Study on exploring the incidence and costs of informal long-term care in the EU

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Executive summary

Aims of the study

The right to affordable quality long-term care is one of the 20 principles in the EU Pillar of Social Rights. The European Pillar of Social Rights Action Plan[1] and the Green Paper on Ageing[2] highlight that while demand for care services is expected to increase in an ageing society, the lack of quality standards in care and gaps in access to quality services, including in rural areas, are a serious concern in many Member States. Long-term care may also be provided informally, but this comes with its own challenges such as combining this with work. A first goal of this study was to develop a common understanding of informal care and its key features and confirm this understanding with experts. The second goal was to estimate the number of people providing informal long-term care and to analyse their characteristics. The third goal was to estimate the costs associated with the provision of informal long-term care for the individual and the State, using different cost concepts.

Definition of informal long-term care

For the purposes of this study, informal long-term care is defined as care provided to people who need support because of disability or old age. The care activities may involve help with activities of daily living (e.g. bathing, dressing and eating) and instrumental activities of daily living (e.g. shopping, preparing meals, housework or administrative tasks). Care is provided for at least three consecutive months by someone from the care receiver's social environment (e.g. a family member, friend or neighbour) and the provider is not hired in a professional capacity.

Millions of people provide informal care

Using data from various surveys, between 12 and 18% of the adult population in the EU provides informal care on a weekly basis, with an average of 14.4% of the adults in the age category 18-74, corresponding to 52 million people. Administrative data indicate that about 90% of informal care lasts longer than three months, hence the average of 14.4% overestimates informal long-term care by approximately 1.5 percent point. The exclusion of informal care that is provided less than weekly underestimates informal care by 3 to 4 percent point.

Formal and informal care as communicating vessels

Informal care rates are highest in the northwest of the EU in terms of headcounts, but lowest in "full-time equivalents". The reason is that in the northwest 80% to 90% of informal care is provided at low intensity (less than 10 hours per week) compared to 54% at EU-level. At EU-level, only 10% of informal carers provide intense help (40+ hours per week). On

[1] The European Pillar of Social Rights Action Plan (europa.eu)

[2] https://ec.europa.eu/info/sites/default/files/1_en_act_part1_v8_0.pdf

average, informal carers help for 16 hours per week. In full-time equivalents, informal carers represent close to 80% of the care providers at the EU level, and one more care professional correlates with 0.84 less FTE of informal carers. However, this correlation does not necessarily imply a causal relationship one way or the other.

The strong negative correlation between formal and informal care does not necessarily mean they exclude each other. However, only 10% of the care receivers combine both formal and informal care and 70% use solely informal care. The use of solely informal care and of solely formal care is also negatively correlated. Thus, informal care already plays a crucial role and more care in the one form (formal or informal) reduces the need for the other form of care.

Unfulfilled care needs

In the EU, 8% of the 65+ population (7.1 million people) receives informal care. However, not everyone in need receives care. Indeed, only 20% of those in need report to receive care and 50% report they need more care (either formal or informal).

Gender imbalance

A 59% majority of informal carers are women. At EU level, women (18% of adult women) are more likely to provide informal care than men (12%). In the age category 45-64 years the gender imbalance is slightly larger (23% of the women, 15% of the men provide informal care). The gender imbalance is particularly pronounced in two Member States, notably Belgium and Spain where between 25 and 30% of the women aged 45-64 provide informal care compared with between 10 and 15% of the men aged 45-64.

Limited burden sharing

A hypothesis that low-intensity care is caused by burden sharing between more people is rejected: there is no statistical relation between the intensity of care provided and the average number of helpers per informal care receiver. For high-intensity care, the burden is more than proportionally born by women: the provided care is intense for 12% of the women providing informal care and for 7% of the men providing informal care. Thus, women not only provide informal care more often than men, but also provide more often intense informal care. The gender imbalance in intensity of informal care is strongest in Italy and Spain.

Informal care lasts years

Survey data and point-in-time administrative data are little suited for an analysis of the duration of informal care, because they miss short spells in the past and the end of long spells. However, if one assumes that these effects cancel each other, reported durations are indicative of ultimate durations of care spells. Under this assumption, informal care spells last on average between 3.5 and 4.5 years according to French and Dutch data.

Using EU-SILC data (see methodology box in Section 4.2 for its limitations), about 80% of informal care is estimated to last longer than one year. In the northwest of the EU, only 60-

70% of the informal care spells last longer than one year, compared to 80-90% in some Eastern European Member States.

Similar educational and income profiles

No significant differences were found in the educational level and the risk of poverty for informal carers compared to the general population.

Informal care affects mental health

This study and other literature find that informal care affects the health of caregivers. There is substantial evidence that providing informal care affects mental health, especially for spousal care. Evidence whether informal care affects the physical health of the caregiver is mixed. To the extent physical health is affected, it seems limited to intense informal care. These findings are based on an analysis of informal carers over time (as in this study) or on an analysis controlling for characteristics of informal carers such as gender, age, education etcetera, to avoid a bias caused by self-selection of healthy people who are more likely to provide informal care than people who themselves also have health problems.

Managers have the least time for informal care

The occupational profile of informal carers in employment reflects gender differences on the labour market rather than educational differences: informal carers are more likely to work in service and sales (26% compared to 17% in general) and less likely to work as machine operators and assemblers (4% compared to 8% in general). A further split by intensity of informal care suggests that high-skilled jobs and in particular management jobs are difficult to combine with informal care of more than 20 hours per week: 3% of people providing informal care for more than 20 hours per week are in management positions compared to 6% of informal carers in general.

Women aged 45-64 most likely to stop working when caring

A significant employment gap of 5.6 percent point was found for women in the age group 45-64 providing informal care, of whom 53% is employed compared to 59% in the general population. This indicates that 5.6% of the informal carers have stopped working. The largest employment gaps were found in Ireland (26%) and countries in mostly the South and East of Europe. The larger employment gap in those countries is partly explained by a greater intensity of informal care, a correlation that is confirmed by earlier literature. For other gender and age groups, the employment gap was not statistically significant.

Women aged 18-44 most likely to work fewer hours

Informal carers work less often full-time (at least 37 hours per week) than others in the working age: 65% compared to 75%. Nevertheless, the difference in average working hours per week is limited to one hour, mainly because part-time working informal carers on average work more hours per week than part-timers in general. One German study found that informal carers on average reduce their working hours by one hour at the start of the

care stint. A possible reason for the larger part-time jobs of informal carers is that slightly over half of the informal carers provide less than 10 hours of informal care per week. Thus, for a large part of the informal carers a small reduction in work hours seems to suffice.

Only among women aged 18-44 providing intense care was a large and significant difference in work hours per week observed: 29 hours compared to 38 hours among employed women aged 18-44 in general. Unfortunately, the number of intense informal carers is too small to analyse differences between countries. Previous literature from Germany confirms both findings in increased part-time work among informal carers and a difference of only one work hour per week.

Loss of income during care can be significant

For those informal carers who stop working, the loss is on average EUR 18,000 per year for women aged 45-64, or about EUR 100,000 over the average duration of 6 years. The loss of income from work, even when taking into account purchasing power parities, is below average in the east and south of the EU except Cyprus and above average in the west. This suggests that informal carers in the east and south of the EU are less likely to lose well-paid work. Informal carers in other gender and age groups face a smaller loss of income because on average their care stints last less long.

A smaller loss of income from work is associated with reduced work hours of informal carers. The percentage loss of net income is similar to the percentage of hours reduction. For women aged 18-44 providing intense informal care, the average hours reduction from 38 to 29 hours causes a net income reduction of between 20 and 25% in all EU countries.

Skills losses cause further income loss after care stint

Informal carers who do not work, also risk a loss of income after their care stint, if they do not immediately re-enter employment. For those who stopped working (women aged 45-64 in the employment gap) their peers are still employed and a 100% likelihood of work is the benchmark. For non-employed women aged 45-64, the re-employment likelihood is 17% for both informal carers and the general population, and thus informal care causes no additional income loss for informal carers.

For younger people (aged 18-44) the difference in re-employment likelihood of non-employed informal carers is only slightly less than that of their non-employed peers: 31% versus 33% for men and 20% versus 24% for women. The largest difference in re-employment likelihood exists for men aged 45-64: 22% versus 30%. These lower re-employment likelihoods reflect skills losses that cause a loss of future income from work, potentially until the age of 65.

This loss of future income can be expressed as a percentage of the income during the care stint that the informal carer would have earned if fully employed. For women aged 45-64 providing informal care who stopped working, the sum of lost income from work after the care stint happens to be equivalent to 100% of lost income during the care stint. For the other groups, assuming that former informal carers are permanently less likely to re-enter employment, the future loss varies from 6% of income during the care stint for men aged 18-44, 25% for women aged 18-44 and 42% for men aged 45-64.

Many informal carers do not receive a care allowance …

Of the 27 EU Member States, 13 pay informal care allowances directly to informal care providers and 9 to the person needing care to spend on either formal or informal care. The other 5 Member States do not have an informal care allowance scheme. In all countries, further conditions apply to informal care allowances, regarding for example the care needs or degree of disability, the relationship between care provider and receiver (family only), and/or intensity of informal care. As a result, the percentage of informal carers receiving a care allowance varies from about one percent in Croatia, Denmark and Malta to slightly less than 50% in Estonia. Benefit levels also vary strongly, from about EUR 29,000 per year in purchasing power parity in Luxembourg to EUR 900 per year in Denmark and Poland and EUR 375 per year in Estonia. Here it should be remarked that the benefit in Luxembourg is subject to income tax, and that the benefit in Denmark is typically given for only a few weeks.

… but still receive other benefits like non-employed people

Informal carers who do not qualify for an informal care allowance may still receive an unemployment benefit or minimum income support. The proportions of non-employed people receiving such benefits are similar for informal carers and people in general. Such support varies from EUR 1,000 or less per year in various Eastern European countries (Bulgaria, Hungary, Latvia, Lithuania, Romania) to about EUR 20,000 per year for unemployment benefits in Cyprus and Luxembourg, the EU average being EUR 5,000 per year. However, as in general these benefits are not always received for the whole year because some move constantly into and out of work, or if the partner has sufficient income.

Informal care reduces pension entitlements by up to 22%

Informal carers may also lose future pensions. Many countries grant pension credits to informal carers, but as for care allowances often additional conditions apply. On average in the EU, the pension loss of informal carers with a career break is 9% of the pension they would be entitled to without a career break. This assumes an average career break of 3 years for informal carers below the age of 45 to 6 years for women aged 45-64, and an immediate return to work after the care stint. The loss varies from 0% in Ireland, Lithuania and Luxembourg to 19% in Latvia and 22% in Slovakia. The variation in pension losses between countries is mainly caused by differences in entitlement criteria of pension credits for informal carers such as the degree of incapacity of the care receiver, the intensity of informal care or existence of a family relation between the care provider and care receiver.

Informal care affects leisure time but not happiness in general

Informal carers rate their life similar as people in general. The largest difference is found with regard to having sufficient time to enjoy life (thus enough leisure time), which 39% of the informal carers report compared to 43% in general.

The hours value of informal care exceeds public formal care spending

At the EU level, informal carers spend 33 to 39 billion hours per year on informal care, depending on assumptions about the average hours of high-intensity informal care

providers (40+). These hours represent a certain value, even if those hours are unpaid. The value of informal care hours ranges from 2.5% to 5.2% of 2018 EU GDP using the proxy good method, which values those hours with the gross wages of care professionals providing similar activities. The range depends on the valuation of hours and the most likely value is 2.7% of EU GDP.

This value ranges from 1.4 to 3.3% of EU GDP using the opportunity cost method, which values hours with the gross wage rate of what informal carers could have earned in their "real" professions, and with the value of leisure for people past the age of 65. The most likely value is 2.4% of EU GDP.

The value of the hours of informal care exceed the cost of public expenditure on LTC, which is 1.7% of 2019 EU GDP according to the 2021 Ageing Report. Only in the northwest of Europe (excluding Ireland) does the cost of public expenditure on LTC exceed the hours valuation of informal care.

Lost revenues cause a strain on the State budget

Informal care affects the State budgets through lost revenues from income taxes and social security contributions and through expenditures on various benefits to informal care providers. Initial estimates of lost revenues based on a number of assumptions are 0.76% of the 2019 EU GDP. The largest part of this is associated with the reduced employment of women aged 45-64 (0.29% during the care stint and another 0.29% after the care stint because the re-employment likelihood is low). Lower re-employment likelihoods of informal carers compared to their peer groups contribute to further lost revenues of 0.16% of EU GDP, while lost revenues due to reduced working hours of women aged 18-44 providing intense informal care amount to only 0.02% of EU GDP.

Increased expenditures further strain the State budget

Expenditures on care allowances account for a further estimated 0.19% of EU GDP. In the working age population, the employment rate of informal carers is similar as among non-carers, except for women aged 45-64 of whom some qualify for informal care allowances. Thus, the additional expenditures on unemployment benefits and minimum income support caused by a difference in employment rates of informal carers is estimated to be only 0.02% of EU GDP. Likewise, the value of pension credits is limited to 0.08% of EU GDP, because conditions apply to qualify as informal carer for pension credits. The above expenditures add up to 0.29% of EU GDP.

Estimated total impact on the State budgets

If only lost revenues due to women aged 45-64 stopping with work when providing informal care is taken into account, the impact on the State budget would already be an approximate 0.5% of EU GDP. Including the other estimated lost revenues and including the increased expenditures, this adds up to 1.05% of EU GDP (EUR 1.46 billion in 2019). The impact of informal care on the State budget is estimated to be largest in Sweden (2.1%) and Greece (1.6%) due to large employment gaps, and in France (1.7%) and Austria (1.6%) which in addition spend substantial sums on informal care allowances. The impact on the State budget is estimated to be smallest in countries where women aged 45-64 providing informal care are actually more often employed, notably in Poland and Romania. The estimated impact is even positive in Belgium and Denmark, where among women aged 45-64 the

employment rate among informal carers is substantially higher than in the general population.

Overall conclusion

This study confirmed the high prevalence of informal care: it is estimated that some 52 million people or 14.4% of the adult population aged 18-74 provide informal care. Although most care is provided in low intensities, even in full-time equivalents 80% of long-term care is provided informally. Expenditures on informal carers amount to a roughly estimated 0.3% of EU GDP. Including invisible costs in the form of lost tax revenues, informal care cost a roughly estimated 1.05% of EU GDP.

Women provide the majority of informal care. These may be due to pre-existing inequalities, such as women already staying at home to care for their children or having a lower income. To incentivise men to take on more caring responsibilities, a formal recognition of their informal care to help a career switch might help with better sharing of care responsibilities between men and women and also bring more men among formal carers.

Efforts to mitigate the impacts of informal care on providers should in particular focus on intense care. Informal care starts to have noticeable impacts from 20 hours per week and has many strong negative effects from 40 hours per week. Especially people caring informally for their spouse feel they stand alone in their burden and suffer mentally from that.

Expansion of formal services would help make informal care a choice for both care giver and care recipient. Furthermore, given the many negative consequences of intensive care on employment, health and income, those helping people with severe care needs or providing help for 20+ or 40+ hours per week clearly need support, not only financial but also in the form of respites and burden sharing with formal care.

1. Methodology

1.1. Overall approach

The right to affordable quality long-term care is one of the 20 principles in the EU Pillar of Social Rights. The European Pillar of Social Rights Action Plan[3] and the Green Paper on Ageing[4] highlight that while demand for care services is expected to increase in an ageing society, the lack of quality standards in care and gaps in access to quality services, including in rural areas, are a serious concern in many Member States. Long-term care may also be provided informally, but this comes with its own challenges such as combining this with work. A first goal of this study was to develop a common understanding of informal care and its key features and confirm this understanding with experts. The second goal was to estimate the number of people providing informal long-term care and to analyse their characteristics. The third goal was to estimate the costs associated with the provision of informal long-term care for the individual and the State, using different cost concepts.

The overall approach was to first agree on a definition that according to experts capture all relevant aspects of informal care, and then to collect data on informal care from various sources to triangulate the incidence and costs, as well as some benefits, of informal care.

The definition of informal care was based on preliminary desk research and eight scoping interviews and then finetuned with the Commission. The incidence of informal care was then estimated by comparing and assessing six multi-country data sources and three single-country data sources, and triangulating on the basis of data sources that best approximate the definition of informal care. The same approach of own analysis of data sources and literature review was applied to analyse characteristics of informal care. The results were validated with findings from a literature review.

The assessment of costs and benefits of informal care was based on a framework of direct and indirect costs and benefits at the individual and society level. Table 1 presents this framework. Direct costs are out-of-pocket expenditures that informal carers incur to provide their caring activities. At society level, direct costs consist of care allowances and other non-employment related benefits, which at the same time are direct benefits for the carers. Indirect costs for the individual relate to time investment, health impacts, reduced income including reduced future pensions and the risk of poverty, whereas indirect costs for society relate to employment gap (time not spent in employment caused by informal care), additional health care expenses on informal carers, and gender inequality.

In addition to costs, the study identifies benefits of informal care for the carer and for society. Benefits for the individual carer include monetary benefits such as care allowances, unemployment benefits and minimum income support, but also a sense of purpose or duty fulfilled. For society a direct benefit is that informal care may reduce the expenditures on formal care. Indirect benefits could relate to affections between carer and person in need (these benefits are negative for some), and perhaps a more caring society at the society level.

[3] The European Pillar of Social Rights Action Plan (europa.eu)

[4] https://ec.europa.eu/info/sites/default/files/1_en_act_part1_v8_0.pdf

Table 1 – Framework on costs and benefits of informal long-term care

	Category	Individual	Society
Direct cost	Expenditures	Costs of travelling to care-recipient	Care allowance
Indirect costs	Time investment	Lost wage due to reduced working hours Lost pension entitlements Skills loss Less leisure	Lost tax revenues from work Loss of labour supply
	Health	Caregiver burden Adverse health outcomes	Health care expenses on carers
	Other	Risk of poverty	Income support Unemployment benefits Gender inequality Lost social security contributions
Direct benefits		Process utility (e.g. sense of purpose) Care allowance Income support, unemployment benefits	Less or different expenses on formal LTC
Indirect benefits		Affections, relation with care receiver	Caring society

1.2. Approach to define informal care

Aim and research question

In order to conduct a proper measurement and valuation of the impact of informal long-term caregiving across Europe, a standard definition of what informal LTC entails is required. Therefore, the objective was to formulate a definition of informal long-term care based on the literature and policy context. This definition will provide guidance for the study and can support future empirical research and policymaking. First, relevant aspects of informal LTC were identified. Second, a narrative review of the literature was conducted. A narrative review is a tool for policy development, which has a qualitative emphasis and is particularly appropriate when the review question is broad. It provides a flexible approach to summarise, explain and interpret evidence, including qualitative and quantitative studies. The review question to be answered in the narrative literature review was formulated as follows:

Research question to define informal care

What are relevant definitions used for informal LTC within the literature that can form the basis of a standard definition of informal LTC?

Third, scoping interviews were conducted to fine-tune the definition, taking into account the policy context and database possibilities. Hence, the aim of the interviews was to achieve qualitative insights from experts to further delineate a formal definition of informal long-term care. Fourth, contractor and client reached consensus on a definition of informal LTC for this study.

Eight experts were interviewed about relevant aspects to cover in a definition. Table 2 - Table provides an overview of the interviewees.

Table 2 - Table Interviewees

Oganisation	Expert
Eurofound	Hans Dubois
European Gender equality institute (EIGE)	Mare Karru
International Labour Organization (ILO)	Laura Addati
The European Centre for social welfare policy and research	Ricardo Rodrigues
European Association for Working for Carers (Eurocarers)	Stecy Yghemonos
University of Amsterdam, professor on informal care	Marjolein Broese van Groenou
AGE Platform	Julia Wadoux
The Organisation for Economic Co-operation and Development (OECD)	Eileen Rocard

The interviews were semi-structured. This type of interview enables the interviewer to cover all relevant issues while having the flexibility to focus on specific points where the interviewee has particular knowledge. Before each interview, the interview guide was shared with the interviewee. The guide outlined the objective of the study in general and the interview in particular. It included a list of topics and questions to discuss during the interview. The interview guide can be found in Appendix A.

1.3. Approach to literature review

Aim and overall approach

The aim of the literature review was to provide a comprehensive overview of studies that quantify the incidence, cost and impact of informal LTC across the EU. To create such an overview of all recent European literature on this topic a systematic literature review was conducted.

To provide an objective, transparent, and replicable overview, the literature review was systematically carried out following the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guidelines[5]. Following this approach, the following steps were carried out:

- Selecting databases and/or search engines.
- Defining the search terms and developing a search protocol.
- Screening of titles and abstracts to make a first selection.
- Screening of full text to make a second selection.
- Quality assessment to make a final selection of relevant literature.
- Data extraction according to a standardized extraction form.

