eligibility) rather than that of the household. Rules regulating OOP payments for residential care usually allow residents to keep only a minimum amount for personal expenses (pocket money or personal allowance). These personal allowances can amount to about 3 per cent of median income after costs are covered in Croatia, 20 per cent of pension income in Austria, more than 25 per cent in Iceland or around 30 per cent of the national minimum income in Slovenia (Oliveira Hashiguchi & Llena-Nozal, 2020). The low amounts of these personal allowances reflect the fact that individuals in residential care already receive (and pay for) board and lodging. Sweden stands out as having a flat cap on OOP payments in addition to regulations that either exempt or substantially limit the amount that can be demanded from low-income individuals (Karlsson et al., 2007). Similarly, a very low flat-rate cap on income-related OOP payments is in place in the Netherlands and as a result financial barriers to accessing residential care are limited. However, unlike Sweden, eligibility for nursing homes in the Netherlands is based not only on assessed need but also on the lack of availability of informal care, rather than on the financial situation of the household (Hussem et al., 2016). This may explain why lower-income individuals use a proportionately higher amount of residential care services even after controlling for the concentration of needs among this group (Tenand et al., 2020).

OOP payments for subsidised home care are typically income-related (i.e. their amount varies with income) in OECD countries with exemptions in place for lower-income individuals, while for users from higher

income quintiles the requested OOP payments may approximate market prices. As with residential care, income considered for the calculation of OOP payments for home care remains basically restricted to the individual (pension as well as cash for care allowances in countries such as Spain, Austria, France and Italy). In addition, entitlement to subsidised home care services is usually capped in terms of service hours and/or total OOP payments that can be charged to users (see eligibility chapter in this volume). Hours or amounts above such cap are then charged at their full cost. For instance, in Austria clients are charged about 1 per cent of their income (calculated as pension and cash for care allowance, both to a defined threshold) per each hour of care service, with a maximum of 60 subsidised service hours per month. As a result, a service hour may be charged at between EUR 10 (low pension and median level of care allowance) and EUR 36 (high pension and high level of care allowance), with considerable variation between Austrian regions. In France the beneficiaries of the *Allocation personnalisée d'autonomie* (APA) are charged an hourly price that depends on both the provider price and a co-payment rate that increases with disposable income. For instance, for individuals with an income below EUR 739 per month (2014), the co-payment rate is zero, while it reaches 90 per cent for those with a monthly income above EUR 2,945. The average monthly OOP payment for home care was estimated to be over one fifth (c. EUR 300 in 2011) of the average pension (Roquebert & Tenand, 2017). Such amounts, plus the cumbersome bureaucratic application procedures they usually entail, may entice users to seek other (cheaper) privately paid solutions, including the employment of a live-in migrant carer (Italy, Austria, Germany and Spain) (Schmidt et al., 2016).

There is still a relative dearth of research on the impact of OOP payments on households in connection with both home and residential care (see Hancock et al., 2013; Fernández & Forder, 2010; Cullen, 2007). The few existing studies however attest that OOP payments remain at exceptionally high levels for the majority of users. In the United States only 15 per cent of older adults could fund extensive home care from their income, as these costs would be similar to a place in a nursing home (Johnson & Wang, 2019). In reality about 63 per cent of home care users in the United States are fully paying costs from their own income alone (Janus & Ermisch, 2015), attesting to the limited number of people qualifying for public support. This suggests

that a high share of potential users may not be able to get the (home) care they need. A recent mapping of different types of OOP payments in OECD countries by Oliveira Hashiguchi and Llena-Nozal (2020) has shown that a number of countries have moved away from strictly means-tested approaches to these payments for home care. Rules governing such payments also have an important impact on how these are distributed across income quintiles. For example, a simulation based on the English system for residential care concluded that increasing the personal expense allowance – the amount one is able to keep after paying for residential care – would likely benefit the lowest three income quintiles the most and the highest quintile the least (Hancock, 2000), thus showcasing the equity implications of different OOP payment designs. Similarly, it is possible to conjecture that flat caps on OOP payments for residential care would mostly benefit middle or even higher income individuals.

In a broader perspective, research by Moody et al. (2019) suggests that income-related payments for services may actually represent only a small fraction of all care-related expenditure. Referrals to support services for medical conditions or functional impairments that are not reimbursed by health insurance, and specific assistive devices or home modifications represent a sizeable share of private expenditure for long-term care. Additional services such as snow removal, gardening or safety measures may have to be purchased in the market too, with related costs fully paid. In other words, the total costs borne by users will reflect what is covered (or not) by social protection systems, and it will often be necessary for the household or even the wider family to step in to cover additional costs which are not adjusted in light of an individual's income.

Asset-related OOP payments

Income is not the only indicator of financial ability to pay, especially among older people who may have accumulated substantial assets along their life course (Colombo et al., 2011). Against this backdrop some long-term care systems include assets (e.g., savings, investments and property) when determining OOP payments and/or eligibility for social assistance schemes, particularly in residential care. Such asset-based OOP payments stipulate various thresholds for the amount of assets that users need to put towards long-term care before being entitled to social assistance. An example of how asset-based OOP

payments function is the Fair Deal scheme in place in Ireland. People moving into residential care must pay 80 per cent of their 'assessable income' (i.e. regular income minus allowable deductions such as health costs) and in addition, if they own assets or property, another 7.5% per year on the value of their assets above a threshold of EUR 32,000, for a maximum period of 3 years. This time limit – in effect a cap on the total asset-based OOP payments that people may expect to pay – attempts to ensure that certain assets such as agricultural land and family-owned businesses are not further eroded in case of long stays (Robinson & O'Shea, 2010). Such caps on the total amounts one may expect to pay are however not always in place in asset-based OOP payments. These types of payment may also be described as an early inheritance tax affecting families with a member in need of long-term care, with a marginal tax rate that may amount to almost 100 per cent. Families may try to circumvent the risk of total exhaustion of assets due to asset-based OOP payments through in vivo transfers (i.e. gifts of living parents to their children with the aim of becoming eligible for subsidies) or early depletion of savings (Hancock et al., 2013). Asset-based payment systems thus usually examine these in vivo transfers (e.g., amounts and elapsed time since those transfers were made) as they may be included when determining the amounts to be paid.

Asset-related OOP payments are more relevant in residential care funding, even if it has been shown that demand for residential care is relatively inelastic to prices (Grabovski & Gruber, 2007). The tightening, reduction or even waiver of asset-related OOP payments may influence individuals' and their families' decision making to some degree, but evidence on the significance of specific factors that influence housing decisions of older people is scarce (Roy et al., 2018). One such example however is provided by the abolishment of asset-based OOP payments for residential care in Austria at the beginning of 2018, which caused demand for residential care to increase by around 10–12 per cent in that same year (Firgo & Famira-Mühlberger, 2020), although by 2019 the rate of increase had returned to earlier levels (Statistics Austria, 2021). This example shows that due to tight household finances and perverse incentives from public regulations, families may give more importance to financial considerations than to needs and preferences.

As mentioned before, asset-based OOP payments may lead to the depletion of assets or limit savings during the life course due to the uncertainty around the actual amount that will have to be paid. To

limit this uncertainty, the Irish Fair Deal scheme described above effectively places a cap on total lifelong OOP payments, thus allowing users and their families to plan ahead or smooth their consumption along their life course. However, the fact that the state still takes a financial interest in the estate has led in practice to many residents opting to pay fully out of pocket, with 'Fair Deal residents' confined to those with no or low assets. As the fees for self-payers are usually higher than those negotiated by public authorities for Fair Deal residents, it is likely that there is a fair degree of cross-subsiding from richer residents to residents with fewer financial resources – in particular, private for-profit providers try to compensate for low tariffs set by public purchasers by charging higher fees from self-payers.

Studies on the distributional impact of asset-based OOP payments are also scarce, but findings from studies on residential care in England and Austria show that these fall more often on lower- and middle-income individuals (Hancock et al., 2013; Rodrigues et al., 2022). These individuals have a higher probability of moving into residential care (and longer lengths of stay) due to poor health, while at the same time having insufficient income to cover the costs of care. This is particularly the case if exemption thresholds are set at a low level (Muir, 2017; Hancock et al., 2007; Simmons et al., 2020). In Austria for example before the abolishment of the asset-based payments, many low-income residents held assets in excess of the defined exemption threshold (between EUR 4,000 and EUR 12,000) and were therefore liable for substantial asset-based OOP payments (Rodrigues et al., 2022). While such payments are usually defended on fairness or equity grounds, given that wealth rather than income may better represent older people's financial situation (Rodrigues et al., 2018), evidence thus suggests that this type of charge may disproportionately fall on the least affluent individuals, for whom affordability of residential care will hinge on asset depletion.

The alteration or waiver of asset-based OOP payments can influence care decisions to some extent as seen in Austria's temporary abolishment of asset-based OOP payments, which led to a spike in residential care demand. Nonetheless, evidence on the significance of such financial factors in influencing care decisions remains limited. These asset-based OOP payments, while aimed at ensuring fairness, have been shown to potentially burden lower- and middle-income individuals disproportionately as the exemption thresholds may not adequately

reflect individuals' financial capacities. This necessitates further examination to ascertain the equitable distribution and impact of asset-based OOP payments in long-term residential care funding.

OOP payments required from partners, adult children or other family members and heirs

Families, adult children or other family members may also be called upon to contribute to the OOP payments of their ageing relatives. Such requirements reflect the distribution of responsibilities between the individual, the family and the state. For instance, in the Nordic countries with a more individualistic welfare system, partners or other family members are not required to contribute to the costs of long-term care at all. By contrast in France, eligibility for social assistance to cover the costs of residential care hinges on a stringent means test with recourse to first and second order heirs, including grandchildren and in-laws who have to reach agreement on how to divide the charges among themselves. If no agreement can be reached, local authorities step in to recompense the care home provider but may reclaim the amount paid from the resident's estate after their death. In Germany too a number of requirements for OOP payments from next of kin were recently simplified but not abandoned: since January 2020 adult children can be required to contribute if their gross annual income exceeds EUR 100,000 (Bundesregierung, 2020). The impact of such regulations is unfortunately not well documented either in economic terms, including public and private transaction costs, or in relation to intra-familial conflicts, decision making and financial impacts beyond the service user.

To summarise the issue of OOPs payments as a whole, flat caps on income-related OOPs payment may mostly benefit middle-class or more affluent individuals, while increasing exemption thresholds or personal expense allowances (i.e. how much of their income users may keep after paying for care) may be more effective in reducing OOP payments for individuals with the least financial resources. Asset-based OOP payments seem attractive from a fairness standpoint but evidence suggests they are regressive and mostly financed through the savings of less affluent users, or they force users to become impoverished before qualifying for social assistance. A lifelong cap on the amounts paid would likely go a long way toward reducing uncertainty and possible depressive effects of these payments on savings.