Search strategy and results

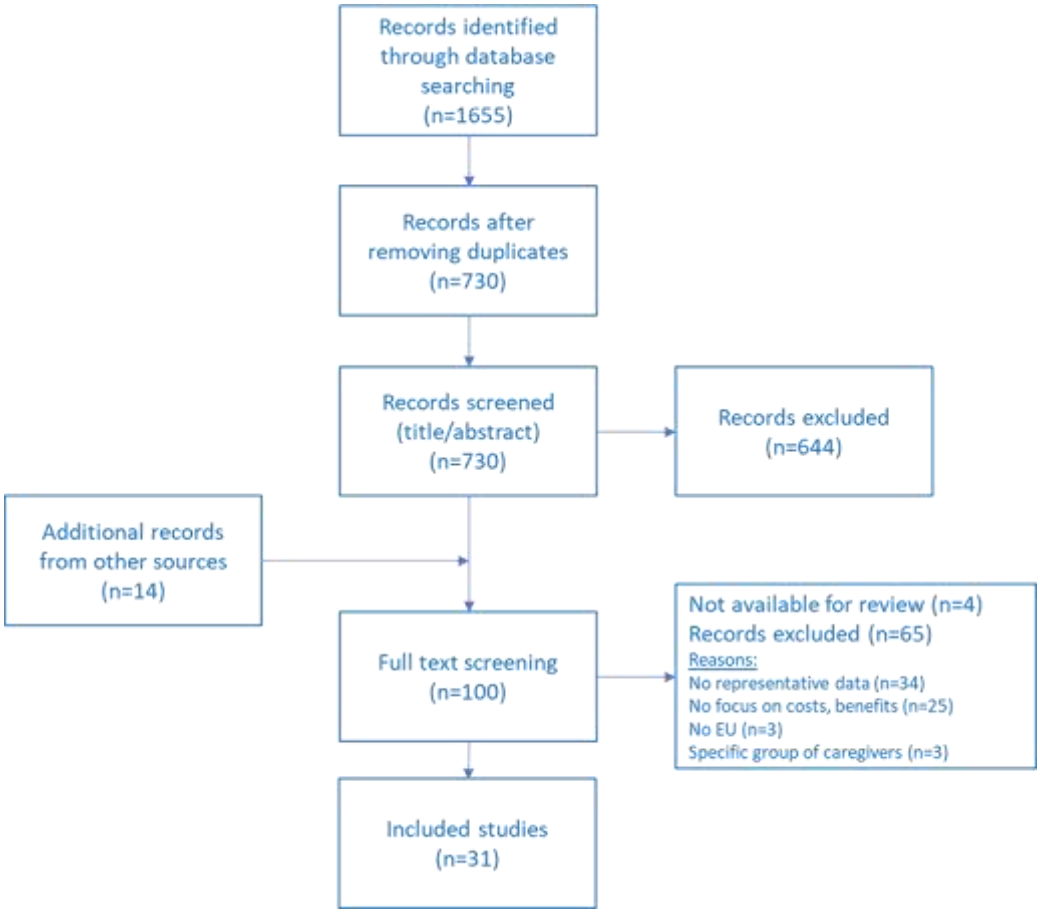
A search was performed in health and social sciences databases, including PubMED/Medline and Embase, as well as the more broadly oriented Google Scholar. A combination of the key words [Informal care] AND [Long-term care] was applied in the databases, which were translated to MeSH (Medical Subject Headings) terms for our search in PubMed, since in PubMED each article citation is associated with a set of MeSH terms that describe the content of the citation. Furthermore, we conducted hand-search and snowballing based on reference lists of the obtained articles. Relevant definitions were selected and a data extraction form was used to analyse these definitions, for example, in terms of the criteria used to define informal LTC. The search included literature published between 2010 and 2020 in English, French and German. Studies outside the European Union were also considered in the narrative literature review, as these studies may also have relevant definitions on informal LTC.

The searches yielded in total 1,655 articles, which resulted in a total of 730 articles after removal of duplicates. Title-abstract screening resulted in the exclusion of 644 papers, for a variety of reasons. Most often studies did not focus on long-term informal care or focused on care for a specific subgroup of care recipients. The hand-search resulted in the inclusion of 14 additional papers. Of the remaining 100 papers the full text was not available for 4 papers and was reviewed for the other 96 papers. During the full text screening, 65 papers were excluded mostly because were published before 2010 or used data before 2010.

[5] Moher, D., Liberati, A., Tetzlaff, J., Altman, D.G., and PRISMA Group. 2008. Preferred reporting items for systematic reviews and meta-analyses: the PRISMA statement. Ann Intern Med; 151: 264–269.

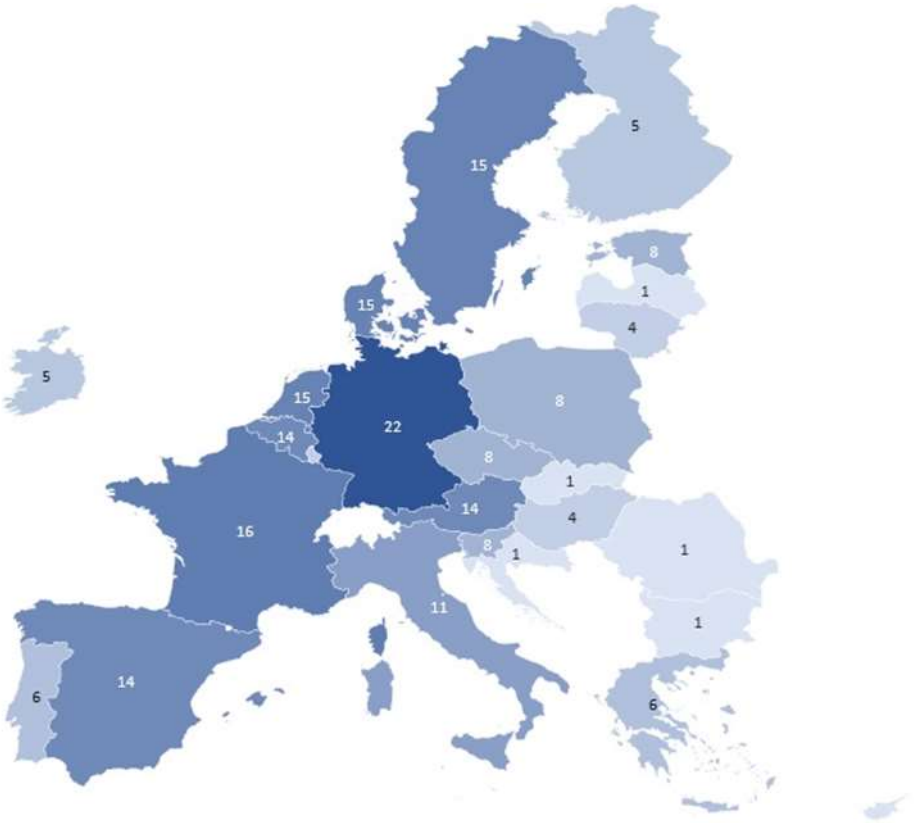
Eventually, 31 articles met all inclusion criteria and were included in the review. Figure 1 depicts the screening procedure.

Figure 1 - Flowchart of screening phases



The oldest paper dates from 2014 (Heger, 2014), the most recent paper was published in 2020 (Kaschowitz & Lazarevic, 2020). Twelve reviewed papers are based on an analysis of the so-called SHARE database (discussed later). Other commonly used datasets are the German Ageing Survey (N=5), the German Socio-Economic Panel (N=3) and the European Social Survey (N=3). Figure 2 provides an overview of the countries that were studied. Inclusion of the paper by Maquire et al. (2019) who used the European Quality of Life Survey resulted in the inclusion of all European countries at least once. Germany was most often included in these studies and Eastern European countries the least often.

Figure 2 - Country coverage by literature



Although the aim was to include articles that adhere to the agreed definition of informal LTC, most studies were not very specific in their definition of informal LTC. An analysis of the surveys used revealed that lack of precise definitions, specifically with regard to the duration of informal care, is inherent to the surveys. It was therefore decided to include these articles even though it is not fully certain whether they fully adhere to the definition of informal LTC used in this report.

In fact, most studies simply refer to informal care or phrase the care activities as any care, help or support regardless of the type of activity. However, for most studies it is clear, either directly or implicitly based on the data that were used, that informal care does not include "normal" domestic tasks in the own household (cleaning, cooking, shopping) and "regular" childcare. For the studies that do not explicitly define informal care, it was assumed that informal care includes all types of informal care covered by the survey on which the paper is based. Some studies explicitly include both personal care and household help (#5, 12, 13) but some other studies limit the analysis to personal care only (#6, 14, 17, 18, 24, 25, 26, 29).[6] Other explicit limitations in scope include:

- Care to parents (#5, 12, 13, 18, 25, 26).
- Care to spouse (#6, 24, 29).
- Care to persons aged 65 and older (#31).
- Female caregivers (#21, 22, 25).

[6] The numbers in brackets refer to numbers in the literature overview table of Annex B.

The SHARE database only includes people (caregivers and care receivers) aged 50-70 so all twelve studies based on this database implicitly have the same age limitation (#2, 5, 6, 12, 13, 14, 16, 17,18, 24, 26, 29).

1.4. Approach to database assessment

Aim and general approach

The aim of the database assessment was to assess which database best approximates the definition of informal LTC of this study or how best to triangulate the incidence of informal LTC from these databases, as well as to assess the characteristics of informal care covered by those databases. The general approach to assess the databases consisted of:

- Reviewing potentially relevant datasets.
- Appraising these datasets.
- Developing a method for triangulation.

Reviewed datasets

The review includes six multi-country datasets:

- EU-SILC (longitudinal version 2010-2017, 2016 ad hoc module)[7].
- Labour Force Survey (LFS, core data[8] and 2018 ad hoc module[9]).
- European Health Interview Survey (EHIS)[10].
- SHARE[11].
- European Quality of Living Survey (EQLS)[12].
- European Social Survey, 2014 health inequality module[13].

[7] See https://circabc.europa.eu/sd/a/165c80b9-5631-4f5b-b847-29c638715c0e/DOCSILC065%20operation%202016%20VERSION%2022-05-2017.pdf.

[8] https://ec.europa.eu/eurostat/documents/1978984/6037342/EULFS-Database-UserGuide.pdf.

[9] https://ec.europa.eu/eurostat/en/web/products-statistical-reports/-/KS-FT-19-006.

[10] https://ec.europa.eu/eurostat/web/products-manuals-and-guidelines/-/KS-02-18-240.

[11] http://www.share-project.org/fileadmin/pdf_questionnaire_wave_6/Generic_main_qnn_6_3_13.pdf.

[12] https://www.eurofound.europa.eu/sites/default/files/ef_survey/field_ef_documents/4th_eqls_final_master_source_questionnaire_12_june_2017_-_updated_07_september_2017.pdf.

[13] https://www.europeansocialsurvey.org/methodology/ess_methodology/source_questionnaire/.

Two single-country datasets were assessed as well:

- Germany: Socioeconomic Panel (SOEP) [14].
- Netherlands: Informal Care Survey (IZG) [15].

In addition, the Eurofamcare survey of 2004 was assessed, but not included in the further data review because this survey is from before 2010. Annex C presents the results of the data appraisal. The triangulation is further discussed in Chapter 3.

1.5. Data analysis – grid procedure

The data analysis consisted mostly of producing tables after weighting respondents with the survey weights. In the end, two databases (EQLS and EHIS) had the best country coverage with incidence rates within the triangulated range. For these two databases, for each country characteristics of informal carers were tabulated by the intensity of care. This helps to analyse characteristics such as gender, age, employment status etcetera of low- and high-intensity carers and to express informal care as full-time equivalents in a consistent way. The average total number of informal carers of these two data sources were calculated per country and per characteristic of informal carers, and further breakdowns by categories of hours of informal care were harmonized through a so-called grid method, in which cell values are iteratively weighted to sum up to row totals (for characteristics) and column totals (per intensity level of informal care). Figure 3 explains the grid procedure in a hypothetical example where not everyone tells their gender so numbers by gender don't add up to the total. The grid procedure adds numbers proportionally to reported gender in such a way that all numbers add up to both row and columns totals.

Figure 3 – Explanation of the grid procedure

Before grid procedure

	Hours informal care					
	1-9 hours	10-19 hours	20-39 hours	40-69 hours	70+ hours	Total
Total	200	50	43	5	2	300
Men	80	20	18	2	.	125
Women	120	25	20	2	1	175

Numbers don't add up if some people don't tell their gender

After grid procedure

	Hours informal care					
	1-9 hours	10-19 hours	20-39 hours	40-69 hours	70+ hours	Total
Total	200	50	43	5	2	300
Men	80	22	20	2	1	125
Women	120	28	23	3	1	175

The grid procedure adds numbers proportionally to both column and row totals

14 http://companion.soep.de/Topics%20of%20SOEPcore/index.html#.

15 https://www.scp.nl/Onderzoek/Bronnen/Beknopte_onderzoeksbeschrijvingen/Informele_zorg_IZG.

1.6. Analysis of costs and benefits

A large part of the costs of informal care relate to the valuation of hours and costs associated with the employment gap (a lower level of employment caused by informal care). This data analysis relied heavily on wage levels. For the valuation of all hours of informal care, wage levels of formal care professions were used for personal care (help with activities of daily life such as feeding, clothing, bathing) and country-specific ILO wage levels per occupational main group (ISCO-1) were used for help with household tasks and paperwork, as well as values of leisure time per country according to literature. The employment gap differs by gender and age, and therefore more granular Eurostat Structural Earnings Survey data were used to estimate the associated costs, with a breakdown by occupational main group, gender and age category for each country.

Part of the other costs were estimated on the basis of regulations, such as for pension contributions on behalf of informal carers. In addition, OECD Pension at a Glance data on the impact of a career break (to provide informal care) on pension entitlements were used. Data on informal care benefit expenditures were collected through desk research, mostly based on statistical reports. Informal care benefit expenditures were compared with data on expenditures on care provided by households, from the Eurostat System of Health Accounts (SHA).

Some impacts of informal care are difficult to estimate because longitudinal data on informal care are virtually absent. This is especially the case for employment transitions and impacts on the labour market in general, and for changes in health status. The EU-SILC is one of the few longitudinal datasets. Unfortunately for this study, the longitudinal version of EU-SILC has no questions about informal care. The initial idea to use EU-SILC was to assume informal care if (a) a different adult household member had difficulties performing daily tasks due to reasons of health or old age and (b) the main activity was “fulfilling domestic tasks and care responsibilities”. It was recognized from the start that this assumption would overestimate informal care because not everyone actually provides care for household members in need[16], and would underestimate informal care because this approximation does not include care to people outside the households (e.g. parents, friends, neighbours). The validity of these assumptions were tested with the EU-SILC ad hoc module of 2016 where people are asked if they provide informal care. It then turned out that the informal care is much more likely if a different adult household member had strong difficulties performing daily tasks and assumption (a) was revised accordingly. In addition, it turned out that the employment rate (main activity is employment) of informal carers is not much less than in the general population and assumption (b) was revised to include employment in small part-time jobs while recognizing that the approximation is far from perfect. The validity of the assumptions and methods to increase the likelihood that an identified potential informal carer actually provided informal care are discussed in a methodology box in Section 4.2. Mainly due to selectivity reasons discussed in Chapter 5 but also because the approximation of informal care is imperfect, changes in health or employment status after people start to provide informal care are discussed as correlations rather than as causal effects.

[16] For example, because formal care was sufficient, or because a third household member provided informal care.

2. Definition of informal care

2.1. Definition of informal care in this study

In light of the results of the narrative literature, a critical reflection during the expert interviews on the findings of the literature study, and a consultation session with DG EMPL, all discussed further below in this chapter, we formulated the following definition for informal long-term care:

Definition of informal long-term care

Informal long-term care entails care provided to people who need support because of disability or old age. The care activities may involve help with activities of daily living (e.g., bathing, dressing and eating) and instrumental activities of daily living (e.g., shopping, preparing meals, housework or administrative tasks). The care is provided for at least three consecutive months by someone from the care receiver's social environment (e.g., a family member, friend or neighbour) and the provider is not hired in a professional capacity.

It should be noted that the definition in this study includes informal care of any intensity in terms of hours per week of informal care, contrary to for example the OECD definition.[17] The below table, Table 3, provides, where applicable, further delineation and clarification of the different concepts related to informal care and/or operationalisation in terms of certain thresholds and breakdowns used in the current study.

Table 3 - Clarification and operationalisation of informal LTC concepts

Concept and clarification	Operationalisation
Care provider: An informal care provider is limited to someone from the social environment of the care receiver, e.g., a partner, child, grandchild, other relatives or household members, or a friend or neighbour. Volunteers and domestic workers (even if they work undeclared) are not considered to be informal caregivers.	Informal carers of 16 years and older are included in the study. Care providers of working age (18-64) are considered to investigate the impact on the labour market.
Care receiver:	The study breaks down the care receivers into different age groups, i.e., people above and below the age of 65

[17] OECD (2019), Measuring social protection for long-term care in old age, https://www.oecd-ilibrary.org/social-issues-migration-health/measuring-social-protection-for-long-term-care_a411500a-en. The OECD classify car needs from 6.5 hours per week as follows: low needs (6.5 - 22.5 hours per week), moderate needs (22.5 - 41.25), and severe needs (41.25+). The EQLS uses this breakdown of hours with an additional category for 70+ hours per week. However, most data sets split hours of care in multiples of 10 hours (0-10 hours, 10-20 hours, …).

Concept and clarification	Operationalisation
People in need of long-term care during at least three consecutive months because of disability or frailty due to old age. Childcare for a healthy child is not considered to be long-term care.	years, as well as an additional age group of 75 years and older, and provide further socio-demographic characteristics of the care receiver and the type of informal long-term care for both groups, where possible.
Care activities: Informal long-term care involves help with activities or instrumental activities of daily living, which are restricted to any form of care that a professional would provide.	The daily living activities for which help is needed may be the self-care activities that a person must perform every day (Activities of Daily Living, or ADLs, such as bathing, dressing, eating, getting in and out of bed or a chair, moving around, using the toilet, and controlling bladder and bowel functions) or may be related to independent living (Instrumental Activities of Daily Living, or IADLs, such as preparing meals, managing money, help with paperwork, help with transportation, shopping for groceries or personal items, performing light or heavy housework, and using a telephone). Emotional support as such is not considered as a long-term care activity.
Paid or unpaid: The care provider is not a hired professional. Informal care providers may receive certain fees or compensation rather than a salary, and may sign a contract as a formality to receive care allowance.	In most surveys it is implicit or explicit that informal care is unpaid. Thus, for example a nurse who provides unpaid care to a relative is included. Danish municipalities and some Swedish municipalities may offer informal carers an employment contract, but here again it is assumed that respondents consider care to relatives, friends or neighbours to be informal as long as they do not provide the care as professional sent by an employer or hired by the care receiver.
Duration: Long-term is defined as a period of at least three consecutive months of needing and giving care	Ideally, duration is analysed for informal LTC provided at a certain point in time. If this data is not available, provision of informal LTC in the past 12 months (annual sum) is used. Shorter-term care to different persons is counted as long as the total duration of care given to all care receivers combined is more than three months. In practice, due to lack of information on durations, informal care of any duration is used for most data sources.
Intensity: No threshold is set for intensity of care, defined as hours of giving care in a week, excluding travel time.	The hours of giving care are broken down into different intensity groups (0-10 hours per week, 10-20, 20-40, 40-70 and 70+). Average hours of care received do not necessarily equate average hours of care given because care may be received from multiple providers and care givers may provide care to multiple persons. Conversely, we draw no inference about hours of care received from hours of care given because on average care receivers get help from multiple informal carers.

With regard to the long-term aspect of informal care, most datasets lack information on the duration of informal care, which makes it impossible to select the care stints that lasted at least three consecutive months.[18] Thus, most of the remainder of this study refers to informal care in general. However, it is assumed that less frequent care than once in a month has never been provided for three consecutive months. Thus, to approximate the limitation of informal care to long-term stints (i.e. stints of at least three months), care that is provided less often than once in a month is excluded from all datasets where this can be excluded.

2.2. The relevant aspects

The relevant aspects of informal care were rather clear from the start of this study, but how informal care is defined in terms of those aspects differs very much in previous literature. The relevant aspects include:

- Characteristics of the informal carer.
- Characteristics of the care receiver.
- Relation between care provider and receiver.
- Type of care.
- Paid or unpaid.
- Duration.
- Intensity.

2.3. Survey definitions

As noted in the previous chapter, most studies on informal care in previous literature are based on surveys. In the multi-country surveys, informal care is defined as follows.

EU-SILC (2016 ad hoc module) suggests the following wording to ask after informal care provision: “Do you provide care or assistance to one or more persons needing help due to long-term physical or mental health illness, infirmity or because of old-age? Only unpaid activities / informal services should be taken into account.”

In addition, EU-SILC provides the following guideline: “Only voluntary (unpaid) assistance should be taken into account. Financial support or benefits from the government to provide this care and assistance (e.g. carer's allowance, carer's credit and tax relief) are not considered to be a pay. All types of care or assistance should be taken into consideration. Childcare is not included, unless it is care provided to children due to their long-term health problems including chronic illness and disability. The care or assistance provided does not need to be frequent but it needs to be something what is repeated.”

[18] An exceptions is SCP (2014), Informal Care: Who does what?, (report in Dutch), https://www.scp.nl/publicaties/publicaties/2015/12/15/informele-hulp-wie-doet-er-wat. The EU-SILC data also looked promising because respondents report their main activity per month, but unfortunately informal care is not a separate activity in this survey.

EHIS includes the following question in the questionnaire: “Providing care or assistance to one or more persons suffering from some age problem, chronic health condition or infirmity, at least once a week (professional activities excluded).”

LFS (ad hoc module of 2018 defines) informal LTC as: “The existence of care responsibilities: caring regularly for own or partner’s children (<15 years) or for incapacitated relatives (15 years or older).”

SHARE distinguishes between informal care inside and outside the household. Outside of the household: “In the last twelve months, have you personally given any kind of help listed on this card to a family member from outside the household, a friend or neighbour? (Excluding looking after own grandchildren): (1) e.g. dressing, bathing or showering, eating, getting in or out of bed, using the toilet, (2) practical household help, e.g. with home repairs, gardening, transportation, shopping, household chores and (3) help with paperwork, such as filling out forms, settling financial or legal matters.”

SHARE introduces informal care inside the household as follows: “Let us now talk about help within your household. Is there someone living in this household whom you have helped regularly during the last twelve months with personal care, such as washing, getting out of bed, or dressing? (By regularly we mean daily or almost daily during at least three months. We do not want to capture help during short-term sickness of family members.)”

EQLS: includes the following question in the questionnaire: “In general, how often are you involved in any of the following activities outside of paid work? (a) Caring for disabled or infirm family members, neighbours or friends under 75 years old; (b) Caring for disabled or infirm family members, neighbours or friends aged 75 or over.”

Central aspects in survey definitions of informal care

A need of the informal care receiver (due to health or old age problems) and some measure of frequency are both central in most of the above survey definitions, although in SHARE the types of activities are central.