8.3 Financial burden of OOP payments on home care users and their families

As described in the previous section, OOP payments are required from home care users across Europe although long-term care systems tend to afford some level of financial protection to users. These range from a ceiling or cap on the monthly fees paid, as in Sweden, Denmark or the Netherlands, to subsidisation of services subject to a means test or a limit on the uptake of subsidised hours in countries such as Austria, France and Belgium (Spasova et al., 2018; Rodrigues & Nies, 2013; Rodrigues et al., 2020). In addition, cash for care benefits may be provided to help individuals choose and afford the costs of home care (e.g., in Austria, France, Italy and Spain). The amount of such benefits may however fall short of covering all the costs of long-term care, which may require individuals to contribute out of pocket for their home care.

In this section, we assess the financial impact of OOP payments for home care across Europe, based on data from SHARE (a representative survey of older adults across European countries), as well as how this impact is distributed across different income groups. More specifically, we provide estimates for OOP payments made and their distribution across income quartiles, before calculating several measures of ability to pay, such as average OOP payments as a percentage of income and the prevalence of catastrophic payments for home care services. The distribution of these indicators across income quartiles is also analysed. The type of home care services considered include those providing help with personal care (e.g., getting in and out of bed) and domestic tasks (e.g., cooking), meals on wheels and other activities such as medicine management.

To this end, we used information on OOP payments by all home care users aged 65 and above across a number of European countries, pooling observations from waves 5 (2013) and 6 (2015) of SHARE. Equivalised household income is used for all calculations in the analysis and is computed based on all income components at the household level, divided by the square root of the household size. We used income rather than wealth as a measure of the resources available to older people as i) OOP payments for home care are overwhelmingly income-related; ii) catastrophic payments are typically defined in relation to consumption expenses or household income and not wealth; and iii) income is a way to provide a measure that is

comparable to the analysis carried out subsequently for informal care, which uses the concept of 'at risk of poverty' that is typically measured in relation to income.

Average OOP payments for home care across the income distribution

Public support for the costs of long-term care is often prioritised for individuals with lower income based on the principle that they tend to have not only higher care needs but also a lower ability to pay than higher income individuals (Oliveira Hashiguchi & Llena-Nozal, 2020). As a result, one would expect more affluent individuals to contribute more in absolute terms (i.e. as a sum of all OOP payments) and as a percentage of the costs of their long-term care, if not a higher proportion of their income. The data confirm this, in that the two upper income quartiles pay the most out of pocket annually for home care in absolute terms in most countries in the sample, with the higher income quartiles tending to pay at least twice that of the lower income quartiles (Figure 8.1). Notable exceptions, among others, are Sweden and Denmark due to the low caps on OOP payments that are in place in both countries.

Absolute amounts however do not provide a complete picture of the financial impact of OOP payments on home care users. Affordability or ability to pay is relative to the income an individual has and therefore varies across the income distribution (Muir, 2017). In examining the proportion of income paid towards home care by quartile, we find that the lower income quartiles (i.e. first and second) pay a larger proportion of their income across all countries, ranging from 5.6% to 20.4%, reflecting the disproportionate impact that OOP payments for home care have on these groups due to their lower average income and lower ability to pay (Figure 8.2). In comparison the average OOP spending on health as a share of final household consumption[1] for the 27 EU member states was 3.3% in 2018 (OECD, 2020). This resonates with previous research, in that low-income individuals are often the most exposed to substantial OOP payments despite the mechanisms in place to direct public benefits to them (e.g., social assistance), while those with higher incomes tend to be able to afford the costs of long-term care

[1] The measure is different from the share of equivalised household income that we use in this chapter and comparing both metrics should be done with caution.

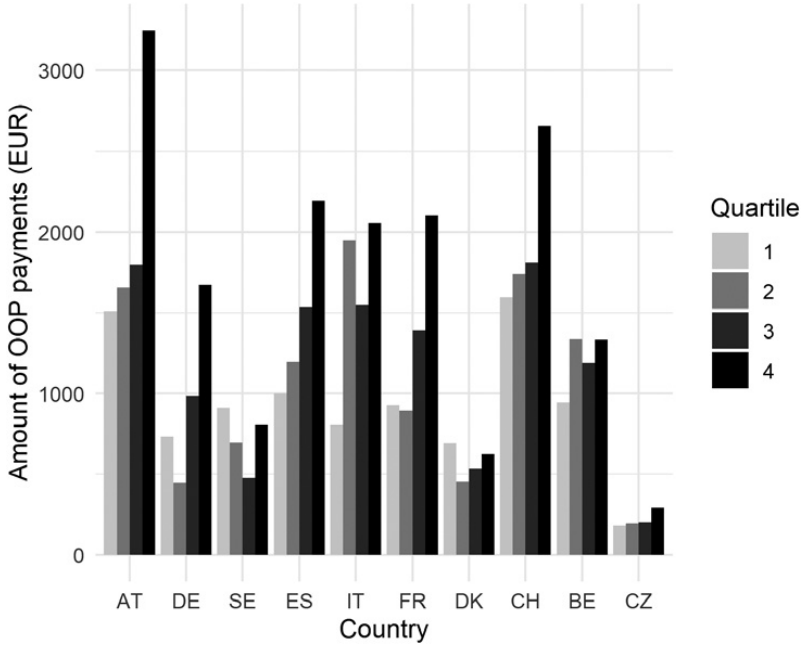

Figure 8.1. Average absolute annual amount of OOP payments (EUR) paid, by income quartile and country

Notes: All adults aged 65 and over using home care services. Countries: Austria (AT), Germany (DE), Sweden (SE), Spain (ES), Italy (IT), France (FR), Denmark (DK), Switzerland (CH), Belgium (BE) and Czech Republic (CZ). Equivalised household income (square root) adjusted for purchasing power. The first quartile represents individuals at the lowest end of the income distribution while the fourth represents those at the highest end. Weighted results.

Source: Own calculations using wave 5 (2013) and wave 6 (2015) of SHARE

on their own (Muir, 2017). This is especially the case given the lower level of income older adults tend to have in conjunction with the often high cost of home care services. In some cases, OOP payments can be so excessive as to push care users into poverty (Del Pozo-Rubio et al., 2020) with women, low-income groups and the very old being most at risk of financial ruin (Scheil-Adlung & Bonan, 2013).

Another way to assess how the average size of OOP payments and ability to pay are distributed across income is to calculate concentration indices (CIs) (see Box 8.1). The concentration of absolute amounts of

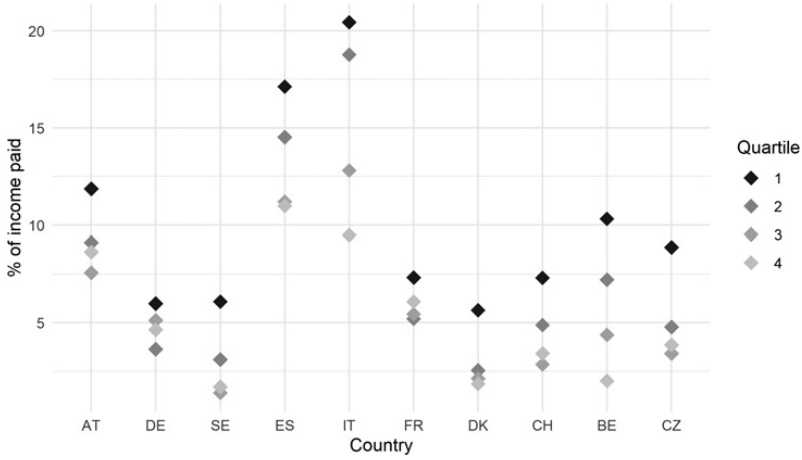

Figure 8.2. Percentage of income paid towards home care OOP payments, by income quartile and country

Notes: All adults aged 65 and over using home care services. Countries: Austria (AT), Germany (DE), Sweden (SE), Spain (ES), Italy (IT), France (FR), Denmark (DK), Switzerland (CH), Belgium (BE) and Czech Republic (CZ). Equivalised household income (square root). The first quartile represents individuals at the lowest end of the income distribution while the fourth represents those at the highest end. Weighted results.

Source: Own calculations using wave 5 (2013) and wave 6 (2015) of SHARE.

Box 8.1. Concentration indices

A concentration index (CI) is a measure of inequality where the concentration of one variable, for example OOP payments or use of home care, is measured across the distribution of another rank variable, often income or wealth. In our case, the CIs capture the concentration of OOP payments, the use of home care services and catastrophic payments across the income distribution. A positive value represents a distribution where payments/use are concentrated on richer individuals, while a negative value represents a distribution where payments/use are concentrated on individuals with lower financial resources.

OOP payments for home care among richer individuals is confirmed by the CIs displayed in Table 8.1 (column 2), where for most countries the value of the CI is positive and for many it is also statistically significant.

Table 8.1. *Concentration indices of distribution of home care use, OOP payments for home care and catastrophic payments by country*

Country	Prevalence of home care users (percentage)	Home care use	Home care OOP payments (total amounts)	Catastrophic payments
Column		**1**	**2**	**3**
Austria	15.3	−0.053**	0.208**	−0.012*
Germany	12.9	−0.121***	0.157	−0.008
Sweden	8.7	−0.114***	−0.230***	−0.007**
Spain	12.1	0.004	0.275***	−0.006
Italy	8.8	−0.017	0.217***	−0.003
France	19.4	−0.120***	0.189*	−0.012**
Denmark	13.6	−0.217***	−0.365***	−0.017***
Switzerland	11.0	−0.104***	−0.022	−0.008
Belgium	24.0	−0.048**	0.074*	−0.021***
Czech Republic	9.0	−0.050***	0.002	−0.007**

Notes: * p-value<0.05, ** p-value<0.01, *** p-value<0.001. The p-value provides a measure of how likely it is that the difference from 0 is due to chance (example: if a p-value is <0.05, for a CI, it means that the probability of that CI being in reality equal to zero is less than 5%). Ranking variable: equivalised household income (square root). Weighted results.

Source: Own calculations using wave 5 (2013) and wave 6 (2015) of SHARE.

Notable exceptions to this are Sweden and Denmark where the absolute amounts of OOP payments are concentrated on people with the least financial resources, even if OOP payments represented a small share of these individuals' income (even those in the first income quartile – see Figure 8.2). This is likely driven by two institutional features of the long-term care systems of these countries. Firstly, the relatively low cap on OOP payments in Denmark and Sweden limits the amounts paid, even by higher income users. Secondly, these systems prioritise provision of home care to lower-income users – as depicted by the CIs for home care use (column 1 in Table 8.1) – even after needs are accounted for (Rodrigues et al., 2018), resulting in use being concentrated on

individuals with lower financial resources. These together pay a sizeable share of the overall amount of OOP payments, even if each individual pays only a small share of their income. Conversely, the very high concentration of these payments among the rich in Spain and Italy may reflect a relatively pro-rich distribution of the use of home care, although the estimate is not statistically significant.