Characteristics of the informal carer are not part of the definition, but in practice all surveys include only adults (from age 15-18 onwards) and the SHARE database includes only people aged 50-70. Aspects of the relation between care provider and receiver concern the childcare (included in LFS, excluded in EU-SILC), and the LFS ad hoc module limits informal care to relatives. The EU-SILC is the only survey that explicitly excludes paid work from informal care in the question, while duration of informal care is not part of any of the survey definitions.

2.4. Literature definitions and expert opinions

Below, we discuss how aspects of informal care are defined in literature and the expert opinions on how to ideally include those aspects in the definition of informal LTC.

Care provider

Many seniors provide care, for example to their spouses.[19] Therefore, the literature generally includes all adults regardless of age, especially when health related outcomes of providing informal care are considered.[20] However, an analysis of labour market outcomes of informal care is typically limited to informal carers in the working age (Appendix C).

Another important aspect to consider when looking at the care provider (although not specifically to define the care provider), is whether the care is provided out of free choice. In some European countries formal LTC services might be lacking, leaving family and friends with practically no choice except to provide the care informally. This is supported by a recent report of Eurofound. This report states that in countries where formal LTC is least available, the employment rate among frequent carers is 10 percent point below that of other people. In countries where formal LTC is most commonly used this employment gap is just 3 percent points. Hence, when formal care is less available, more people need to give up work to provide frequent informal care (and informal care is more likely to be involuntary).[21]

The eight interviewed experts remarked the following on informal carers:

- Women are the largest group of care providers. Furthermore, when multiple children are present in one family, the female child with the lowest income tends to provide the care primarily to her parent or parents. However, it was also mentioned that it is important to include men in the analyses as they might increasingly provide informal long-term care.

- An age limit might not be required for the care provider, given that people are increasingly longer active on the labour market. In addition, it was mentioned that the older people get, the more likely they are to provide care.

- It is important to analyse characteristics such as gender and age, as well as socioeconomic conditions such as income level of the care providers.

Care receiver

Central in most definitions of informal caregiving within the literature, is that a need of care must be caused by old age or health problems, such as chronic illness, disability or other physical or mental health problems[22]. For example, the Social Protection Committee (SPC), states that long-term care services are meant for individuals, "*who as a result of mental and/or physical frailty and/or disability over an extended period of time, depend on help with daily living activities and/or are in need of some permanent nursing care*"[23]. Although individuals in need of care may include persons of all ages, frailty and, in turn, a risk of

[19] Lundsgaard. Consumer Direction and Choice in Long-Term Care for Older Persons, Including Payments for Informal Care: How Can it Help Improve Care Outcomes, Employment and Fiscal Sustainability? 2005 OECD health working papers.

[20] Bom et al. 2019 The Impact of Informal Caregiving for Older Adults on the Health of Various Types of Caregivers: A Systematic Review. The Gerontologist.

[21] Eurofound (2019), Challenges and prospects in the EU: Quality of life and public services, Publications Office of the European Union, Luxembourg.

[22] Hoefman, R. (2015) The Impact of Caregiving The measurement and valuation of informal care for use in economic evaluations. https://repub.eur.nl/pub/78028/Proefschrift-Renske-Hoefman.pdf.

[23] European Commission and Social Protection Committee. 2014. Adequate social protection for long-term care needs in an ageing society.

developing disability in (I)ADL and a need for help, is particular the result of old age[24]. In line, there seems to be a focus on care for older persons within the current literature (Appendix C). Also, the SPC report focusses on the risk of becoming LTC dependent in old age[25]. Hence, typical definitions in literature refer to both people with a disability or needing medical help which may include children and to older people, although some literature focuses on elderly people needing care.

The eight interviewed experts remarked the following on informal care receivers:

- When considering informal long-term care, there is typically a focus on older persons. However, according to some of the respondents young people and people with a disability should not be excluded, since the care for children with disabilities may have a significant impact on carers as well. Because of the differences between people with disabilities and older people, it was hence considered relevant to distinguish between these groups, although it might be challenging to determine an age limit for different groups of care receivers.

- With regard to older persons it was mentioned that their need for help is not defined or hard to define by the presence of a disability. Older people might be in need of care or support, but not meet the label of having health problems. Instead, these older persons could be considered as being frail. However, it was also mentioned that it might be difficult to define frailty. Therefore, it was suggested to use this concept not too strictly to define the need of care because of old age.

Relationship between care receiver and provider

Across the literature there seems to be an agreement that the social relationship between caregiver and care recipient prior to the start of caregiving is an important feature characterizing informal caregiving, for example a family member, friend or neighbour (the social environment). As stated by Oliva-Moreno et al., the emotional relationship between the care receiver and care provider is one of the most distinctive features of informal care[26]. According to Van den Berg et al., it is even important to consider what this social relationship between the recipient and carer actually entails, e.g., in terms of whether they live in the same household[27]. A spousal caregiver who lives together with the care recipient may face greater challenges than an adult child who lives apart and assists a parent. For example, in terms of freedom of choice or it might be more difficult to separate informal care tasks from normal household activities when the caregiver lives in the same house as the care recipient. On the other hand, caregiving may affect the adult child's working life[28]. This, in turn, may have greater impact on women than men, since women more often provide

[24] J., Lundsgaard. (2005). Consumer Direction and Choice in Long-Term Care for Older Persons, Including Payments for Informal Care: How Can it Help Improve Care Outcomes, Employment and Fiscal Sustainability?. OECD Health Working Papers. https://www.oecd.org/health/health-systems/34897775.pdf.

[25] European Commission and Social Protection Committee. 2014, ibid.

[26] Oliva-Moreno et al. The Valuation of Informal Care in Cost-of-Illness Studies: A Systematic Review. 2017. PharmacoEconomics.

[27] Van den Berg B, Brouwer W, and Koopmanschap M. 2004.Economic valuation of informal care. An overview of methods and applications. European Journal of Health Economics 5:36-45.

[28] Adelman et al. 2014 Caregiver Burden A Clinical Review. JAMA. 311: 10.

informal care compared to men, and when they provide the informal care, they are more often the main caregiver and care for longer hours.[29]

In addition to persons from the social environment, informal care might also be provided by volunteers. The European Commission defined volunteering as "*all forms of voluntary activity, whether formal or informal. Volunteers act under their own free will, according to their own choices and motivations and do not seek financial gain. Volunteering is a journey of solidarity and a way for individuals and associations to identify and address human, social or environmental needs and concerns. Volunteering is often carried out in support of a non-profit organisation or community-based initiative*"[30]. Care provided by volunteers to dependent persons might be substantial and in Europe, volunteer work, informal help, and care among persons aged 50 years and over are complementary and interdependent.[31] The (mostly Dutch) literature that discusses volunteer work, excludes volunteer work from the definition of informal care (Li 2005; Swinkels et al. 2015; Geerts and Van den Bosch 2012 and M. Broese van Groenou and A. De Boer 2016).[32]

The interviewed experts also reflected on the relation between care provider and receiver:

- According to some, informal carers should come from the social environment of the care receiver.
- Some indicated that some volunteers could be considered as informal care providers as well, such as for example volunteers from the community (e.g., church) with no formal contract. However, most interviewed experts considered volunteers working for a professional organisation (e.g., the red cross) as formal carers. However, because it might be difficult to distinguish between these two types of volunteering they advised to either include or exclude all types of volunteers.
- Some mentioned that persons providing care illegally, e.g., migrants who provide care without a formal contract could in some cases be considered as informal care providers as well. However, it was also mentioned that this form of (informal) care is probably outside the scope of the current study.
- Women are the largest group of care providers. Furthermore, when multiple children are present in one family, the female child with the lowest income tends to provide the most care to her parent or parents. However, it was also mentioned that it is important to include men in the analyses as they might increasingly provide informal long-term care.

In this study, volunteers and undeclared workers are excluded from the definition of informal care, and men are included in the scope.

Type of care provided

Across the literature, it is often not specified what kind of activities the informal care actually entails. In case it is specified, the care activities described mainly relate to ADL, such as

[29] Carmichael F and Charles S. 2003 The opportunity costs of informal care: does gender matter? European Journal of Health Economics.

[30] https://ec.europa.eu/citizenship/pdf/doc1311_en.pdf.

[31] Hank and Stuck. 2008 Volunteer work, informal help, and care among the 50+ in Europe: Further evidence for 'linked' productive activities at older ages. Social science research.

[32] M. Broese van Groenou, A. De Boer (2016) Providing informal care in a changing society. European Journal of Ageing.

dressing, bathing, getting in and out of bed, and IADL, such as grocery shopping, help with travelling, preparing meals or help with paperwork.

The interviewed experts commented on the type of care:

- Both ADL and IADL are relevant. One expert mentioned that it is important to make a distinction between ADL and IADL because they have a significantly different impact on the care provider.

- One could include (emotional) support as a form of informal care. One of the respondents mentioned, however, that informal care activities should entail activities that otherwise a professional would do (indicated care).

This study includes both ADL and IADL. Help that consists solely in the form of emotional support is excluded.

Paid or unpaid

In many studies, informal care is defined as unpaid work. Also, for example, Eurocarers defines a carer as "a person who provides usually unpaid care to someone with a chronic illness, disability, or other long-lasting health or care need, outside a professional or formal framework"[33]. However, given that a carer may receive cash benefits, and given that certain payment schemes for informal carers may exist,[34] absence of a professional or formal framework seems more relevant when considering a definition of informal LTC. Formal care, by contrast, involves trained and qualified professionals and formal care services are monitored by (public or private) organisations.

The interviewed experts commented on paid versus unpaid care:

- Unpaid care might not cover all forms of informal care, since there might be some small fees provided to the care provider. However, an important distinction with formal care is that informal care entails a compensation rather than a salary, which in most cases does not even cover the expenses made related to the provided care.

- Most respondents indicated that informal care can be defined as care that is organised without a professional contract. This also relates to the absence of quality checks in the case of informal care, although in some cases quality checks might also occur in the case of informal care.

This study defines informal care as all care where the provider is not paid as a professional. Thus nurses but also priests and housekeepers providing informal care as part of their job are excluded from this study. However, an informal carer who receives a care allowance is included.

[33] https://eurocarers.org/.

[34] DG EMPL and LSE. Informal care in Europe. https://op.europa.eu/en/publication-detail/-/publication/96d27995-6dee-11e8-9483-01aa75ed71a1/language-en.

Duration of care

Most literature does not define the duration of "long-term". Instead, it is often asked whether a person has provided care in, for example, the last 12 months and the duration of the care is not further defined. Given that care providers may slowly grow in their role (this is often the case with informal care for people with dementia), it may be complex to determine the exact duration of the care provided[35]. However, the duration of care may significantly influence outcomes, such as on employment or health[36]. For a clear delineation of the concept informal long-term care, it might be important to consider a certain threshold to define long-term. Among the studies used in the narrative review, only two indicated categories for the duration of care (e.g., 0–3 months, 4–12 months, 1–5 years and > 5 years)[37] and only De Zwart et al., set a threshold of 3 months[38], following the definition of the Netherlands Institute for Social Research[39].

One of the interviewed experts mentioned that it is important to consider whether the care is long-term, because of the economic impact. Providing care for example for a couple of years, might have a great impact for a person on the long-term. Hence, where possible it was deemed relevant to consider the duration of the care. However, most respondents said it would be difficult to argue what should be the minimum duration to define care as long-term, although they agreed it should be in terms of months. One respondent mentioned that 3 months would be an appropriate threshold.

As noted earlier, in practice most data sources have no information on duration, and all informal care is included although care that is provided less than once per month is excluded.

Intensity

Throughout the literature, several thresholds for hours per week of informal care are used, e.g., ranging from 4 hours a week[40]or 6.5 hours per week[41] to 2 hours a day[42]. Most of the studies identified several levels of intensity, e.g., <20h a week versus >20h a week[43], or

[35] Van den Berg B, Brouwer W, and Koopmanschap M. 2004.Economic valuation of informal care. An overview of methods and applications. European Journal of Health Economics 5:36-45.

[36] Brown & Brown. 2014. Informal Caregiving: A Reappraisal of Effects on Caregivers. Social Issues and Policy Review. 8(1) 74-102.

[37] Plaisier et al. 2015. Combining work and informal care: the importance of caring organisations. Human Resource Management Journal. 25: 2.

[38] De Zwart et al. 2016. Will you still need me, will you still feed me when I'm 64? The health impact of caregiving to one's spouse. Health Economics. 26:127-138.

[39] The Netherlands Institute for Social research. 2014 https://www.scp.nl/Publicaties/Alle_publicaties/Publicaties_2015/Informele_hulp_wie_doet_er_wa.

[40] Lamura et al. 2008. Family Carers' Experiences Using Support Services in Europe: Empirical Evidence From the EUROFAMCARE Study. The Gerontologist.

[41] OECD (2019), Measuring social protection for long-term care in old age, https://www.oecd-ilibrary.org/social-issues-migration-health/measuring-social-protection-for-long-term-care_a411500a-en.

[42] Schmitz and Westphal. 2015. Short- and medium-term effects of informal care provision on female caregivers' health. Journal of Health Economics.

[43] Heitmueller. The chicken or the egg? Endogeneity in labour market participation of informal carers in England. Journal of Health Economics. 26: 536-559.

almost every day/week/month or less often[44]. However, informal care is rarely defined in terms of intensity in policy documents, although in one policy paper long-term informal care was defined as care provided for more than eight hours per week[45].

The experts remarked two things about the intensity of informal care:

- It is difficult, yet relevant, to set a certain threshold in terms of hours.
- Intensity also includes frequency. For example, it should be considered whether the care is provided one hour every day compared to 8 hours during one day of the week.

This study sets no limit on the hours of informal care. With regard to frequency, as discussed above less than monthly care is excluded because it unlikely meets the three months duration criterion. In practice, the intensity of informal care is an important aspect of this study and several surveys only ask after weekly hours of informal care if that help is provided at least once every week. Hence, most of the results of this study are about weekly informal care.

[44] Bolin et al. 2008. Your next of kin or your own career? Caring and working among the 50+ of Europe. Journal of Health Economics. 27: 718-738.

[45] The Netherlands Institute for Social research. 2014 https://www.scp.nl/publicaties/publicaties/2015/12/15/informele-hulp-wie-doet-er-wat.

3. Incidence of informal care

3.1. Methodological notes

The occurrence of informal care can be measured at a certain moment (point-in-time) or during a certain period such as a year (annual sum). Some refer to point-in-time estimates as prevalence and period estimates as incidence. In order to avoid confusion, this study refers to moment and period estimates as point-in-time and annual sum respectively. Some surveys ask if informal care was given in the past 12 months and the occurrence of informal care based on such a survey is an annual sum. Other surveys ask if the person currently gives informal care and in that case the occurrence is a point-in-time estimate. By definition, the occurrence of informal care measured as an annual sum is higher than measured as point-in-time (other things being equal). When comparing the occurrence of informal care across studies, one should ideally correct for such differences in definition.

However, in practice the difference between point-in-time and annual sum definitions is not likely to be very large. The reason is that, according to various sources, informal care normally lasts several years rather than months. For example, in 2016, in Germany about 75% of the persons receiving a nursing allowance (Pflegegeld) got it for at least one year before dying[46]; in France the "personal autonomy benefit" was received on average during 3.5 years[47] and in the Netherlands the average duration of informal care was 4.5 years[48]. Thus, most people who provided informal care during the past twelve months (annual sum) still provide care at the moment of an interview (point-in-time). Hence, point-in-time and annual sum estimates cannot differ by an order of magnitude, but still the difference could be several percent points, as will be discussed in the next section.

It is important to multiply the number of respondents with their sample weights. Sample weights correct for overrepresentation or underrepresentation of different groups of people because they were easier or harder to reach, or because they are more or less likely to participate in the survey. For example for the SHARE data (respondents aged 50-70), the proportion of informal carers was 35% before weighting and 25% after weighting.

3.2. Observed incidence rates (different definitions)

This study uses data from different sources. Each of these sources have their own limitations. This section has several purposes. Firstly, to provide the incidence rate of informal care that approximates the definition of this study as best as possible given the limitations of the data source. Secondly, to explain differences between incidence rates from different data sources and to determine which data sources are potentially useful. Thirdly,

[46] Jacobs, K. Kuhlmey, A., Greß, S., Klauber, J., Schwinger, A. (2017). Die Versorgung der Pflegebedürftigen. In Pflegereport 2017. Retrieved from: https://www.wido.de/fileadmin/Dateien/Dokumente/Publikationen_Produkte/Buchreihen/Pflegereport/2017/Kapitel%20mit%20Deckblatt/wido_pr2017_kap21.pdf, Section 21.2.3, Figure 21.16. Note that only 38% of Pflegegeld is spent on informal care, according to Table 3.10 in https://www.bundesgesundheitsministerium.de/fileadmin/Dateien/3_Downloads/P/Pflegebeduerftigkeitsbegriff_Evaluierung/Abschlussbericht_Los_2_Evaluation_18c_SGB_XI.pdf

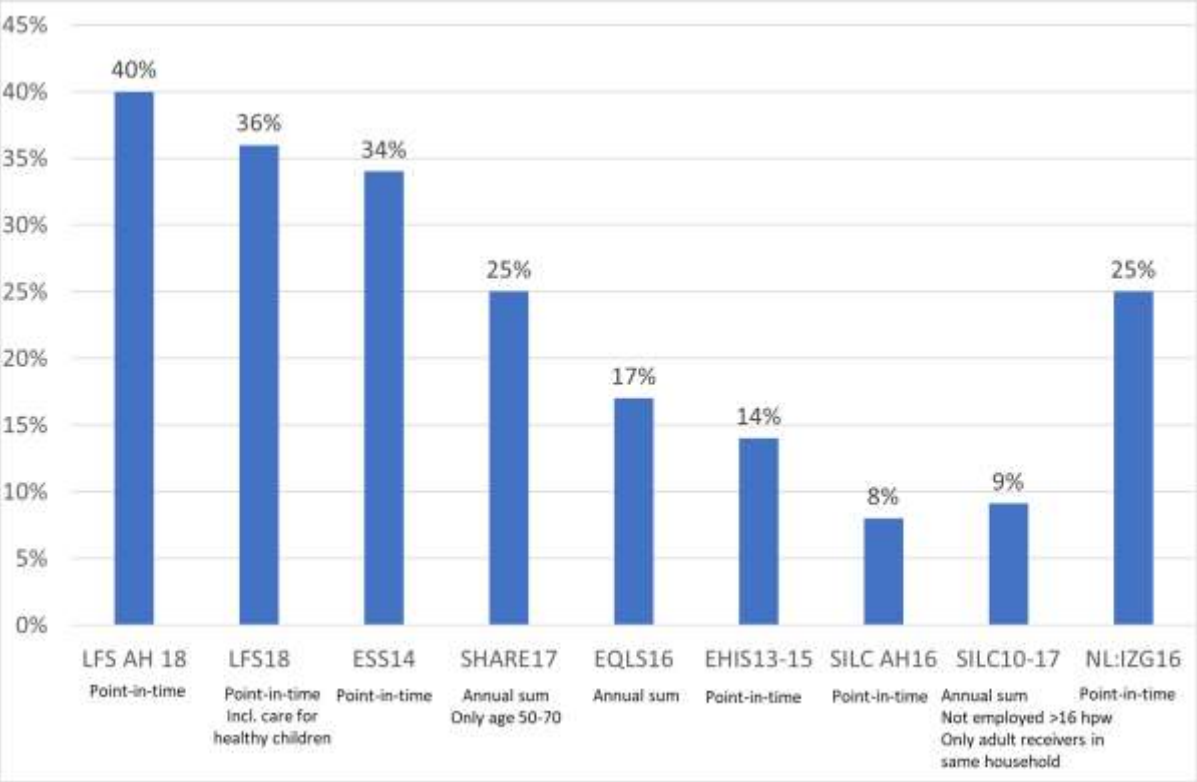
[47] See https://drees.solidarites-sante.gouv.fr/IMG/pdf/infographie-apa.pdf

[48] Based on the Informele Zorg (IZG) 2016 survey, https://www.scp.nl/over-scp/data-en-methoden/onderzoeksbeschrijvingen/informele-zorg-izg

a “harmonized” operational definition of informal is introduced to compare incidence rates of the potentially useful data sources.

Starting with the definition of informal care used in various data sources (the main differences are indicated per sources in Figure 4) and with less than monthly care already excluded,[49] the percentage of the adult population (18+ in most sources) providing informal care ranges from 8% based on the 2016 EU-SILC ad hoc module to 40% based on the 2018 LFS ad hoc module (Figure 4).

Figure 4 - Proportion of informal carers in adult populations



Various sources. *Informal care provided at least once per week (EQLS, EHIS), at least once per month (SHARE, IZG) or undefined other than as “regularly” (LFS, ESS, SILC). SHARE: at least once per month for help provided to others outside the household (selection used for this chart); daily or almost daily personal care for help provided to others in the household (survey definition). SILC 10-17: assumed informal care to household members (see methodology box in Section 4.2 later).*

In the remainder of this section, the incidence rates according to various data sources are discussed more or less in descending order:

- LFS survey
- ESS survey
- IZG survey
- SHARE survey

[49] EHIS only asks about informal care that is provided at least weekly, and EQLS only asks hours of informal care that is provided at least weekly. So the incidence rates of EHIS and EQLS actually relate to weekly instead of monthly care.

- EQLS survey
- EHIS survey
- SILC 2016 ad hoc module
- Regular EU-SILC

LFS survey

First of all, it can be noted that in the regular LFS survey (respondents aged 15-74 but for this study only those aged 18-74 were selected) informal care to healthy children (out of scope of this study) cannot be identified separately from informal care to persons with health or old age problems. In addition, the variation in LFS was very low: from 34% in several countries (Croatia, Denmark, Greece, Lithuania, Portugal, Romania and Slovenia), to 38% in the Netherlands and the UK. Since the LFS is one of the most representative surveys, this suggests that the point-in-time rate must be lower than 36% at the EU level (excluding UK). The percentages of the LFS ad hoc module (40%) and the ESS (34%) are similar. So the next questions that arise, are how well informal care to healthy children is excluded in those two surveys and what is the impact of including informal care to healthy children on the point-in-time rate.