8.4 Prevalence and distribution of catastrophic payments

Another measure of the impact of OOP payments on users' financial situation is the prevalence of catastrophic payments, a concept commonly used in the health care literature (Cylus et al., 2018), although still relatively novel in long-term care (see Del Pozo-Rubio & Jiménez-Rubio, 2019). We use the denominated *budget share method* in which OOP payments are considered catastrophic if they are above a certain threshold (or percentage) of the user's equivalised household income (Cylus et al., 2018) – in this case if they amount to at least 25 per cent of this income. This is also one of the thresholds used in the context of the United Nations' Sustainable Development Goals to assess access to universal health coverage. Given that some home care services may substitute for basic expenditure (e.g., meals on wheels for food and cleaning), this might be a more appropriate threshold for hardship than, for example, using 10 per cent of income. It provides in any case a lower bound for the prevalence of catastrophic expenditure given how significant 25 per cent of income is. The prevalence of catastrophic payments among the total population aged 65 and older is relatively low, ranging from 0.27% to 1.89% across countries (Figure 8.3a). However, the prevalence of catastrophic payments conditional on use of home care ranges between 2.5% and 19.6% of home care users across the countries considered, with lower-income individuals comprising the majority of these (Figure 8.3b). This means that once a person is in need of care, the risk of facing long-term care-related catastrophic expenditure can be quite high in Europe.

The impact of institutional context, namely the level of protection afforded by the state against costs for home care services, can be directly seen in the proportion of home care users experiencing catastrophic payments across the different countries. In the Nordic countries, where protection against OOP payments is generous with the state covering the majority of long-term care costs and where a low cap

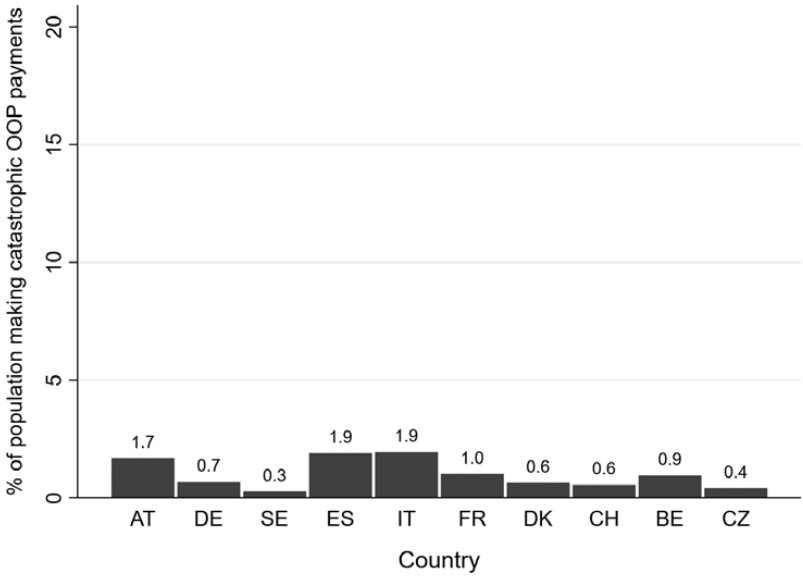

Figure 8.3a. Percentage of individuals experiencing catastrophic payments among those aged 65 and over

Notes: Catastrophic payments defined as 25% or higher of equivalised household income spent on OOP payments. Countries: Austria (AT), Germany (DE), Sweden (SE), Spain (ES), Italy (IT), France (FR), Denmark (DK), Switzerland (CH), Belgium (BE) and Czech Republic (CZ). Weighted results.

Source: Own calculations using wave 5 (2013) and wave 6 (2015) of SHARE

on OOP payments is also in place (Karlsson et al., 2012), only a minority of people are not insulated from catastrophic payments, although these are concentrated on the lowest-income quartile. At the other end of the spectrum, in countries with little or no such protection a substantial proportion of individuals paid 25 per cent or more of their income towards home care fees (e.g., Spain and Italy). This may also include individuals paying the full costs of care (i.e. buying services in the market) to circumvent poor availability of public services. As for the distribution of catastrophic payments, these are concentrated primarily on lower-income individuals in all countries (column 3 in Table 8.1), although not all of the CIs are statistically significant. The concentration of catastrophic payments is arguably higher among less well-off individuals in Belgium and Denmark, showing that even in

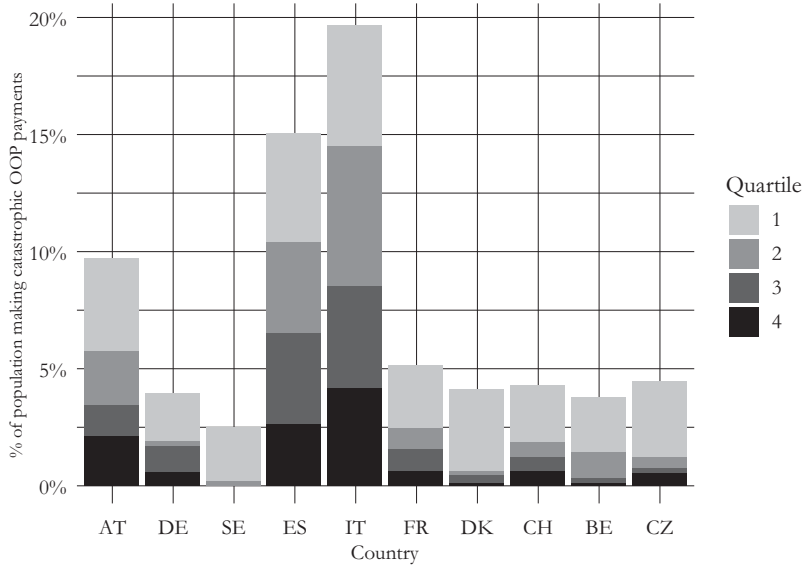

Figure 8.3b. Percentage of individuals experiencing catastrophic payments per quartile among those aged 65 and over using home care

Notes: Catastrophic payments defined as 25% or higher of equivalised household income spent on OOP payments. Countries: Austria (AT), Germany (DE), Sweden (SE), Spain (ES), Italy (IT), France (FR), Denmark (DK), Switzerland (CH), Belgium (BE) and Czech Republic (CZ). Weighted results.