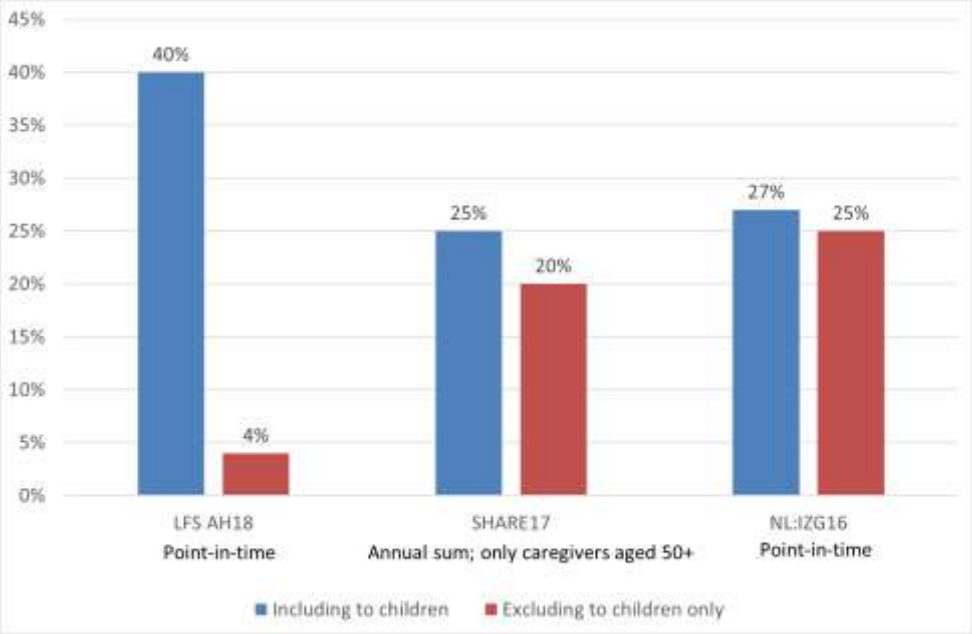
The LFS ad hoc module (respondents aged 18-64) asks about care provision to relatives including elderly people in general and children aged 15 and over who are ill or have a disability. However, the LFS ad hoc module question has six checkboxes about care for children.[50] Based on experience from pilot testing surveys, respondents form their own opinions about what is asked and in addition check one of the top boxes if the question is long. Therefore, it is conceivable that respondents interpreted the question incorrectly to include care provided to healthy children. That the percentage of informal carer is even higher for the LFS ad hoc module may be explained by the explicit inclusion of family outside the household in the ad hoc module, as opposed to the regular LFS.

None of the studies in our literature overview (Annex B) used the LFS ad hoc module. In the LFS ad hoc module, the estimated proportion of informal carers in the adult population drops sharply if persons who solely provided informal care to children are excluded, namely from 40% to 4% (Figure 5). This is another indication that the question was understood by most respondents to refer to care provided to healthy children instead of to people with problems due to health or old age.

It is possible with only three of the databases considered for this study to exclude informal carers who provide care exclusively to children (LFS ad hoc module, SHARE, the Dutch IZG. In the SHARE and the Dutch IZG the impact of inclusion of persons who provide informal care to exclusively children (or grandchildren) in general is limited: two percent points based on IZG and five percent points based on SHARE. This makes it likely that respondents only provided care to children with health problems (in accordance with the question). In the LFS ad hoc module, the impact of the exclusion of care to children is huge and indicates that the proportion of informal carers of 40% is caused by the inclusion of informal care to healthy children.

[50] Out of a total of nine checkboxes: 1. No care responsibilities, 2. Only for own children in the household, 3. Only for own children outside the household, 4. For own children in- and out the household, 5. Only for incapacitated relatives 6. For own children in the household and incapacitated relatives, 7. For own children outside the household and incapacitated relatives, 8. For own children in and out of the household and incapacitated relatives, 9. Don't know

Figure 5 - Share of informal carers in the adult population, incl. and excl. care to children only



Source: LFS ad hoc module (2018), SHARE (2017), IZG (2016); *informal care provided at least once per month*. *SHARE: see further footnotes to Figure 4.*

ESS survey

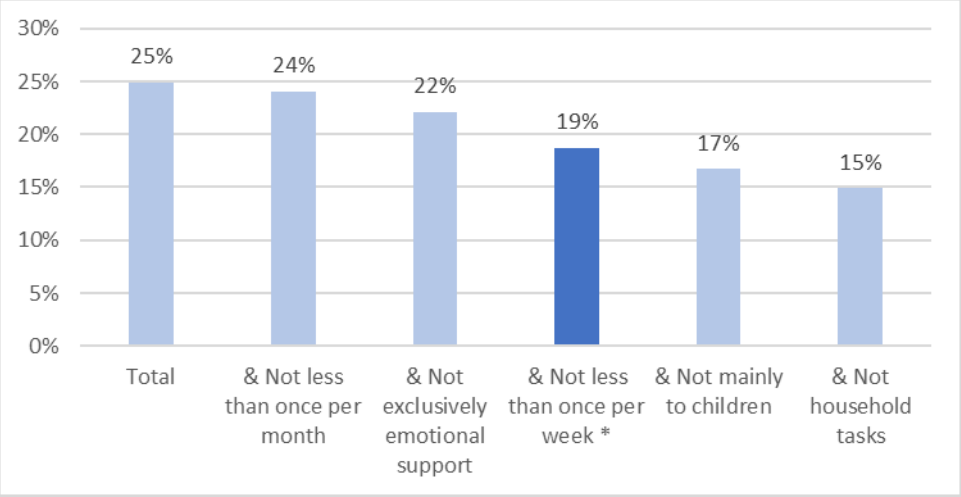
The ESS (respondents aged 15+, no upper limit but for this study only those aged 18+ were selected) asks about providing care for reasons of long-term ill health or disabilities or problems related to old age. The analysis for this study estimated the percentage of informal carers using this database at 34%. The percentage of 30-40% informal carers is confirmed in the literature, see e.g. references #7 and #27-28 in Annex B. In the ESS, respondents can look up explanatory information about a question in so-called cards. The question about provision of informal care does not include any description of what informal care means – only the card specifies that care should be related to health problems or old age. Because the question about informal care was at the very end of the survey, it is also conceivable for the ESS that respondents incorrectly included care provided to healthy children. The fact that the proportion of informal carers according to the ESS (34%) is similar to that according to the regular LFS (36%) which certainly includes informal care to healthy children, is another indicator. Therefore, this study is not considered further in this study.

IZG survey

The next-highest estimated proportion of informal carers (Figure 4) is 25% point-in-time rate of the Dutch IZG survey (respondents aged 16+, no upper limit but for this study only those aged 18+ were selected) if only care lasting at least 3 months is included. The Dutch IZG survey is representative for the total population. Although it is exclusively about care activities as respectively informal care provider or voluntary worker (both separately identifiable), it is introduced as a survey about “help and voluntary work”. This makes it less likely that respondents refuse to participate rather than answering “no” to the first question

about informal care[51]) and then getting routed out. A possible reason for the relatively high proportion of informal carers is that it includes help in the form of "keeping company" and "odd jobs". Because "emotional support" is out of scope of this study (and not included as a category of informal care in some other surveys) and because IZG explicitly includes occasional help (less than once in a month) which does not meet the criterion of at least 3 consecutive months of informal care, the next step is to exclude people who solely provide care in the form of "keeping company" or "odd jobs". Some of the informal care providers who provide care for longer than 3 months do so rarely, i.e. less than once per month. Excluding these persons reduces the proportion of informal carers by one percent point. Further excluding informal care providers who exclusively provide emotional support further reduces the point-in-time rate to 22%. Two other data sources on informal care provision, EQLS and EHIS, only include informal care that is provided at least once per week. Further excluding informal carers who provide informal care less than once per week in line with EQLS and EHIS reduces the point-in-time rate to 19%. According to IZG, some informal carers provide the main informal care to a child or provide informal care exclusively in the form of help with household tasks, but not enough to cast doubt that the informal care question is misunderstood to include care to healthy children or "regular" household tasks that are also done if no-one has health or old age problems (Figure 6).

Figure 6 - Impact of definitions on the percentage of informal carers (IZG)

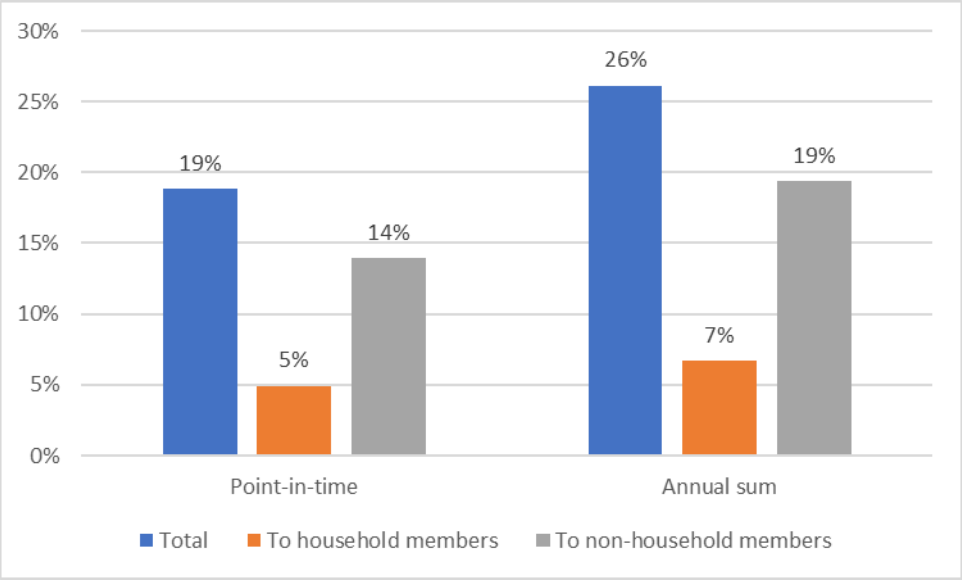


Source: IZG (2016), ** This is the definition in line with EQLS and EHIS (dark blue bar).*

The IZG survey is the only one that asks both about the provision of informal care at the moment of the interview and about the provision in the past twelve months. A comparison between the two indicates a difference of seven percent points between the two definitions. The survey in addition asks questions about the person to whom informal care is mainly given, including whether to another person in the household or to a person outside the household. The majority of informal care is provided to persons outside the household (Figure 7).

[51] The first questions are actually about gender, age and marital status; followed by "Before we start with questions about help and voluntary work, we would like to ask some general questions".

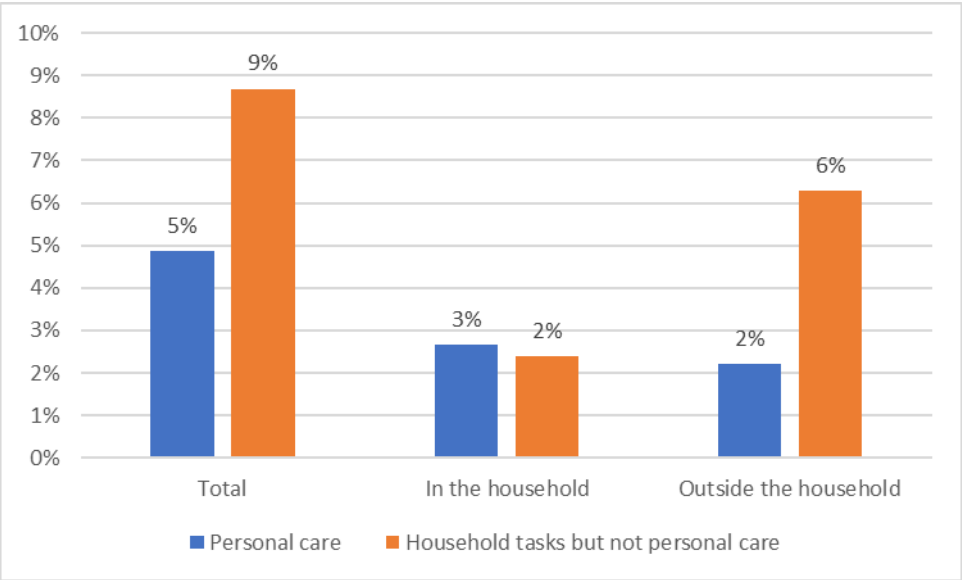
Figure 7 - % informal carers by household relation, point-in-time & annual sum (IZG)



Source: IZG (2016). Definition: excluding emotional support only, help provided at least once per week

An interesting aspect of the IZG data is that it allows examining the type of informal care activities provided to others in and outside the household. It shows that informal carers provide personal care in similar proportions to others in the household (3%) and outside the household (2%). However, help in the form of domestic tasks without personal care is given much more often to people outside the household (6%) than to people in the household. A potential explanation is that most people do not consider doing household tasks in the own home as informal care.

Figure 8 - % informal carers by care activity to others in and outside the household (IZG)



Source: IZG (2016, point-in-time). Excluding emotional support only, informal care provided at least weekly.

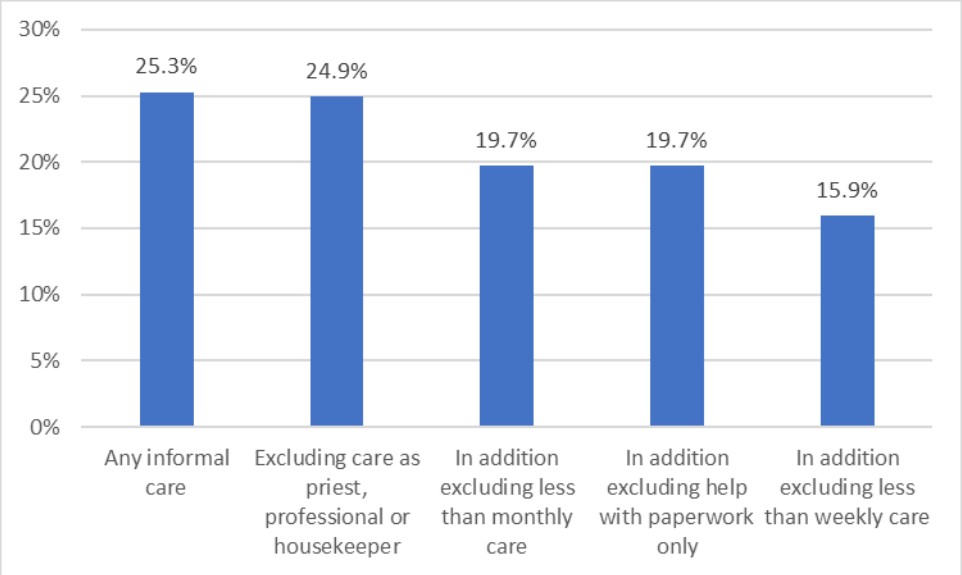
SHARE survey

The SHARE data covers only persons aged 50-70 years old, and is often used in studies on informal care. The obvious limitation of the SHARE data is that it does not include

information about informal carers younger than 50, except indirectly in the sense that people aged 50-70 may report they receive care from their daughter or son. The SHARE data allows many breakdowns, and estimates of the relevant proportion of the population aged 50-70 providing informal care range from 5% to 50% based on different sub-populations and definitions.[52] However, not all reviewed studies use a definition of informal care that is similar to the one in this study and none specifically exclude less than monthly care.

In the SHARE data, almost no reported informal care was provided as a priest, professional or housekeeper (in which cases the care is actually provided as formal care). However, part of informal care was less often than once a month. As explained below Table 3 in Section 2.1, care that is provided less often than once per month is not likely to have lasted three consecutive months and is thus unlikely to be long-term. Very infrequent care is excluded because it so unlikely meets the three consecutive months criterion of long-term informal care. Lastly, almost no informal care was only in the form of help with paperwork (strictly speaking not included in the definition of informal care). This made the proportion of informal carers aged 50+ drop from 25.3% at the EU-level to subsequently 24.9%, 19.7% and 19.7%, respectively. Further excluding people who provide informal care monthly but less than weekly (in line with EHIS and EQLS) would cause the proportion of informal carers to drop to 16%.[53]

Figure 9 – SHARE % of informal carers aged 50+ under various assumptions



Source: SHARE (2017).

The drops in the incidence rate after excluding informal care provided less than monthly (from 24.9% to 19.7%) or in addition care provided less than weekly (from 19.7% to 15.9%) indicate that a substantial part of informal carers provide infrequent care. Indeed, according to SHARE, 28% of the informal care providers aged 50+ provide care less than monthly and 22% in addition less than weekly; only 20% provide informal care on a daily basis (and the

[52] Uccheddu et al. (2019, #24 in Annex B): 5% of the people aged 50-70 provide help with personal care for a spouse or partner within the same household; Heger (2017, #12 in Annex B): 51% of the women aged 50-70 with a living parent provide informal care to a parent.

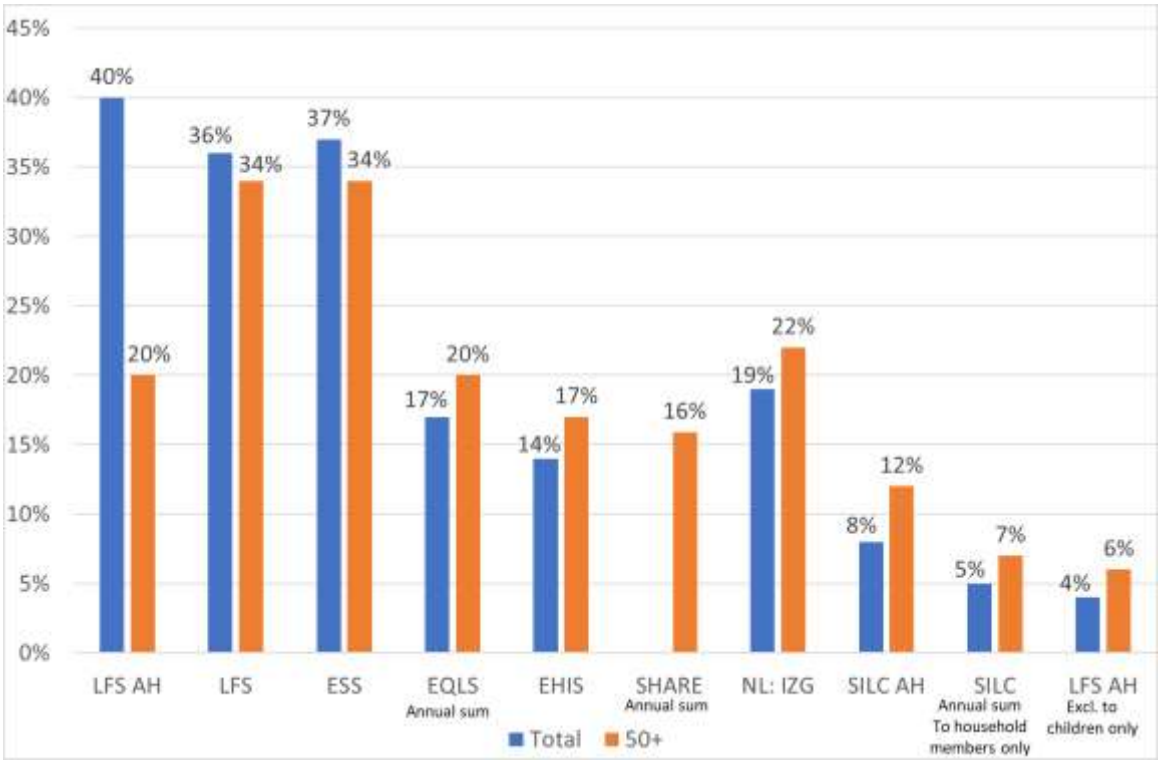
[53] SHARE asks people who provide informal care to multiple persons outside the household for each of them how often the care is provided. A person who provides informal care less than monthly to all of them is classified as providing informal care less than monthly. Informal care provided less than weekly is defined similarly. Note that SHARE only asks about informal care to household members if it was (a) personal care and (b) provided daily or almost daily (for at least three months).

remaining 30% provide care weekly but not daily). Surprisingly, the percentages are almost the same for people aged 50+ receiving care from others outside the household[54]: 28% less than monthly, 22% in addition less than weekly, 20% daily and 30% weekly but not daily.

According to SHARE, nearly four in five informal carers provide help to people outside the household (19% of all people aged 50+) and two in five informal carers provide help to household members (10% of all people aged 50+), implying that 4% of all people aged 50+ provide informal care to both people in and out of the household.

The EHIS survey only asks about informal care provided at least weekly, and in EQLS the intensity of informal care is only asked for weekly informal care. For comparison with EHIS and EQLS it therefore makes sense to limit informal care in SHARE also to at least once per week (instead of at least once per month). In that case, the annual sum of informal care drops from 25% to 16%. At the same time, it makes sense to select people aged 50+ to compare these results with SHARE. According to most databases where a split by age of the care provider is possible, the proportion of informal carers among persons aged 50-70 is 2 to 4 percent points higher than in the total adult population (Figure 10). The only two exceptions are the LFS ad hoc module and the regular LFS, which includes care to healthy children. This suggests that the SHARE proportion of people providing informal care every week of 16% among persons aged 50 and older is equivalent to a rate of 12-14% in the total adult population.