Source: Own calculations using wave 5 (2013) & wave 6 (2015) of SHARE.

countries with generous long-term care systems lower-income individuals are at greater risk of catastrophic payments. This confirms the disproportionate impact that OOP payments have on lower-income individuals for whom costs of care can still be substantial despite means-tested social assistance (Muir, 2017). As shown in Table 8.1 and Figure 8.3b, Spain and Italy do not have such a concentration of catastrophic payments among the less well-off because OOP payments are also substantial for middle-income and even more affluent individuals.

From a policy standpoint, the findings indicate that despite means-tested eligibility rules and income-related OOP payments that increase with income, these payments still represent a sizeable share of the income of lower-income individuals. Low caps on income-related OOP payments could be an option as they seem to limit the prevalence of catastrophic

expenditure overall. However, OOP payments are still concentrated among those with low income even where such caps are present, because low-income households are more likely to utilise long-term care. There is also a clear interplay between accessibility of services and OOP payments: where supply of home care services is limited, OOP payments and the prevalence of catastrophic payments are high even for more affluent families. In such contexts, an improved supply of public or subsidised home care may bring about a reduction in these payments for families.

8.5 The financial impact of providing informal care on families

Caregiving generates a competing demand for time which may reduce the number of hours available for paid work. This is discussed more extensively in chapter 10 with respect to the macroeconomic effects of long-term care needs on economic growth. Evidence on the impact of informal caregiving on employment seems to confirm this, although the effect is relatively small in size and heterogenous. Carers are on average 5–10 per cent less likely to be employed and they work less hours than non-caregivers (Lilly et al., 2007; Bauer & Sousa-Poza, 2015). These effects are concentrated among lower-income carers and especially on those providing intensive (i.e. longer hours) informal care. This reduction in labour supply may have a negative effect on earnings, although here the evidence is much less conclusive (Bauer & Sousa-Poza, 2015). In some countries, informal carers may receive social benefits that compensate for the loss of income, either provided directly to carers or as 'routed wages' passed on by the relatives they care for (Courtin et al., 2014). Nonetheless, the possibility of caregiving having a negative impact on carers' financial situation is very real.

One way to assess this is therefore to estimate the impact of becoming an informal carer on employment and income, and consequently on risk of poverty. To this end, we used a sample of informal carers aged 50–64 years old from ten European countries drawn from SHARE. Taking advantage of the longitudinal characteristics of SHARE, we compared employment, equivalised household income and the risk of poverty[2] in the period immediately before and after starting to provide

[2] The poverty threshold for each country was anchored around the year 2011 and subsequently only adjusted for inflation for 2013 and 2015 (Eurostat, 2021a, 2021b). This approach enabled us to compare changes to the carers' income with a constant level of real income, removing possible changes to the poverty

care for each informal caregiver, using waves 4 (2011), 5 (2013) and 6 (2015) of SHARE. Risk of poverty for each country is defined as having an equivalised household income below 60 per cent of the national median equivalised income (defined for a single person). In addition, we estimated how many carers became *impoverished* after starting to care and how many carers witnessed an increase in the gap between their income and the poverty threshold after taking up caregiving (*further impoverished*). Informal care is defined as someone providing personal care inside and outside the household or home help outside the household. This approach captures the short-term effect of informal caregiving and allows for some of the potential self-selection effect of individuals into caregiving to be accounted for[3].

Effect of caregiving on employment and income

Data confirm that taking up caregiving leads to a reduction in labour market participation and earnings for a sizeable share of carers (Table 8.2). This reduction was mostly at the intensive margin as most carers that reported a downward change in labour supply reduced their working hours rather than dropping out of the labour market altogether. Across the sample of countries represented, exiting the labour market was reported by 8–10 per cent of carers. Only in Sweden and Switzerland was this percentage markedly lower, possibly denoting better opportunities to provide low-intensity informal care since affordable home care services are more readily available and users may thus combine informal care with care services instead of relying on full-time informal care alone (Bolin et al., 2008). Reductions in the number of hours were reported by close to one quarter of carers across our sample of countries. The relatively low percentage of carers that reduced labour at the intensive margin in Spain and Italy, as opposed to the higher percentages observed among the Nordic countries and Switzerland, reflects differences in the employment rates of would-be carers between countries (e.g., female employment rates,

threshold resulting from merely recompositing the income distribution in a given year or country (Atkinson et al., 2015).

[3] Individuals may become informal carers because they are of low income or are out of the labour market in the first place, which would overestimate the effect of caregiving on such outcomes if observed only after caregiving has started. In other words, individuals may be impoverished when providing care because they were already of low income before taking up care and that was actually one of the reasons why they became carers.

Table 8.2. *Reductions in labour supply and equivalised household income after becoming a carer*

Country	Percentage of carers who stopped working	Percentage of carers who reduced their working hours	Percentage of carers who reported a reduction in income
Austria	8.6	22.2	46.2
Germany	9.0	21.4	46.4
Sweden	4.9[a]	25.6	59.7
Spain	10.2	19.6	43.3
Italy	8.2	16.2	45.3
France	12.0	23.1	50.0
Denmark	9.1	26.6	49.4
Switzerland	6.4	33.9	39.5
Belgium	10.8	22.2	49.3
Czech Republic	9.5	21.7	48.3
Total	9.7	21.8	47.2

Notes: [a]Low sample size. Weighted results. Sample size refers to individuals that transitioned into caregiving roles between waves of SHARE. The 'total' refers to the overall figures for the countries considered.