Figure 10 - % of informal carers, total adult population and population aged 50+



Source: ESS (2014), LFS (2018), IZG (2016), EQLS (2016), EHIS (2013-2015), SHARE (2017), SILC ad hoc module 2016, SILC longitudinal (2010-2017). *Informal care provided at least weekly (EQLS, EHIS, SHARE, IZG) or undefined other than regularly (LFS, ESS, SILC). SHARE: see further footnote to Figure 4.*

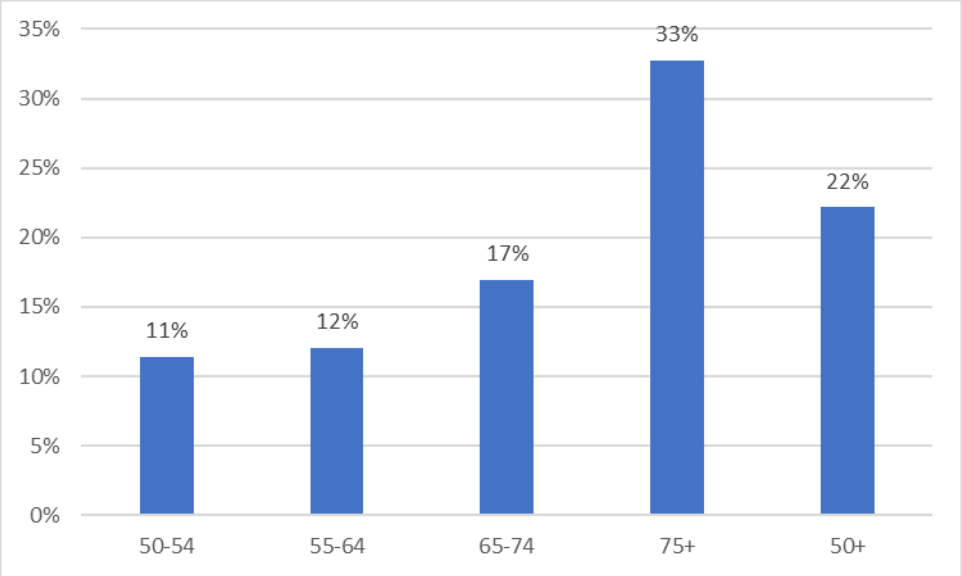
However, the help given could include weekly cleaning the house of a healthy adult child. Excluding people who do not provide help to any other family, friends or neighbours but who provide help to children or grandchildren only, and only in the form of help with household tasks or paperwork, the proportion of informal carers in the age 50+ population

[54] SHARE does not ask about the frequency of informal care received from household members.

drops to 21.4%.[55] Keeping in mind that people above the age 50 are on average 2-4 percent points more likely to provide informal care than younger adults, the more refined definition of informal carers would correspond with a proportion of informal carers of 17-19% in the total population.

According to EHIS and EU-SILC, the need of care increases with age. The SHARE survey certainly confirms this for people aged 50 or older (Figure 11). A limitation of the SHARE survey is that it only asks about care received from people outside the household. This percentage is 23% according to SHARE which is higher than the 19% of the people aged 50+ who provide informal care to others outside the household. A major explanation is that informal care receivers get help from more than one person; on average informal care receivers aged 50+ get help from 1.4 informal carers outside the household. The percentage of people aged 50+ receiving informal care is also higher than according to other sources discussed further below. What SHARE and other sources discussed below have in common, is the spike in the percentage receiving informal are beyond the age of 75.

Figure 11 - % of the population aged 50+ receiving informal care from others outside the household (SHARE survey)



Source: SHARE survey (2017), annual sum estimate. Informal care received at least weekly.

EQLS survey

As noted in Figure 4 above, 17% of the adults provide informal care based on EQLS data (respondents aged 18+).[56] This differs from the figure of 12% in Eurofound[57] which is also based on the EQLS. The cause of this difference is that the Eurofound study limited informal

[55] When any help to children (including personal care) is excluded, the proportion of informal carers drops further to 19.7%.

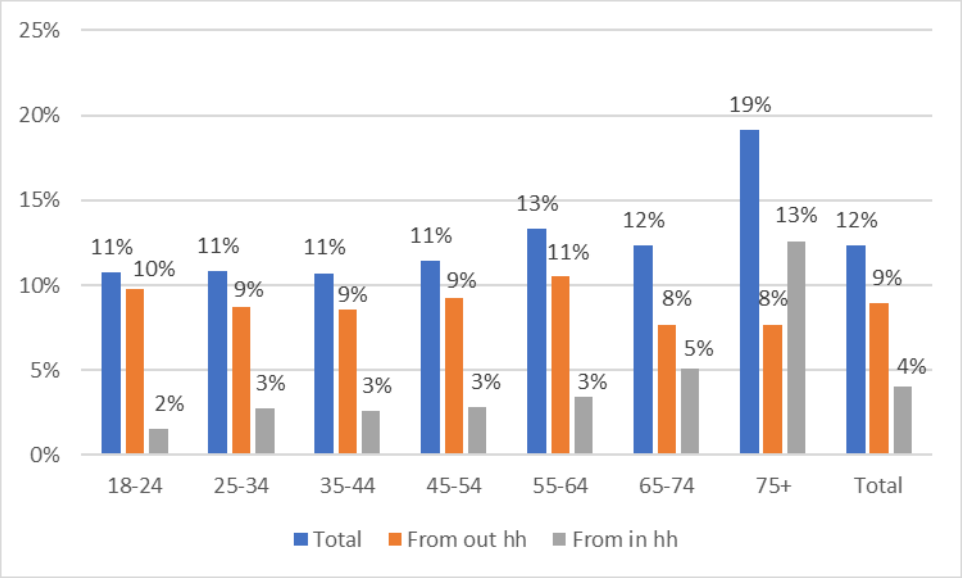
[56] Informal care is only included if weekly hours are reported. The percentage of informal care with unknown hours is neglible in SHARE (0.2%) and limited in EHIS (2.2%) but not in EQLS (13%): including care of unknown hours the proportion of informal carers would be 19.5% instead of 17%. Informal care of unknown hours is excluded under the assumption that informal care in that case is unlikely to be long-term: if it were long-term then people should be able to estimate average weekly hours.

[57] Eurofound (2020), Long-term care workforce: Employment and working conditions https://www.eurofound.europa.eu/publications/customised-report/2020/long-term-care-workforce-employment-and-working-conditions

care to frequent care given more than twice per week whereas in this study informal care also includes care given once per week.

The EQLS is one of the few datasets asking people whether they received informal care .[58.] EQLS asked people if they have received help *at least several times a week* in the past twelve months. At the EU average, this percentage is 12% (Figure 12), which is the same as the percentage providing informal care *more than twice per week*. This percentage does not vary much by age until the age of 75 years. The percentage of the population receiving informal care spikes at 19% in the age group 75+. Interestingly, this spike is entirely caused by a spike in the percentage receiving informal care from household members (13% compared to 5% in the age group 65-74). The percentage of people receiving informal care from others outside the household is between 8 and 11% across all age groups.

Figure 12 - Incidence of receiving informal care by age of care receiver and household relation to care provider (EQLS)



Source: EQLS 2017, annual sum estimate. Informal care provided at least weekly.

The percentages of people receiving informal care from others in and out of the household add up to slightly more than the total percentage of informal care receivers. The reason is that people can receive informal care from more than one other person. According to SHARE data, people aged 50-70 on average receive informal care from 1.4 informal carers[59], and people aged 50-70 on average provide informal care to 1.25 people. According to Dutch administrative data, 132,963 people needing care concluded 158,164 informal care contracts[60] in 2019, on average 1.19 contracts per person receiving informal care.

EHIS survey

The EHIS survey covers people aged 15+ (no upper age limit). An interesting feature of EHIS is that it asks people needing care whether they receive care and specifically whether

[58] The SHARE database is another such database, but it covers only people aged 50-70.

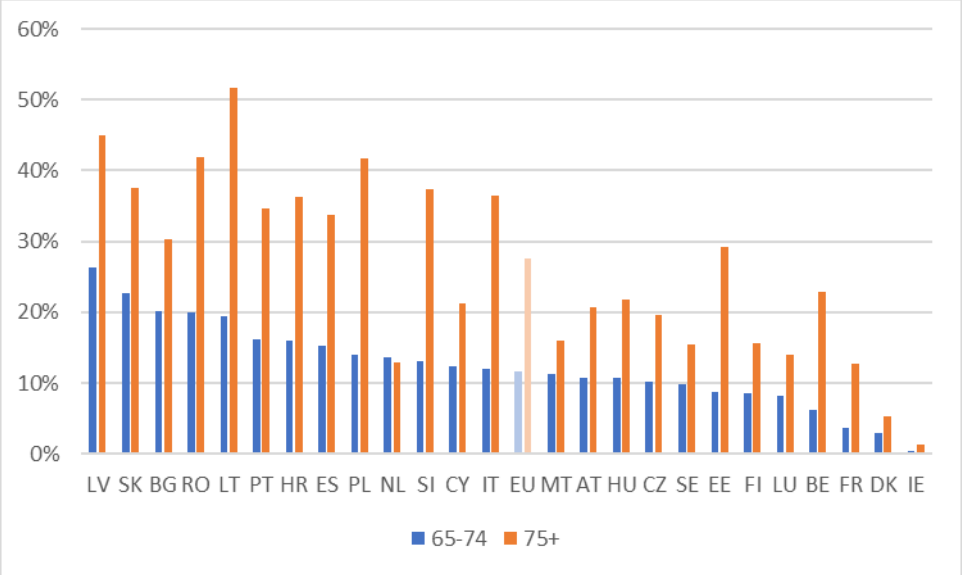
[59] Note that SHARE only asks about help with ADL for people giving/receiving help from another household member. Also, note that informal care inside the household is assumed one-on-one in SHARE.

[60] In the Netherlands, a person in need of care receive a personal care budget, which can be spent on formal care (a professional) or informal care (family, friends, neighbours etc.). In either case, a contract must be concluded.

they receive they receive care from (formal) home care service providers. This implies that if someone received care but not formal home care, then the person must have received solely informal care. Unfortunately, if someone received formal home care, it cannot be deducted whether the person combined it with informal care. Another drawback is that questions about receiving care are only asked to people aged 65+ in EHIS.

Nevertheless, it is an interesting finding that according to EHIS, 20.7 million people aged 65+ receive care, of which 6.0 million receive formal home care, implying that 14.7 million people aged 65+ receive care solely from informal sources, or 18% of the total population aged 65+. Keeping in mind that this 18% excludes informal care combined with formal care, the proportion of older people receiving informal care is much higher according to EHIS than according to EQLS. The reason is that the spike in receiving care at age 75+ in EHIS is much higher at 28% than in EQLS at 19%. Informal care is received most often in the east and south of Europe, according to EHIS (Figure 13).

Figure 13 - Incidence of receiving informal care by country (EHIS)



Source: EHIS (2013-2015), point-in-time estimate. Informal care provided at least weekly (survey limitation).

SILC 2016 ad hoc module

The SILC 2016 ad hoc module covers respondents aged 16+ without upper limit, but only persons aged 18+ are selected for this study. The literature overview of Annex B includes no studies based on the EU-SILC ad hoc module. The point-in-time rate according to the EU-SILC ad hoc module of 2016 of 8% is low compared to the other databases. A potential explanation is that domestic tasks are covered in a different question in the SILC questionnaire, and the question about providing informal care in the ad hoc module does not explicitly include domestic tasks.

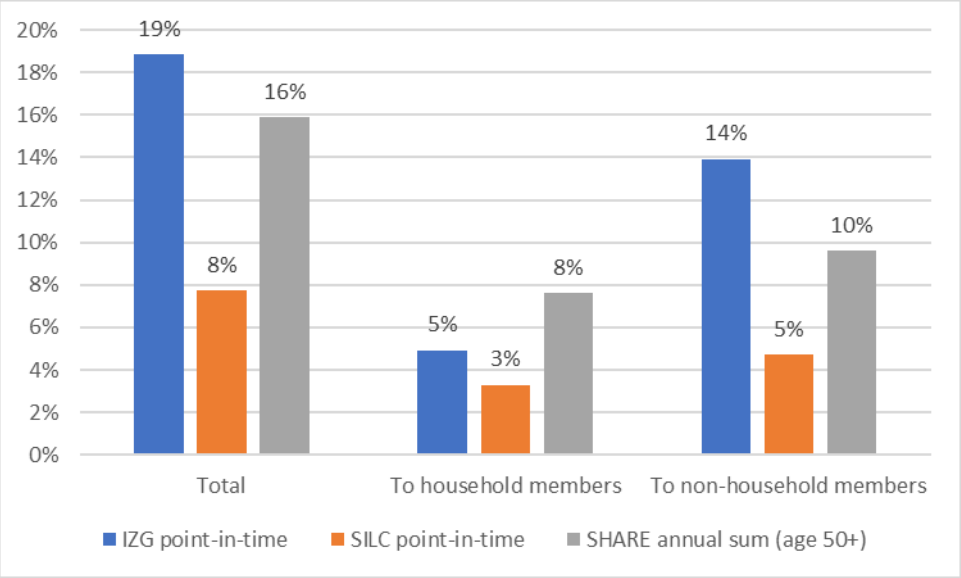
A closer inspection of the relationship with the care receiver and comparing with two other data sources shows that the discrepancy is largest for informal care to people outside the household (Figure 14). According to point-in-time estimates, 3% (SILC ad hoc) to 5% (Dutch IZG survey) of all adults provide informal care to household members, compared to the SHARE annual sum rate of 8% among people aged 50+.[61] However, the 5% of all adults

[61] Given that annual sum rates and informal care provision above age 50 both tend to be a few percent points higher than point-in-time rates and informal care including below age 50, this might explain the higher SHARE rate.

providing informal care to others outside the household according to SILC ad hoc is much less than the rate among either the Dutch IZG survey (14%) or the SHARE data (10%). Indeed, as Figure 8 shows, care provided to others outside the own household is predominantly help with household tasks (Dutch IZG survey).[62]

The above provides support to the hypothesis that the low rate of informal care in the SILC ad hoc module can be attributed to underreporting of help with household tasks (because another SILC question is already about that), because this underreporting should affect specifically help to others outside the household, as is indeed the case.

Figure 14 - Impact of care to only household members on proportion of informal carers



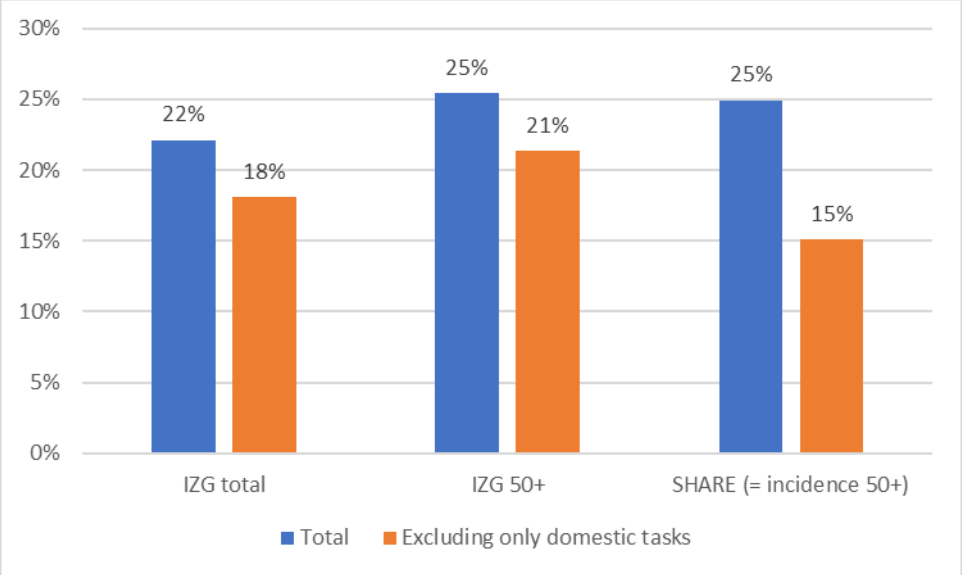
Source: IZG (2016), SILC ad hoc module 2016, SHARE (2017). *Informal care provided at least weekly.*

Excluding informal care in the form of exclusively domestic tasks, the point-in-time rate drops by 4 percent points in the Dutch IZG data and by 10 percent points in the SHARE data (Figure 15)[63]. Thus, the SILC ad hoc module could underestimate the proportion of informal carers by 4 to 10 percent points due to not explicitly including domestic tasks (household help) in the question about informal care.

[62] SHARE only asks about help with household tasks to others outside the household (it does not ask about help with household tasks to household members) so in SHARE all help with household tasks is to others outside the household.

[63] This 10%-point decrease is entirely due to domestic care for people outside the household, since SHARE does not ask after types of care given to members in the household.

Figure 15 - Impact of excluding exclusively domestic tasks on estimated share of informal carers



Source: IZG (2016), SHARE (2017). *Informal care provided at least weekly.*

Regular EU-SILC

Lastly, regular EU-SILC only allows to indirectly approximate informal care to household members by assuming informal care is given if a household member has strong limitations in daily activities due to health problems (and the person is not employed or employed at most 16 hours per week).The assumptions and the validations are discussed in further detail in the methodology box of Section 4.2. As can be seen from Figure 4, the annual sum rate under these assumptions is 9%. To compare this with other data, data sources are needed that distinguish between informal care to members in the household and others, namely the Dutch IZG survey, the SILC ad hoc module and the SHARE data allow a split by informal care provided to members in the household and others. The point-in-time rate of informal care provided to household members is 3% (SILC ad hoc) to 5% (IZG). Given that the annual sum rate is likely a few percent points greater than the point-in-time rate the approximation of informal care with the regular EU-SILC is not inconsistent with the SILC ad hoc module and the Dutch IZG survey. The SHARE data annual rate is 8%.[64] It should be noted that care to household members in the SHARE data is limited to personal care, so informal care exclusively in the form of help with household tasks to other household members is not even included in this 8%. On the other hand, the SHARE data only has reliable data on the population aged 50+. Because two thirds of informal care is provided to people aged 75+, the likelihood that informal care is provided to a household member (the partner) is higher for older people. Thus the limitation of SHARE data to people aged 50+ may be a source of overestimation of the share of informal care provision to household members in the whole adult population. In short, the 9% approximation using regular (and longitudinal) SILC data is arguably in line with the 8% according to SHARE. Still, the approximation with regular SILC data only approximates informal care to household members. It is therefore not used to estimate the incidence of informal care as defined in this study, but it is still useful to assess impacts of informal care over time, as long as one keeps in mind that the impacts of informal care to household members may overestimate the impacts of informal care in general, as explained in the methodology box of Section 4.2.

[64] De Zwart et al. (2017) report a percentage of 4% for earlier waves of the SHARE data, see [6] in Annex B but Kaschowitz and Brand (2017) report percentages varying from 5% for Sweden to 14% for Spain and Italy using SHARE data, see [16] in Annex B.

Semi-harmonized incidence rates

To compare incidence rates from different data sources, the underlying definitions should be as similar as possible. The following choices were made to maximize the number of comparable data sources:

- Point-in-time rate (then the most databases are comparable).
- Including informal care to children with long-term health problems or disabilities (cannot be excluded from most databases).
- Including domestic tasks as the best approximation of help with instrumental activities of daily living (IADL such as household help).

The frequency of informal care is difficult to harmonize. Ideally, care less frequently than monthly is excluded. Unfortunately, this is not possible with EHIS (which only covers care that is provided at least once per week)[65] and EQLS (which has a category "less than weekly" but not a category "less than monthly")[66]. To assess the impact of data limitations on frequency, detailed frequency data of the Dutch IZG survey were analysed. According to IZG, of informal care 30% is provided daily, 53% weekly, 15% monthly and 2% less than monthly. Excluding informal care less than once per week to bring the definition in line with EHIS and EQLS drops the IZG point-in-time rate from 21% to 19%. Hence, a rough estimate of 2 percent point of the incidence of informal care according to the definition of this study is missing from EHIS and EQLS data.

For IZG, it should be noted that in most databases the point-in-time rate of informal care in the Netherlands is a 2 to 4 percent points higher than the EU average. To make the IZG incidence more comparable with EU-level incidence rates, 3 percent points were subtracted from 19% with a 16% equivalent rate as a result.

According to the SILC 2016 ad hoc module, 8% of the population provided informal care. However, one reason to suspect that this underestimates informal care is that the question in the SILC 2016 ad hoc module could be interpreted as including only personal care[67] and in addition other questions are about the main activity including "domestic tasks and care responsibilities". The percentage of people providing informal care solely in the form of help with household tasks is 4% of all adults in the Netherlands according to the Dutch IZG data, and is 10% of all adults aged 50+ according to SHARE data. Adding 4 percent points (IZG) or 10 percent points (SHARE) to the 8% of the SILC ad hoc module estimate gives a range of 12-18%. Note that the regular SILC estimate is not included in Figure 12 because the informal care approximation only approximates informal care to household members.

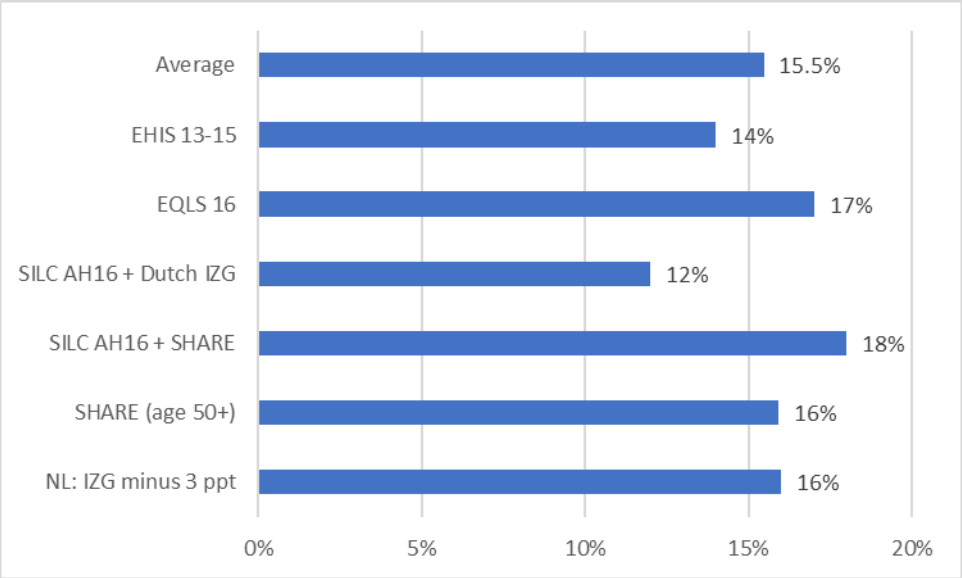
[65] The EHIS question was "Do you provide care or assistance to one or more persons suffering from some age problem, chronic health condition or infirmity, at least once a week?"