Source: Source: Own calculations using wave 4 (2011), wave 5 (2013) and wave 6 (2015) of SHARE.

as women are the main group of carers in this age group) which already existed before taking up care. On average, carers that remained employed worked 8 hours less per week after starting informal care.

The reduction in labour supply, which affected about one third of carers altogether, contributed to a deterioration of their financial situation after the onset of caregiving (Table 8.2). For most countries included in the sample, between 40 and 50 per cent of carers reported a reduction in their equivalised household income immediately after

the onset of caregiving. This figure was even higher for Sweden, where close to 60 per cent of carers reported a deterioration of their financial situation. The magnitude of the income lost was also substantial: equivalised household income after taking up care was 35 per cent lower on average in comparison with the period before. It is worth pointing out however that increases in equivalised household income were also observed for some households. These increases in income mostly came from withdrawing savings (for 83.4% of carers whose income increased), some of which may have been intergenerational in vivo transfers received as a reward for care (Rodrigues et al., 2018). However only 5.2% of all carers reported such transfers after the onset of care[4]. Increasing labour supply of the spouse/partner (5.1%) or self (5.0%) and taking up of old-age pensions (3.9%) were other causes of increased income. Cohabitation, often referred to as being spurred by the care needs of older relatives[5], was only reported by 0.8% of carers.

Effect of caregiving on risk of poverty

Despite a reduction in income observed overall, carers may still have sufficient income or, as just mentioned, they may be able to tap into savings to smooth consumption while caring. Yet at lower levels of income, even marginal declines in earnings can have an impoverishing effect, that is, they may cause people to fall below the poverty line. The impoverishment effect of caregiving is sizeable (Table 8.3, column 1), albeit with significant country differences. In Spain, Italy and the Czech Republic, between 11.4% and 12.0% of carers become newly impoverished after the onset of caregiving, while in Austria the impoverishing effect of informal caregiving is also relatively high at 8.5%. It is worth noting that this impoverishment effect seems the highest among countries that have cash for care benefits as the most prominent way to provide support for those in need of care. These are also countries with

[4] SHARE asks interviewees whether they have received financial gifts or support of at least EUR 250 or an inheritance/bequest of at least EUR 5,000 in the previous 12 months. It is not clear whether these amounts include payments for care ('routed wages') or if these transfers are linked to care. Furthermore, the exact amount of these transfers is impossible to determine. This figure should therefore be interpreted with caution.

[5] Depending on the individual incomes of household members, intergenerational cohabitation may result in a higher equivalised household income and further enable the routing of cash for care benefits to carers.

Table 8.3. *Impoverishment and poverty rates in connection with caregiving*

Country	Impoverished (%)	Poverty rate before caregiving (%)	Poverty rate after caregiving (%)
Column	1	2	3
Austria	8.5	23.1	21.5
Germany	5.8	13.5	13.9
Sweden	4.3[a]	6.9[a]	6.2[a]
Spain	11.4	37.1	34.4
Italy	12.0	34.2	28.7
France	5.8	14.3	14.2
Denmark	5.5	4.9[a]	6.4
Switzerland	5.1[a]	5.6[a]	5.6[a]
Belgium	5.5	8.8	9.0
Czech Republic	12.0	32.5	26.0
Total	7.5	19.4	18.2

Notes: [a]Low sample size. Weighted results. Sample size refers to individuals that transitioned into caregiving roles between waves of SHARE. Poverty thresholds are anchored (2011) and subsequently updated for inflation only. Poverty thresholds used refer to 60 per cent of the national median equivalised income in the given country for a single person. The 'total' refers to the overall figures for the countries considered.

Source: Own calculations using wave 4 (2011), wave 5 (2013) and wave 6 (2015) of SHARE and Eurostat (2021a, 2021b) poverty thresholds and inflation rates.

a much more limited supply of formal home care (Austria excepted), which may hamper the possibility of combining care services with provision of low-intensity informal care while remaining employed (Rodrigues et al., 2013). In most of these countries, informal care is indeed of a more intensive nature (Bolin et al., 2008).

However, despite some households in all countries being newly impoverished after becoming caregivers (Table 8.3, column 1), the

overall effect of caregiving on the risk of poverty among caregivers varies substantially. We discuss this complicated phenomenon below.

First, it is important to note that poverty rates among would-be carers were highest in Spain, Italy, the Czech Republic and Austria even before they began to provide care (Table 8.3, column 2), despite the relatively high GDP per capita and relatively low poverty rates overall for some of these countries (Eurostat, 2021a). For example in Spain more than one third of informal carers were below the poverty line even before the onset of caregiving. In comparison, in Sweden, Denmark and Switzerland only between 4.9% and 6.9% of carers were in poverty before taking up care (although underlying sample sizes for these countries are small). This suggests important differences between countries in the types of individuals who provide informal care and highlights how in many countries it is those who are already impoverished who often take up caregiving. As a group, carers face economic difficulties that go beyond those arising from caregiving alone and a disproportionate share of carers were already struggling financially before taking up care. It indicates that people who already have lower incomes and may not be able to contribute to financing formal care services may be pushed into providing informal care.