[66] The EQLS question was "*In general, how often are you involved in any of the following activities outside of paid work?*" with answer categories 1 = Every day, 2 = Several days a week, 3 = Once or twice a week and 4 = Less often for Q43d = Caring for disabled or infirm family members, neighbours or friends under 75 years old and Q43e = Caring for disabled or infirm family members, neighbours or friends under 75 years old. The annual sum percentage of the population providing informal care is: 17% at least once a week (12 ppt. to people under age 75, 12 ppt. to people over age 75) and 30% including less often than once a week (22 ppt. to people under age 75, 21 ppt to people over age 75). EQLS only asks about hours of week of informal care provision if the person provides care at least once a week.

[67] Each national statistical office develops its own questionnaire in the home language, but the suggested question about informal care provision is "Do you provide care or assistance to one or more persons needing help due to long-term physical or mental health illness, infirmity or because of old-age? *Only unpaid activities / informal services should be taken into account*."

For SHARE (people aged 50+), the analysis is more complicated. It only asks about how often informal care is provided to people outside the household; SHARE only includes informal care to others in the same household if it was provided daily or almost daily (survey definition). According to SHARE, 20% of all informal care to others outside the household is provided daily, 30% weekly, 22% monthly and 28% less often. Assuming that informal care to others in the same household is provided at least weekly, the SHARE percentage of people older than 50 years providing informal care drops from 25% (any informal care) to 16% (weekly informal care).

Figure 16 - Semi-harmonized estimates of point-in-time shares of people who provide informal care at least once per week, at the EU level



Note: for SILC and UK USS it is not possible to exclude people who provide informal care less than once per week. Source: EHIS (2013-2015), SILC ad hoc module (2016), EQLS (2016), IZG (2016).

Overall, the estimated point-in-time rate of informal care that is provided at least once per week is estimated to range between 12 and 18% (Figure 16). The average of the six estimated point-in-time rates in Figure 16 is 15.5%. The figure of 12% of Eurofound[68] is at the lower bound of this range but it should be noted that the Eurofound definition is limited to informal care that is provided more than twice per week, while this study also includes informal care that is provided only one or two times per week. In the literature where similar definitions are used as in this study, the percentages vary between 10 and 15%. However, it should be noted that lower percentages are mostly in earlier studies, and two related studies showed an increasing trend in informal care provision in Germany over time.[69]

3.3. Choice between data sources

Given the fact that all data sources have limitations to estimate the incidence of informal care according to the definition of this study, it makes sense to choose the data sources

[68] Eurofound (2020), Long-term care workforce: Employment and working conditions https://www.eurofound.europa.eu/publications/customised-report/2020/long-term-care-workforce-employment-and-working-conditions

[69] The studies [1], [3], [4], [5], [9], [10], [11], [14], [15], [19] and [20] in Annex B report incidence rates of informal care provisions using similar definitions as in this study. The studies [10] and [11] reported a trend of increasing incidence informal care provision over time in Germany between 2002 and 2011.

with the least limitations, namely the EHIS and EQLS. The following data sources were assessed to have more limitations:

- in SILC help to persons outside the household is underreported compared to all other data, likely because help with household tasks is underreported (because already covered by another question which includes household tasks not relating to informal care).
- SHARE only includes people aged 50+
- The Dutch IZG includes only one country
- LFS and ESS do not sufficiently clearly exclude care to healthy children

In both the EQLS and the EHIS, the reference population is the whole adult population according to Eurostat, with this difference that adults are defined as 18+ in EQLS and 15+ in EHIS; and the EQLS (2016) and EHIS (2013-2015) took place in slightly different years. For this study, the Eurostat population aged 18+ in 2015 was used, with a total of 362 million people in the EU excluding UK. Averaging between EQLS and EHIS, the population of informal carers is estimated at 52.0 million, or 14.4% of the population of 362 million adults.

It was also noted that the number of informal carers dropped sharply past the age of 75 years. Including people aged 18-74 years only, the number of informal carers drops slightly to 48.3 million, and the population drops slightly more to 321 million. Hence, among people aged 18-74 the proportion of informal carers according to the EQLS-EHIS average is slightly higher (15.0%).

Incidence of informal care provision by country

As discussed above, the two EU-level databases suited to the purpose of this study are the EQLS (2016) and EHIS (between 2013 and 2015) – the bullet list just above explains the drawbacks of other data sets. About 15% of the adult EU population excluding UK provided informal care (EQLS annual sum: 17.1% of those aged 18-74 provide informal care at least once a week and EHIS point-in-time: 14.3% of those aged 16+ excluding France, Germany, Slovakia provided informal care at least once a week). Dividing the number of informal carers by the population aged 18-74 (very few informal carers are older than 75 years) slightly increases the EHIS percentages.

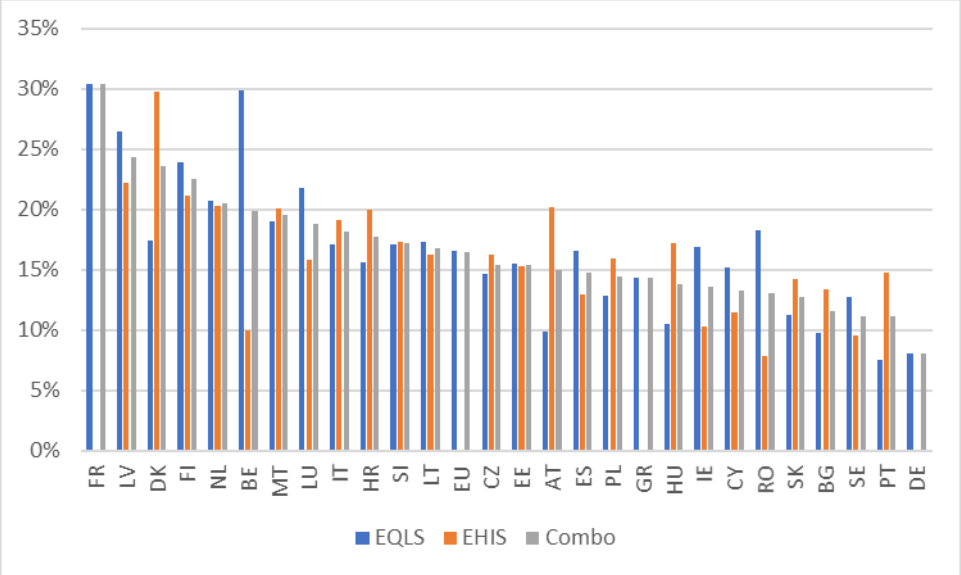
Informal care is clearly provided above the EU average according to both databases in Finland, Latvia, the Netherlands and Malta (Figure 17). The incidence rate is also above the EU average in Belgium and France according to EQLS. The incidence rate is clearly below the EU average in Sweden, Bulgaria and Slovakia, and in Portugal and Germany according to EQLS. Large discrepancies of 10 percent points or more between the two datasets exist for Belgium (-20 ppt), Denmark (+12 ppt) and Romania (-10 ppt). The selected intensity (weekly in both EQLS and EHIS) and cause of care (problems due to health or old age in both EQLS and EHIS) cannot explain the differences. Differences in the fielding method (EQLS is web-based and EHIS is mixed web/phone depending on national customs) are unlikely to explain differences between Belgium and Denmark.

To explain the differences, it is good to keep in mind that informal care provision is a subjective concept that is based on other subjective concepts such as health status of the care recipients, which activities to include in the care concept, and how to deal with temporary care. Thus, small differences in the questionnaires can lead to different

responses. After harmonization of frequency (at least weekly and leaving out care of unknown hours), the main difference in definition between EQLS and EHIS is that EQLS rates are annual sums[70] and EHIS rates are point-in-time estimates[71]. So it is conceivable that in Belgium and Romania informal care is more often given for shorter periods so that people in those countries may report informal care even though they stopped doing it.

In order to reduce the sensitivity of the analysis to the specifics of one single questionnaire, this study averages between the two data sources.

Figure 17 - Percentage of informal carers in the population aged 18-74



Source: EQLS 2016, N = 83 informal carers in PT to 370 in FR and EHIS 2013-2015, N = 532 in CY to 4243 in IE. *Informal care provided at least once per week. No EU average for EHIS because data for Germany and Greece are missing.*

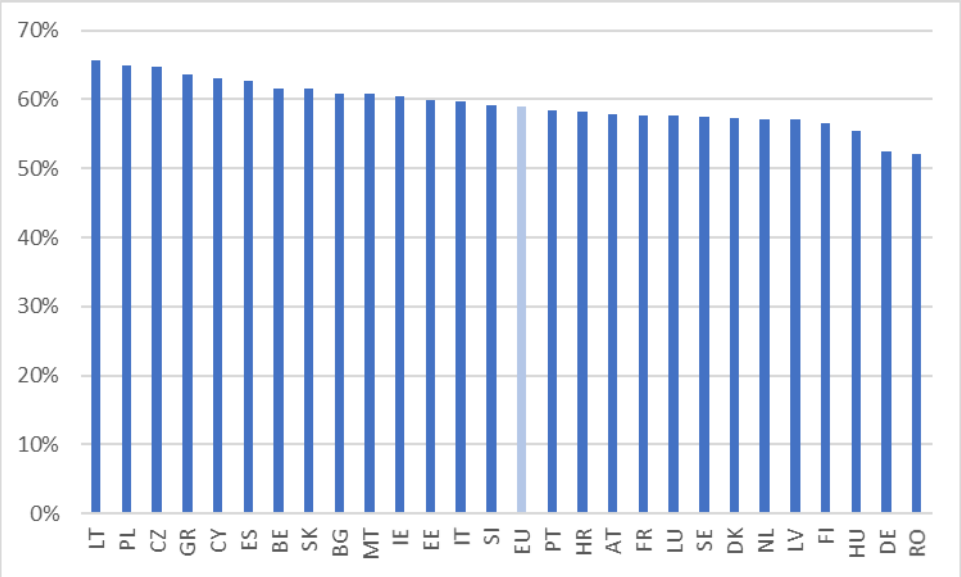
3.4. Gender imbalance of care provision

A majority of 59% of the informal carers are women, based on combined EHIS-EQLS data (see methodology box below). Women are the majority of informal carers in all Member States (Figure 18). The percentage of women is highest in some Member States in the east and south of Europe and lowest in the northwest of Europe, although also in Hungary and Romania. It should be kept in mind that these are the results of a survey, and people may report informal care even if they do not receive a care allowance. It should also be noted that in the EQLS, Germany is the only country where no intense informal care (more than 40 hours per week) are recorded. Because in general women are more likely to provide intense informal care (as discussed in the next chapter), this may cause the percentage of women in that country to be underestimated.

[70] Based on the question "In general, how often are you involved in …"

[71] Based on the question "Do you provide … at least once a week"

Figure 18 – The percentage of women among informal carers by Member State



Source: EHIS (2013-2015) and EQLS (2016).

Combining EHIS and EQLS

EHIS and EQLS are in principle weighted equally. Thus, the share of the population providing informal care is in principle the unweighted average of EHIS and EQLS.

However, when splitting the data by characteristics, there is some non-response to deal with, meaning that some respondents do not answer some questions. In addition, the hours categories of informal care of EHIS and EQLS do not match exactly. Specifically, the hours categories of informal care are 1-6.5, 6.5-22.5, 22.5-41.25, 41.25-70 and 70+ in EQLS and are 0-9, 10-19, 20+ in EHIS.

The numbers of informal carers by categories are calculated in seven steps (after applying the population weights). First, the weighted numbers of informal carers by certain characteristics are extrapolated to the weighted total population for each country and for both databases. For example, not all respondents report in which type of household they live, so the weighted sum of respondents could hypothetically be 20,000 for each of four categories while the total is 100,000. The weighted numbers in this hypothetical situation are then adjusted to 25,000 each so that they add up to the overall total of 100,000.

Second, not everyone reports how many hours they provide informal care. For each characteristic and country and for both databases, the weighted numbers are adjusted to the total. For a hypothetical example, if numbers by the five hours categories of EQLS were originally 4,000 each for a certain type of household with an adjusted total of 25,000 informal carers, the numbers by hours categories are adjusted to 5,000 each so that they add up to the sub-total of 25,000.

Third, the adjusted sub-totals (across all hours categories) of both databases are averaged to calculate combined sub-totals.

Fourth, the EHIS share of people providing care for 1-9 and for 10-19 hours per week is applied to each of the combined sub-totals (the averages of the two databases). Informal care above 20 hours per week is split further by the hours breakdown of informal care

above 22.5 hours per week in EQLS (assuming that 22.5-41.25 is equivalent to 20-40 hours per week).

Fifth, for some countries and small categories, intense care is reported in one database but not in the other. In this case, the hours breakdown of the database with missing numbers is assumed to be the same as for a "close" category, for example 65-74 for men in the age category 75+, or for a category of similar occupations (professionals for managers, craft workers for skilled agricultural workers). In some cases where there is no "close" category such as tertiary education (but this is quite rare), the hours breakdown of the total population of informal carers in that country is used.

Sixth, the adjustment of numbers by hours categories to sub-totals by characteristics ensures that numbers add up to sub-totals for each characteristics, but this does not ensure that for each hours category of informal care, numbers add up across all categories to the total numbers per hours category. Technically, all numbers to the row totals, but they only add up to column totals if the response on a certain question (for example, educational level) was 100%. To ensure that all numbers add up to both hours categories and to characteristics such as gender, age, educational level etcetera, a grid method was applied with nine iterations. In each iteration, numbers are first adjusted to row totals and then to column totals. The five steps described above ensure numbers add up to row totals in the first iteration. The adjustment to column totals is similar as in step 1 described above, but then applied to the combined dataset instead of for both datasets separately. After nine iterations, the adjustment was less than one person for each country, category and hours category of informal care, and all numbers were considered fully corrected for missing reponse to some questions.

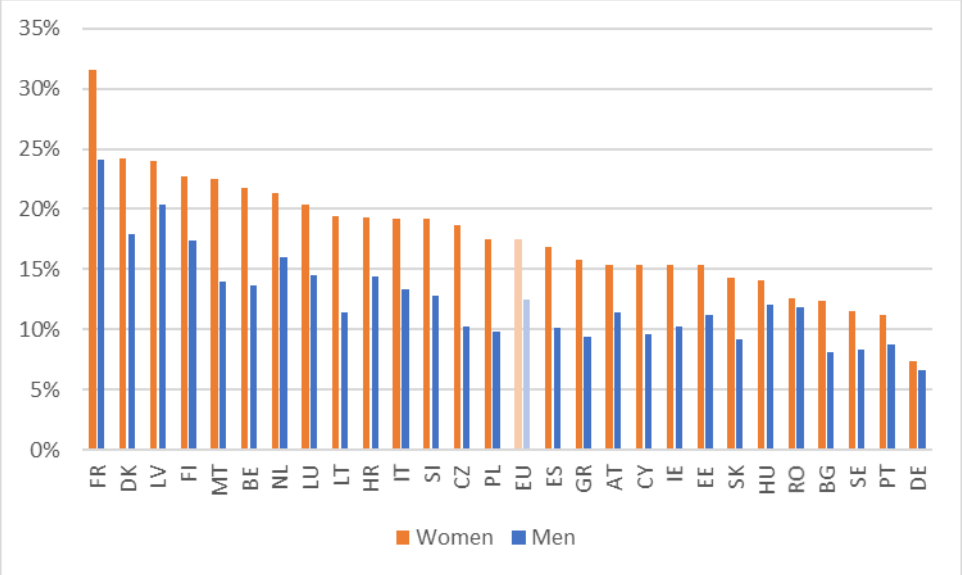
Seventh, EU totals for each characteristic of informal carers and each hours category of informal care were calculated as the sum across all countries.

Since EHIS does not cover France, Germany and Greece, the combination of EHIS and EQLS is actually simply EHIS for these countries.

Whenever the remainder of this study presents combined data with reference to EHIS and EQLS, it refers to the result of the exercise in seven steps described in this box.

The gender imbalance in the provision of informal care is explained by differences in the incidence of informal care. In the age group 18-74 years, 18% of women provide informal care compared to 12% of men. The incidence rates of women are highest in the northwest of the EU although also in Malta, and lowest in the east and south although also in Germany (where intense care is disregarded in the survey) and Sweden (Figure 19).

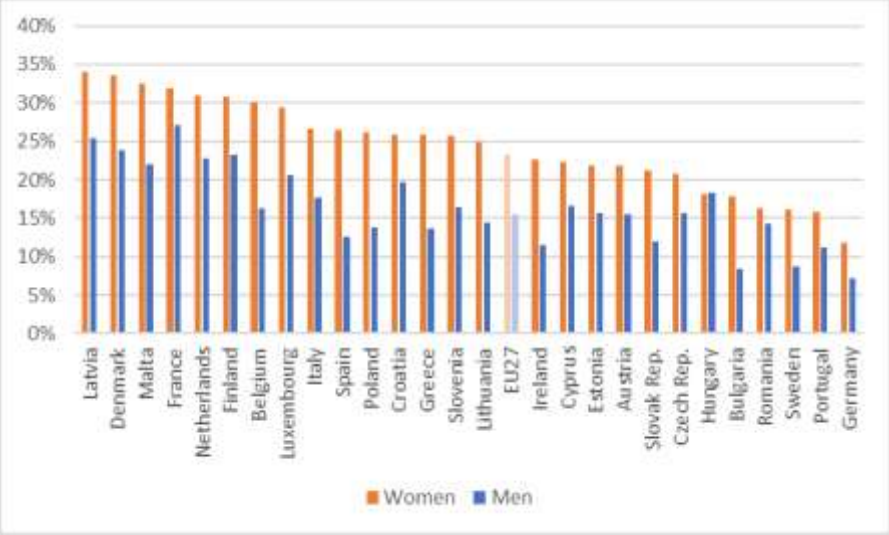
Figure 19 – The share of the population 18-74 providing informal care, by gender



Source: EHIS (2013-2015) and EQLS (2016).

The gender difference is sligthly larger in the age group 45-64 years, where 23% of the women and 15% of the men provide informal care (Figure 20). The percentages vary between 10 and 30% for men and between 20 and 40% for women across EU Member States. The gender difference in the age group 45-64 years is largest in Belgium and Spain (14 percent points, respectively).

Figure 20 - The share of the population 45-64 providing informal care, by gender



Source: EHIS (2013-2015) and EQLS (2016).

3.5. Relation between informal care and formal long-term care

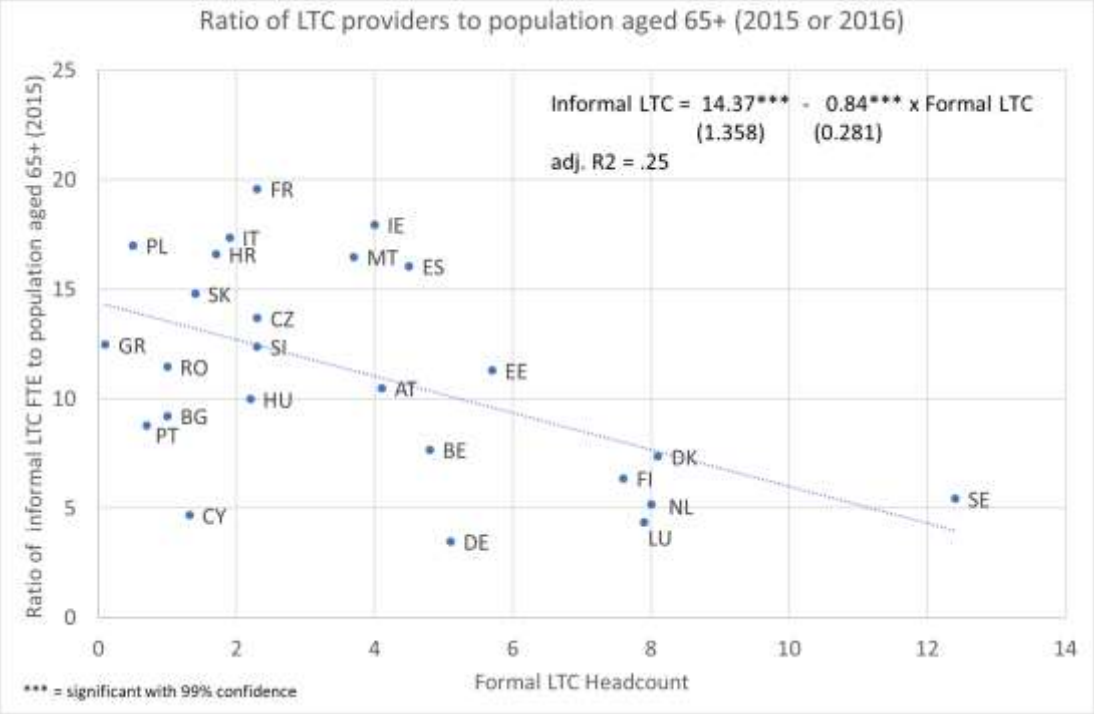
Informal care is more common in countries, where employment in the formal care sector is low. Since most of the informal care is provided less than 10 hours per week, it is important to relate a “full-time equivalent” of informal care with the number of formal care

professionals: in headcounts there is no relationship. However, even in full-time equivalents of informal carers, they represent close to 80% of the care providers.

With the exception of Cyprus, Member States with less than five formal carers per 100 people aged 65+ have more than seven full-time equivalents of informal carers per 100 people aged 65+ (Figure 21)[72]. At the other extreme, all Member States with more than seven formal carers per 100 people aged 65+ have less than eight informal carers per 100 people aged 65+.

This suggests that the incidence and intensity of informal care are negatively correlated with formal care provision[73]. Indeed, as Figure 21 indicates, one additional headcount of formal care is associated with a reduction in the provision of informal care (measured in full-time equivalents) to people aged 65+ by 0.84.

Figure 21 - Relation between prevalence of informal care and formal long-term care



Note: to compare with formal care, informal care is here limited to to recipients aged 65+ based on EQLS.
Source: OECD Health indicators (www.oecd.stat) + LFS (2015, formal care), EHIS 2013-2015 + EQLS 2016 (informal care).

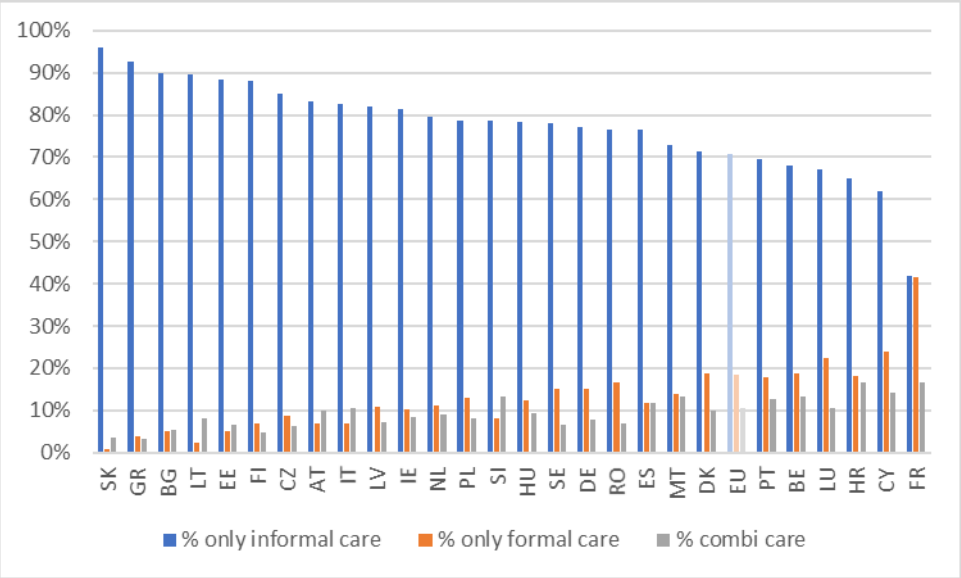
Although a higher incidence of formal care is often combined with a lower incidence of informal care, the two are not mutually exclusive. In the EU, about 70% of people receiving care use solely informal care according to both the EQLS and the EHIS. The EQLS asks separately whether people receive informal care and whether they receive formal care (nursing care, personal care or residential care although the latter is rarely reported). According to EQLS, 19% of the care recipients use solely formal care, and 11% use a combination of both formal and informal care. With EHIS, it is not possible to examine the combination of formal and informal care.

[72] Although formal carers do not always work full-time either, it is more necessary to correct informal care for the intensity of care. Therefore, it makes sense to compare the sum full-time equivalents (FTE) of informal care to people aged 65+ with formal care (also measured in in FTE). Expressed in headcounts, no significant correlation between the numbers of informal and formal carers was found.

[73] In addition to the lack of the offer of formal care provision there might be also other reasons for the use of informal care, such as cultural or financial reasons.

According to the EQLS the percentage of using solely informal care varies from 42% in France and 62% in Cyprus to 96% in Slovakia (Figure 22). The use of solely formal care is correspondingly highest in France (again 42%) and lowest in Slovakia (1%), confirming the negative correlation between formal and informal care. The combined use of formal and informal care is again highest in France (17%) and again lowest in Slovakia (3%) but the differences are much less pronounced.

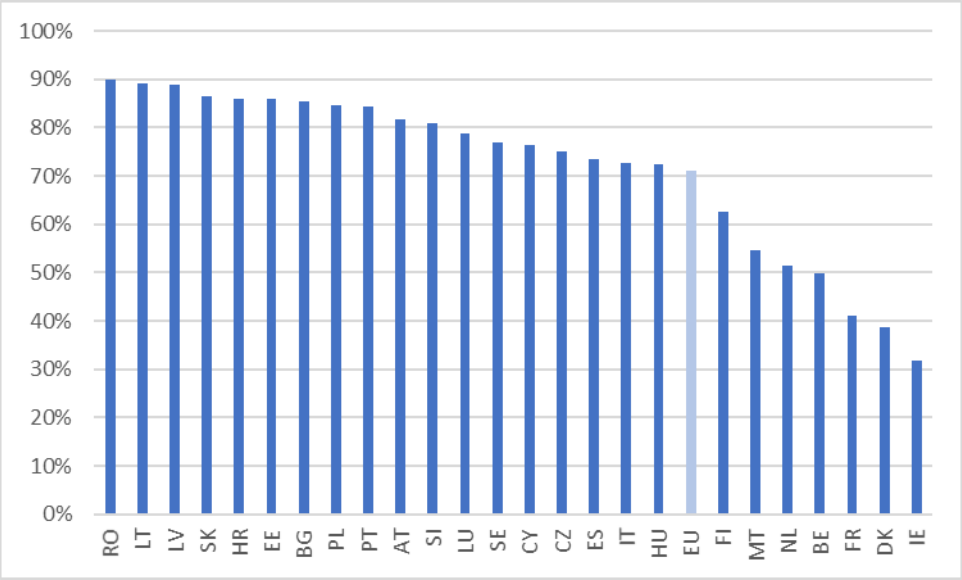
Figure 22 - The use of formal and informal care in the EU - EQLS



Source: EHQLS (2016).

According to EHIS, the use of solely informal care varies from between 30% and 40% in Ireland and Denmark to between 80 and 90% in east European Member States (Figure 23). EHIS asks people whether they received care and whether they received professional home care services. Thus, people who received care but not from professional home care services use solely informal care. Unfortunately, if people report both receiving care and formal care services, it is not possible to assess whether they combined formal and informal care. Interestingly, the use of solely informal care is highest in the east of the EU where generally a lower proportion of the population provides informal care (see previous section). This might seem to contradict a conclusion that provision of informal care is negatively correlated with availability of formal care, however as discussed before, the negative correlation is only found after expressing informal care in full-time equivalents to correct for the fact that particularly in the northwest of the EU low-intensity informal care is predominant.

Figure 23 - The use of solely informal care in the EU - EHIS

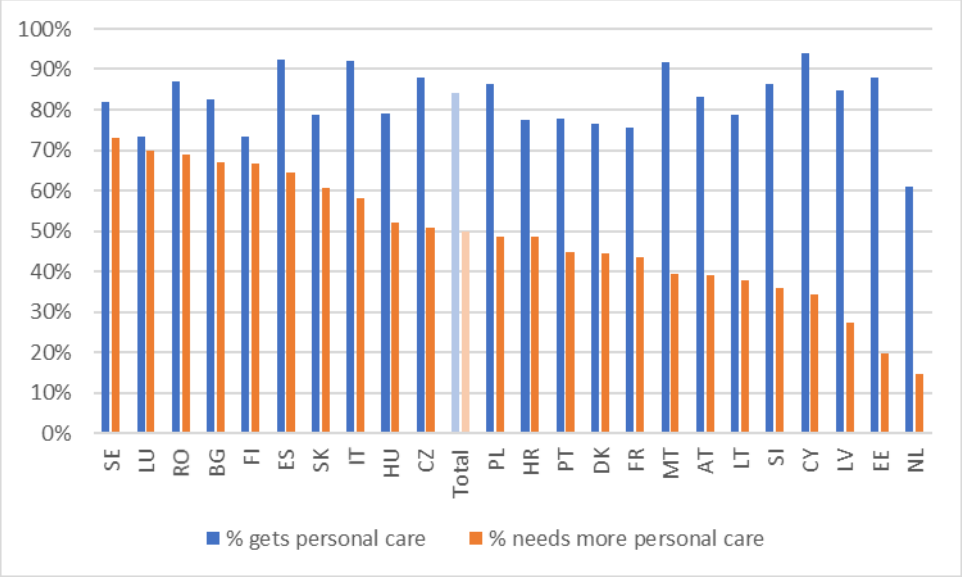


Source: EHIS (2013-2015).

Nevertheless, informal care seems to be the only real alternative for some people due to a lack of availability or affordability of formal long-term care services. According to the EHIS, both waiting lists (+4 percent points) and costs of healthcare (+2 percent points) are slightly more often mentioned by receivers of solely informal care. These differences are not extreme. It should also be noted that according to EHIS, 84% of the people aged 65+ who have a lot of difficulty with activities of daily life (ADL) such as eating or bathing or cannot do those tasks at all receive (formal or informal) personal care. Also, 78% of the people aged 65+ who have a lot of difficulty with instrumental activities of daily life (IADL) such as cooking or shopping or cannot do those tasks at all receive (formal or informal) help with household tasks. This percentage varies from 61% in the Netherlands to 94% in Cyprus for personal care and from 61% in Denmark to 94% in Malta for help with household tasks.[74] This does not necessarily mean that care receivers perceive this help as adequate. Indeed, of those reporting a lot of difficulty or inability to perform daily activities 50% state they need help or more help (Figure 24). For household tasks, this percentage is 44% (Figure 25).

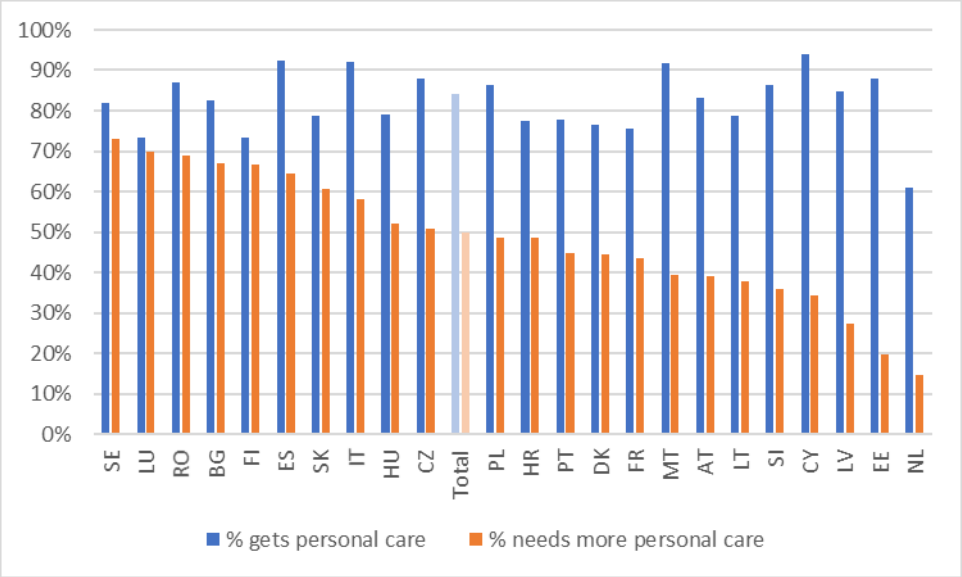
[74] Ireland is excluded from this analysis due to high non-response, also on the web portal of Eurostat

Figure 24 – ADL, strong needs of help: % receiving this help and % needing more help



Source: EHIS (2013-2015). ADL includes activities such as help with household tasks and shopping.

Figure 25 – IADL, strong needs of help: % receiving this help and % needing more help



Source: EHIS (2013-2015). IADL includes personal care activities such as washing and feeding

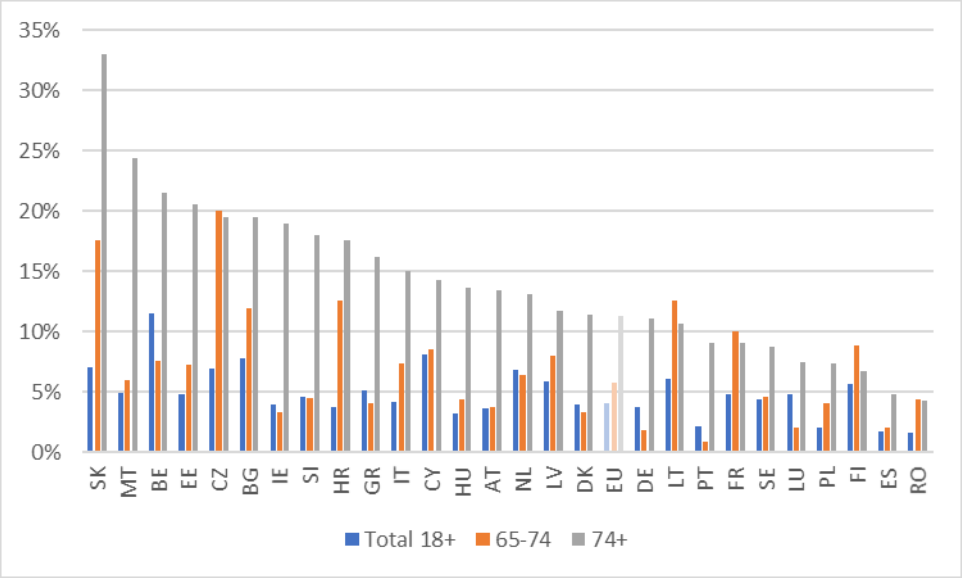
3.6. Share of informal care to older people

Various surveys ask people whether they receive informal care. However, the European Quality of Life (EQLS) survey is unique in asking people about the age of the care recipient. We therefore analyse the EQLS specifically to explore the incidence of informal care to older people. It comes as no surprise that by age of the care recipients, those aged 75 and over are most likely to receive informal care during a year (Figure 26). At the EU level, 11% of the people aged 75+ receive informal care according to the EQLS. This is slightly less

than the percentage of the population aged 18+ providing informal care (17% according to EQLS). This difference is largely explained by the fact that older recipients receive informal care from more than one person (on average 1.4 persons outside the household for care recipients aged 50+ according to SHARE data as noted above Figure 11 above).

The geographical spread of informal care recipience above age 75 is difficult to explain. The incidence rates is high in some east European countries like Slovakia, Estonia, the Czech Republic and Bulgaria, but low in other east European countries like Poland and Romania. Given the high incidence rates of informal care provision, the low incidence rate of care receiving in Spain may seem surprising. One partial explanation is that in Spain, people in need of care are more likely to receive (informal) care than in other countries: 92% in Spain for personal care compared to an EU average of 84% according to EHIS. Another partial explanation is that in Spain informal care provision is shared between more people, 1.5 per care receiver aged 50+ compared to 1.4 at EU average. The high overall percentage of people receiving informal care is partly due to a high percentage of people aged 25-34 receiving informal care (15%), as is also the case in Cyprus (13%) and the Netherlands (11%) – not shown in Figure 26.

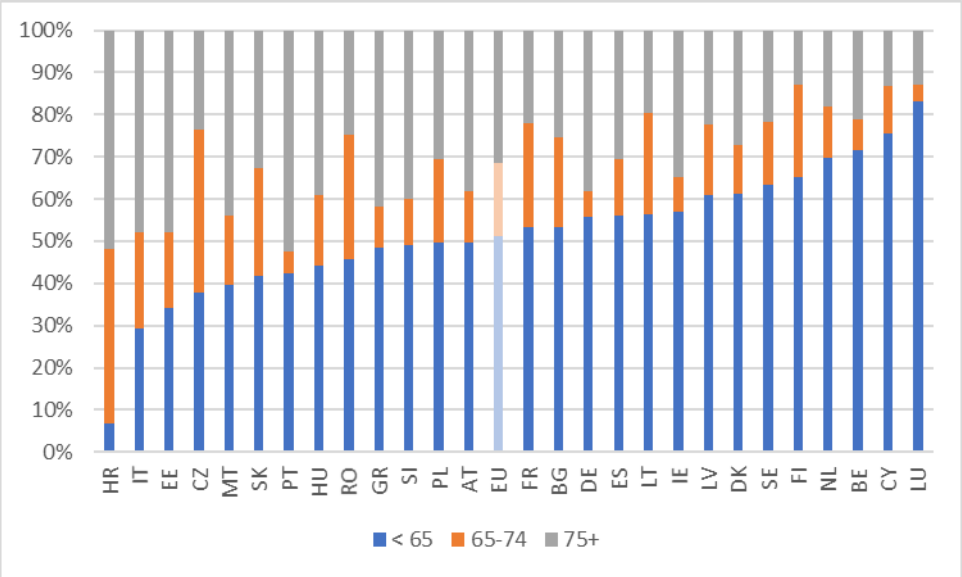
Figure 26 – % of the population receiving informal care by age and country



Source: EQLS (2016).

In the age group 65-74 about 6% of the population receives informal care, which drops to only 2% of the population aged 18-24. The overall incidence rate of care receipt is 4% at the EU level. One implication of the higher incidence of receiving informal care among older people is that their share in informal care recipients is much higher than in the general population: the share of people aged 65+ is 49% among adult informal care recipients compared to 23% among the general adult population. The share of people aged 75+ among adult informal care recipients is still 31%, while their share in the general adult population is only 11%. The oldest populations of informal care receivers are in the east and south of the EU and the youngest populations are in the north and west of the EU.

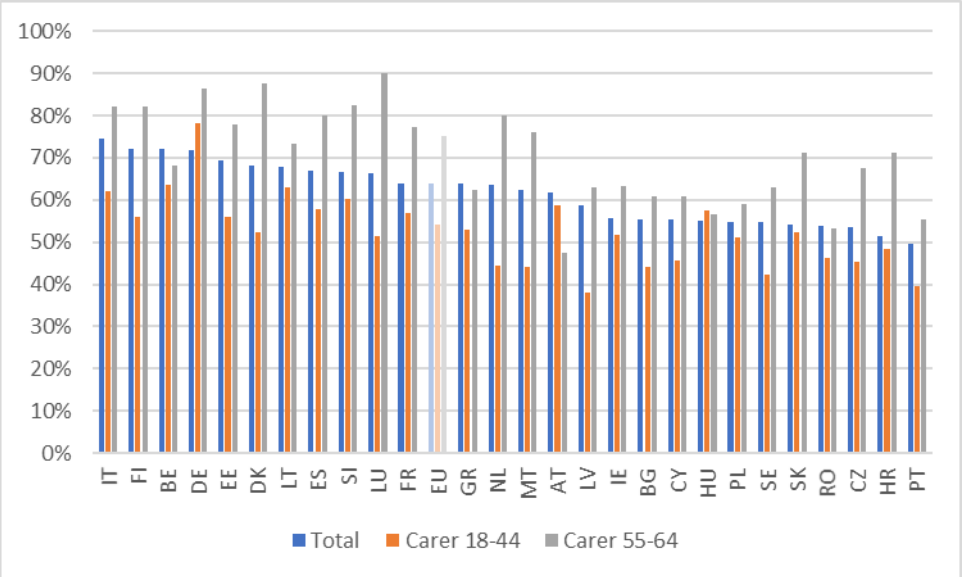
Figure 27 – age breakdown of care recipients



Source: EQLS (2016).

As noted shortly above, only above age 75 the incidence of informal care recipience (11%) comes close to the incidence of informal care provision (17%). This indicates that the majority of informal care is provided to people aged 75+. Indeed, according to the unique EQLS data on this, about two thirds of the people providing informal care, provide help to people aged 75+ (Figure 28). This percentage varies from 49% in Portugal to 75% in Italy. By age group, informal carers aged 18-44 are least likely to provide help to people aged 75+ at the EU level and informal carers aged 55-64 are most likely to provide help to people aged 75+. In all EU Member States, informal carers aged 45-64 are more likely to provide help to people aged 75 and over than informal carers aged 18-44.

Figure 28 – % of informal carers providing help to people aged 75+, by age of the informal carer



Source: EQLS (2016).

3.7. Conclusions

Of the people with strong difficulties in daily tasks such as bathing, feeding and clothing, 80% report they receive (formal or informal) care and 50% report they need more care. The adults receiving informal care constitute 4% of the total adult population. Of the population aged 65+, 8% (7.1 million people) receives informal care and among the population aged 75+ even 11% (4.6 million people) receives informal care. The recipience of informal care increases with age, starting from 2% of the population aged 18-24 up to 11% of the population aged 75+. As a result, half of the adult population receiving informal care is aged 65+. The population aged 75+ is still one third of the total adult population receiving informal care.

According to SHARE data, per informal care receiver aged 50+ on average 1.4 informal carers in the age category 50+ provide help. As a result, the share of the adult population providing informal care is greater than the share of the adult population receiving informal care. The share of "informal care" providers ranges from less than 10% to up to 40% of the adult population in the literature. However, percentages of less than 10% typically include only part of the informal care as defined in this study, limiting informal care to for example personal care, intense care or only care to some categories of people. Percentages above 30% may include care of healthy children, including any help in any form in the past year, or zoom in on a selective part of the population that is more likely to provide informal care such as women aged 50-64 with living parents.

Using surveys that explicitly exclude informal care to healthy people and that do not suggest that only personal care counts, between 12 and 18% of the adult population aged 18+ is estimated to provide informal care at least once per week. The provision of informal care drops sharply past the age of 75 years. In the age category 18-74 years, an average 14.4% of the adults across various surveys provides informal care, corresponding to 52 million people. If the definition of informal care is further limited to only care provided more than 2 days per week, this number drops to 44 million (Eurofound).

Since slight differences in definitions between surveys already cause the range of informal care rate to vary between 12 and 18% at the EU level, even larger discrepancies between surveys are to be expected in individual Member States. For this reason, the analysis of most of this study is based on the average of two EU level surveys that cover all adults: the European Health Interview Survey (EHIS) 2013-2015 and the European Quality of Life Survey (EQLS) 2016.

According to the EHIS-EQLS combination, a 59% majority of informal carers is a woman. If reflects that women (18% of adult women) are more likely to provide informal than men (12%). In the age category 45-64 years the gender imbalance is slightly larger at the EU level (23% of the women, 15% of the men provide informal care). The gender imbalance is particularly pronounced in two Member States, notably Belgium and Spain where between 25 and 30% of the women aged 45-64 provide informal care and between 10 and 15% of the men aged 45-64.

Informal care rates are highest in the northwest of the EU and lowest in the south and east, at least in headcounts as opposed to full-time equivalents as explored in the next chapter. As a result, in full-time equivalents the informal care rate becomes the lowest in the northwest of the EU. There is no relation between the "headcount" of informal carers and the number of care professionals. In full-time equivalents, one more care professional correlates with 0.84 less FTE of informal carers. However, this correlation does not necessarily imply a causal relationship one way or the other.