Counterintuitively, in some of the countries with the highest overall rates of poverty among carers – Spain, Italy, the Czech Republic and to a lesser extent Austria – the rate of poverty among carers actually *reduces* after taking up care. This may well be a short-term effect explained by take-up of social benefits by previously unemployed people or only marginally employed carers who were previously living below the poverty line. Of note, these are all countries with sizeable cash for care benefits and so it may be that for some individuals, cash for care benefits help to lift them out of poverty. In the case of Austria, Germany or Italy, for example, there is no obligation to declare how cash for care benefits are spent, so it is not possible to identify specifically whether increases in income are coming from cash for care schemes. Cohabitation, which is often motivated as much by economic difficulties of carers as by filial duty to care for ageing parents (Gierveld et al., 2012), could be another possible motive for this, although changes in cohabitation seem to be marginal in our sample.

At the same time there are many households where the financial situation deteriorates after beginning to provide care. Indeed, Sweden, which has very low poverty rates among individuals before

taking up care, reported the highest share of informal carers that saw their income decrease because of care (Table 8.2). About 4.6% of carers in the SHARE sample overall became further impoverished – that is, were already impoverished before taking up care and their equivalised household income moved farther away from the poverty threshold after starting to care[6].

The main policy message arising from these findings is the precarious financial situation in which many carers find themselves even before taking up care. For many this is exacerbated by the sizeable reductions in labour market participation observed immediately after starting to care. Income-maintenance policies for carers therefore seem like a key priority and among these, policies that would expand some access to services and thus allow carers to continue some paid work. Conversely, cash for care benefits, which are partially meant to provide such income support, seem to have an overall positive impact although many people seem not to benefit from them perhaps due to eligibility criteria. Countries where these are in place have, on the one hand, a high share of people who became impoverished after starting to care but on the other hand, they also have many carers lifted out of poverty after taking up care.

8.6 Policy implications and conclusions

The need for care is clearly associated with financial hardship for users and their carers in Europe. For users, this is connected with high OOP payments when accessing care and/or from the need to spend down their savings – in effect diminishing their socioeconomic standing – in order to qualify for long-term care services. Income-based OOP payments and means tests alone seem unable to protect users from catastrophic payments as shown by our findings. Data does not afford us definite conclusions, but this seems to stem from the following (non-exclusive) factors: i) potentially high eligibility thresholds to qualify for affordable long-term care in systems that still make access dependent on resources of users; ii) poor targeting of income-related OOP payments rules (e.g., OOP payments for home care mostly do not have personal expense allowance guarantees in place); and iii) limited

[6] Limited sample sizes do not allow for a breakdown of further impoverishment by country.

availability of public or subsidised home care services, requiring families to seek alternatives at full market prices (Geerlings et al., 2005). The latter is relevant for countries with less developed long-term care systems outside of Europe. Although beyond the scope of this chapter, the limited protection afforded against high costs of care could also lead to unmet care needs, as older adults forgo services due to lack of funds. As unmet needs are unaccounted for in our analysis, it is likely that the unaffordability of home care is underestimated here.

Care needs of relatives also spell increased financial hardships for carers, namely through reduction in employment and income as a result of informal caregiving. The estimates presented in this chapter show that the effect can be quite substantial, although the resulting impoverishment of those that transition into informal care is somewhat limited. On the one hand, poverty rates among carers do not seem to be too affected by the onset of caregiving, perhaps as a result of the amounts provided in cash for care benefits (Huber et al., 2009). On the other hand, carers both before and after taking up care are at an increased risk of poverty relative to the wider population, especially in countries considered to be familialist (Saraceno, 2016). This finding nonetheless calls for policies that are able to ensure carers a living care wage that current social benefits are apparently unable to do. The correlation between caregiving and poverty has been highlighted before (Eurocarers, 2018), albeit with the qualification that many carers are already impoverished before taking up care. The figures reported here seem to confirm this. The existence of poverty prior to care among caregivers only reiterates that their vulnerable economic situation stems from life-course trajectories for which care is only a supplementary factor (Carmichael & Ercolani, 2016). Nonetheless, if informal care can be considered as an in-kind subsidisation of long-term care by families, it seems clear that this subsidy is disproportionately being paid by lower-income individuals.

Data reported in this chapter capture only the short-term or immediate impact of caregiving on the financial situation of informal carers. It is very plausible that as time evolves this represents the lower bound of this impact. For example, research has shown that the negative impact on wages from caregiving likely increases with time (Bittman et al., 2007), thus producing a scarring effect on earnings over the life course akin to that observed for unemployment in early youth (Genda et al., 2010).

Another example of the potential deferred impact of caregiving is how the loss of or diminished earnings may impact pension rights. As a review of care policies in Europe documented, pension rights associated with caregiving are still absent in a number of European countries (Courtin et al., 2014). Even if caregiving is temporary, it may have a detrimental effect on the health of caregivers (Bauer & Sousa-Poza, 2015) and thus hamper their chances of returning to the labour market or lead to early onset of long-term care needs for themselves. A number of carers in our sample reported an equivalised household income above the poverty line, or even an increase in their income, because of liquidation of savings – in a parallel with the spending down of assets to qualify for care from users. These savings may eventually be depleted and land those carers in poverty and/or be unavailable later on in the carers' life cycle to smooth consumption in their old age (e.g., when they find themselves in need of care). These longer-term effects of caring are particularly worrying for countries with less developed long-term care systems where informal carers are still often the only providers of care.

The findings presented here show the sizeable contribution that users and their families make towards long-term care costs. It exposes the reasoning that such contributions, especially from informal carers, may be seen as a free good and highlights the potential for paying catastrophic payments and/or falling into poverty as a result of needing long-term care that still permeates the experiences of older people and their carers in Europe. Closing this gap in social protection among the wealthiest countries in the world is another powerful case for investing in public long-term care systems.

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