The strong negative correlation between formal and informal care does not necessarily mean they exclude each other; however only 10 percent of the care receivers combine both

formal and informal care and 70% use solely informal care. The use of solely informal care and of solely formal care is also negatively correlated. From these findings it is clear that informal care plays a important role and that more of one form of care (formal or informal) may reduce the need of the other form of care.

4. Intensity and duration

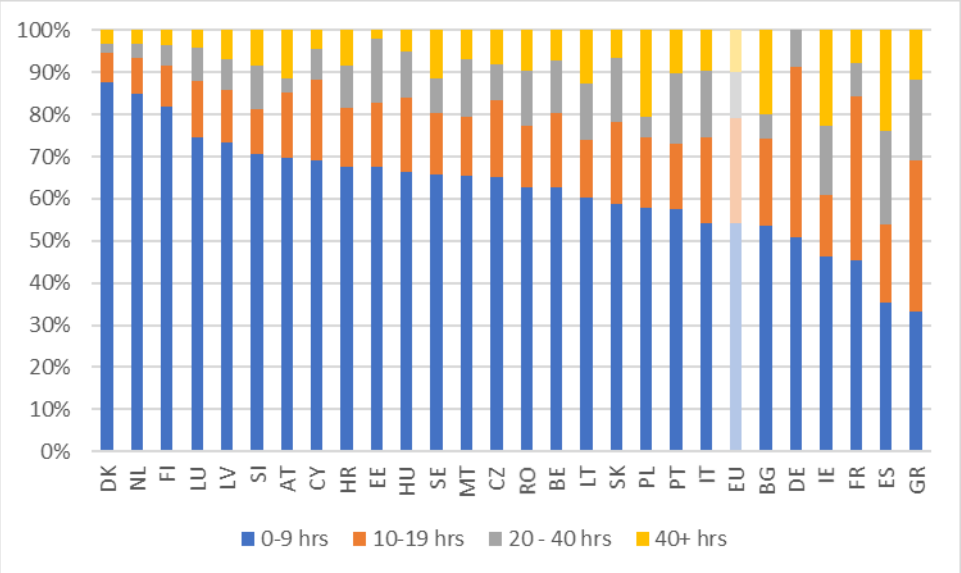
4.1. Intensity of informal care

Distribution of care intensity

Both the EQLS and the EHIS surveys ask informal care providers how many hours per week they provided informal care. It should be noted that both surveys only ask this question to people who provided informal care at least once a week. In this section, first the distribution of the intensity of informal care is discussed and then aspects of low-intensity, medium-to-high intensity care and specifically intense care are explored.

According to the combination of EHIS and EQLS, at the EU level more than half of informal carers (54%) provide care for less than 10 hours per week (Figure 29). Another 25% provides care between 10 and 20 hours per week, and roughly equal proportions provide informal care for 20-40 and 40+ hours (11% and 10% respectively). Low-intensity care is most common in the northwest of the EU (Denmark, Netherlands, and Finland). This may very well explain the high incidence rates in the northwest of the EU that were shown in the previous chapter.

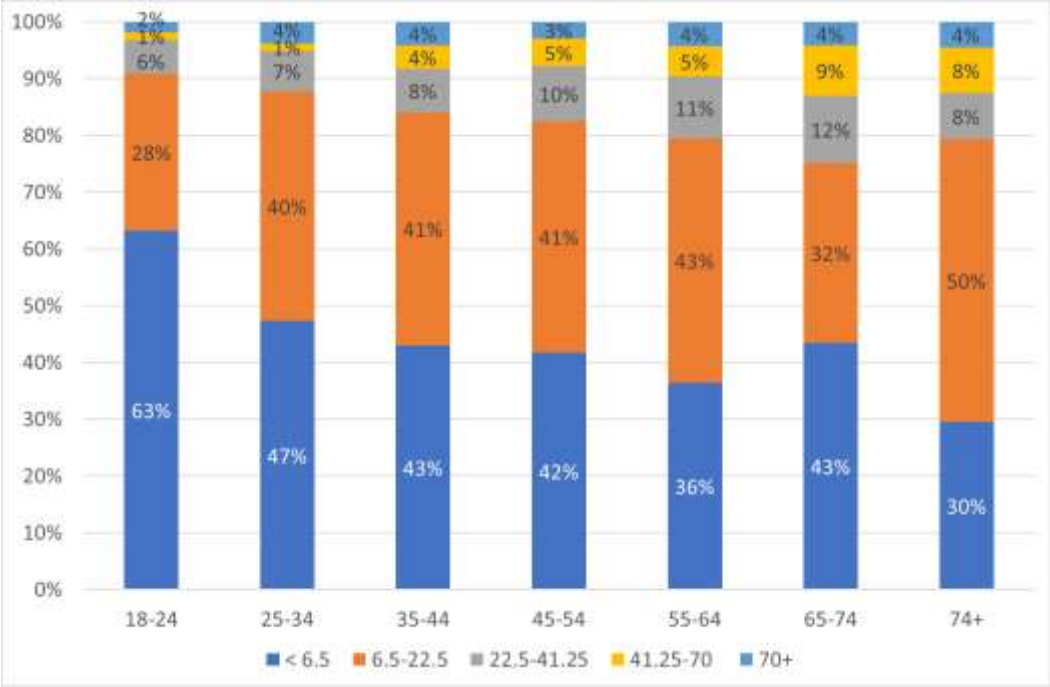
Figure 29 – Distribution of care intensity



Source: Combo of EHIS (2013-2015) and EQLS (2016). Note that for Germany, the category of 40+ hours is absent in the EQLS data (and Germany made no EHIS data available so the EHIS-EQLS combo is just EQLS for Germany).

The likelihood of informal care being intense increases with age (Figure 30). Among informal care givers younger than 25 years old, almost two thirds provide informal care for less than 6.5 hours per week according to EQLS. The likelihood of informal care taking more than 40 hours per week is highest past the age of 65 years.

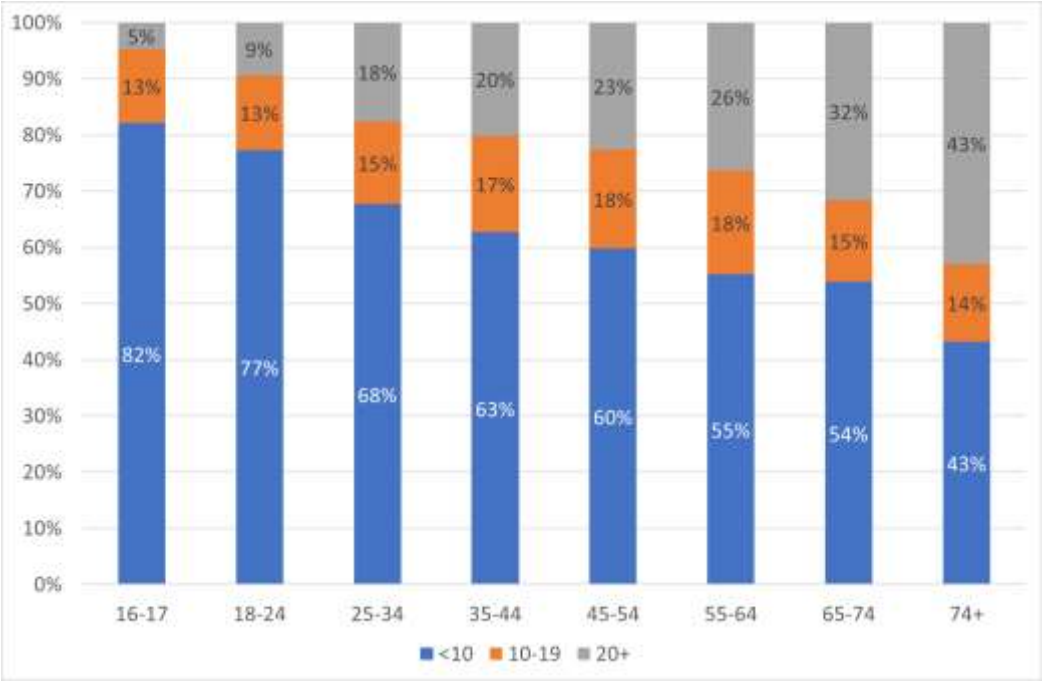
Figure 30 - Distribution of hours per week of giving informal care (EQLS)



Source: EQLS 2016 (excl. UK).

EHIS data confirms that the intensity of informal care increases with the age of the informal care giver (Figure 31). According to this data source, about 80% of the informal carers below age 25 provide informal care for less than 10 hours per week, and the percentage of low-intensity care falls with age and drops to 43% in the age category 75+. This is mirrored by the proportion of informal care for at least 20 hours per week which increases from less than 10% below age 25 to 43% in the age category 75+. The proportion of informal carers providing between 10 and 19 hours per week of informal care is comparatively stable across the age categories.

Figure 31 - Distribution of hours per week of giving informal care (EHIS)

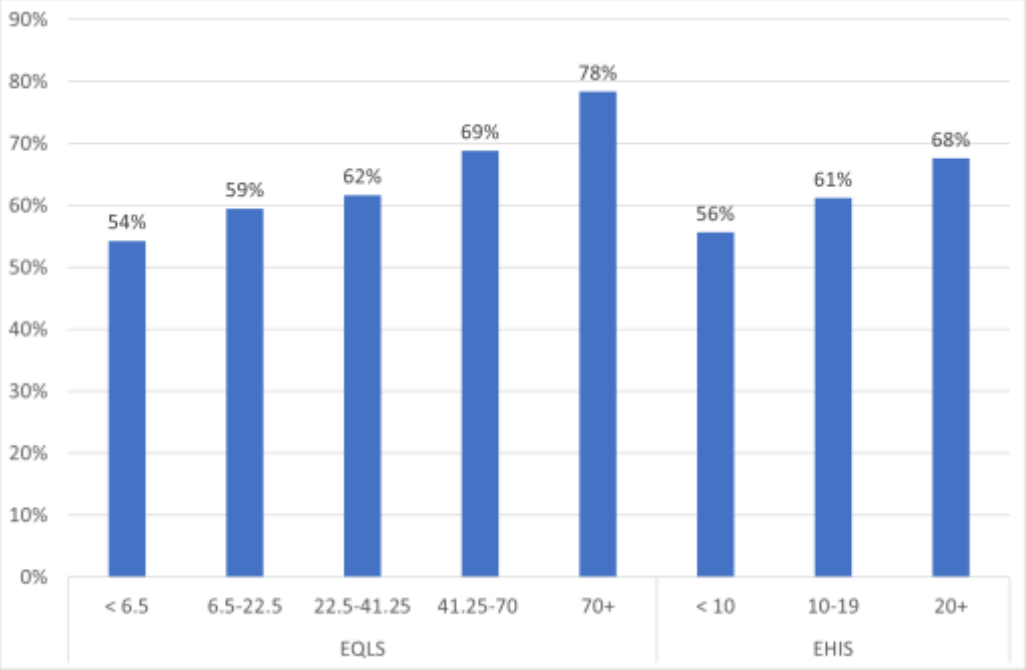


Source: EHIS 2013-2015 (excl. DE, FR, GR).

Within the working age (18-64), the intensity of informal care does not change much by age. However, beyond this age the intensity increases. Especially women aged 65+ provide substantially more intense informal care, with up to 41 hours per week on average for Spanish women aged 65+[75]. The high intensity of help that informal carers past the retirement age provide is likely driven both by the dependency of family members (such as partner) on care and by time availability of the informal carer.

Both the EQLS and the EHIS show that while low-intensity informal care is almost evenly balanced between men and women, the proportion of women providing informal care increases with the intensity (Figure 32).

Figure 32 - Share of women providing informal care by intensity (hours per week, EU)



Source: EQLS (2016) and EHIS 2013-2015 (excl. DE, FR, GR).

Low-intensity informal care

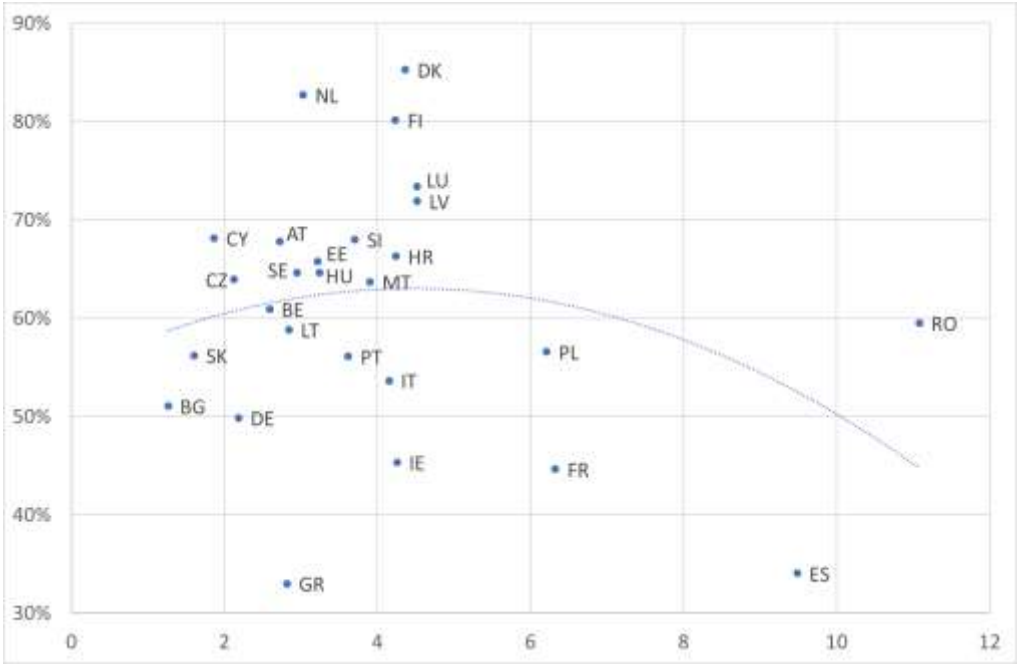
Low-intensity informal care is discussed in order to understand the nature of informal care for the largest group of informal carers. At EU average, slightly more than half of the informal care providers do so for less than 10 hours per week according to both databases (EQLS: 52% and EHIS: 60%). However, substantial differences exist between countries. In Denmark and the Netherlands even around 85% of informal carers provide help for less than 10 hours per week according to both databases. Only in Spain less than half of the informal carers provide care for less than 10 hours per week according to both databases (EQLS: 41% and EHIS: 35%).

In the previous chapter (Section 3.2, under heading EQLS) it was observed that people may receive informal care from more than one person. One might expect that the more people

[75] Ibid.

one receives care from, the fewer hours each informal carer needs to put in. However, especially in Spain many people provide informal care relative to the number of informal care receivers and still the proportion of low-intensity care is far below EU average. There is indeed no significant relation between the number of informal carers per person in need and the intensity of care. Leaving out Spain, the trendline would even be completely flat (Figure 33). However, it should be noted that the sample of informal carers is below 400 for all countries in the EQLS. This limits the likelihood of finding significant relations and it is possible that with more data a significant relation would be found ("absence of evidence is not always evidence of absence").

Figure 33 - Share of low-intensity informal carers versus the informal care givers/receivers ratio



Source: EQLS 2016. N = 83 in PT to 370 in FR.

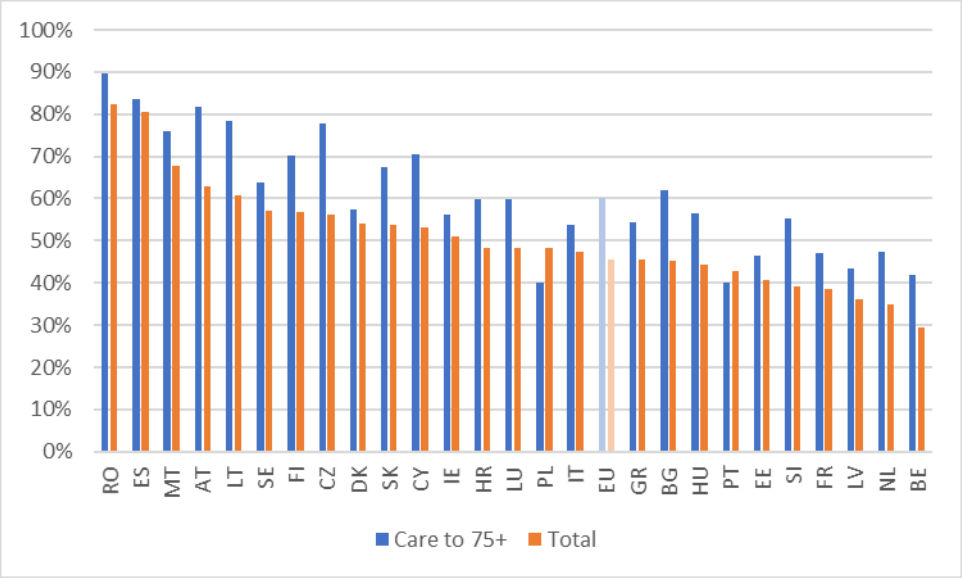
The absence of a relation between hours of informal care and number of informal carers per person in need suggests that if people receive care from several people, it is because they need more hours of care. Assuming that people with poor health need more care, this seems to be confirmed by SHARE data, the one database with data on the number of persons that informal carers provide care for. According to SHARE, on average 11% of the whole population aged 50-70 report to be in poor health. Among those receiving informal care the percentage is much higher: 23% if receiving informal care from one person, 29% if receiving help from two persons and 34% if receiving help from three persons.[76]

Based on a combination of EHIS and EQLS data, slightly over half of the informal carers provide informal care for less than 10 hours per week (Figure 29 above). Perhaps contrary to expectations, informal care to people aged 75 and over is on average provided for fewer hours per week than informal care in general. Using EQLS alone to compare informal care in general to informal care to people aged 75 and over, it turns out that according to EQLS, slightly less than half of informal carers in general provide this help for less than 10 hours per week (46%). Among informal carers providing help to people aged 75+, 60% provide

[76] For informal care providers, the opposite as regards health conditions is true. Of those providing care for only one person, 7% reports to be in poor health. This drops further to 4% and 2% for those providing care to two and three persons, respectively.

this help for less than 10 hours per week (Figure 34). Informal care to people aged 75+ is more often low-intensity than informal care in general in all EU Member states, with the exceptions of Poland and Portugual. One potential explanation for the low intensity of informal care to older people might be that informal care to older people is shared between more family and friends. Another potential explanation is that informal care to older people is more often complementary to formal care. However, data are lacking in reliable numbers to explore these potential reasons in more detail.

Figure 34 - Percentage of informal carers providing low-intensity care, care to people aged 75+ and total



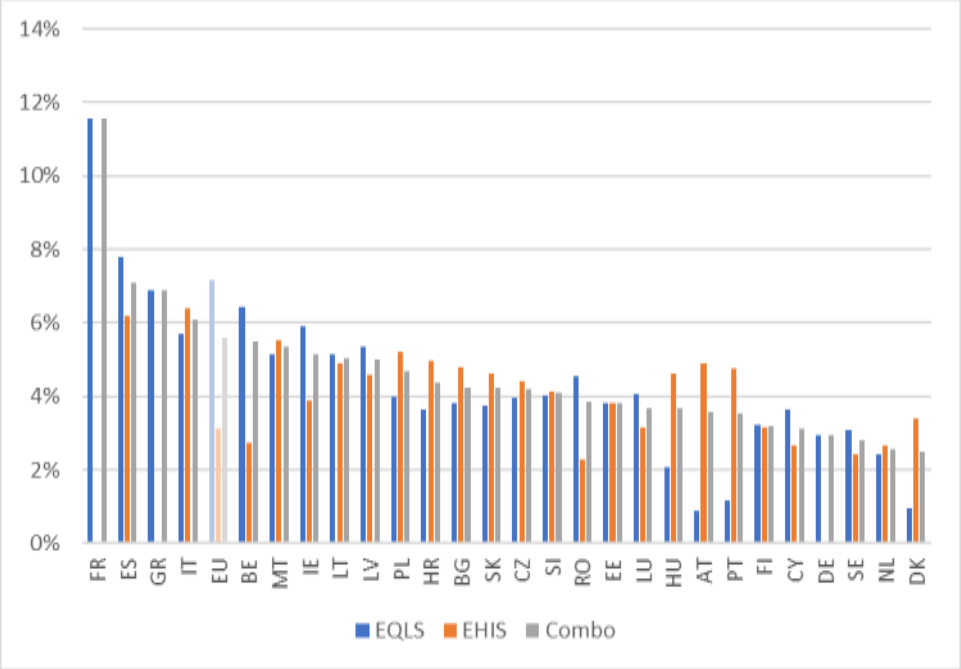
Source: EQLS 2016 (excl. DE). Germany is not included because no answers of 40+ hours of informal are recorded for this country.

By country, Member States where low-intensity informal care is more frequent in general, low-intensity informal care is in general also more frequent among informal carers providing help to people aged 75+. This is not surprising because two thirds of informal care is provided to people aged 75+, as noted in the previous Chapter (Figure 28).

Medium-to-high informal care intensities

Since about one half of the population of informal carers provide their help for less than 10 hours per week (Figure 29), the other half provides their help for 10 or more hours per week, and it is relevant to know the size of the medium-to-high informal care providers as a percentage of the population. At the EU level, 24 million people provide informal care for at least 10 hours per week. Indeed, only six per cent of the adults provide at least 10 hours of informal care per week (Figure 35). The countries with above EU-average medium-to-high intensities (10 or more hours per week) according to both databases are four Mediterranean countries: France, Spain, Greece and Italy. The countries with the lowest medium-to-high intensities are Denmark, the Netherlands, Sweden and Germany. The samples of informal carers in the EQLS are generally too small for statistically reliable conclusions while those in EHIS are large enough, so EHIS and the EHIS-EQLS combo should be regarded as more reliable.

Figure 35 - Percentage of the population providing informal care for at least 10 hours per week



Source: EQLS 2016, N = 83 in PT to 370 in FR and EHIS 2013-2015, N = 532 in CY to 4243 in IE.

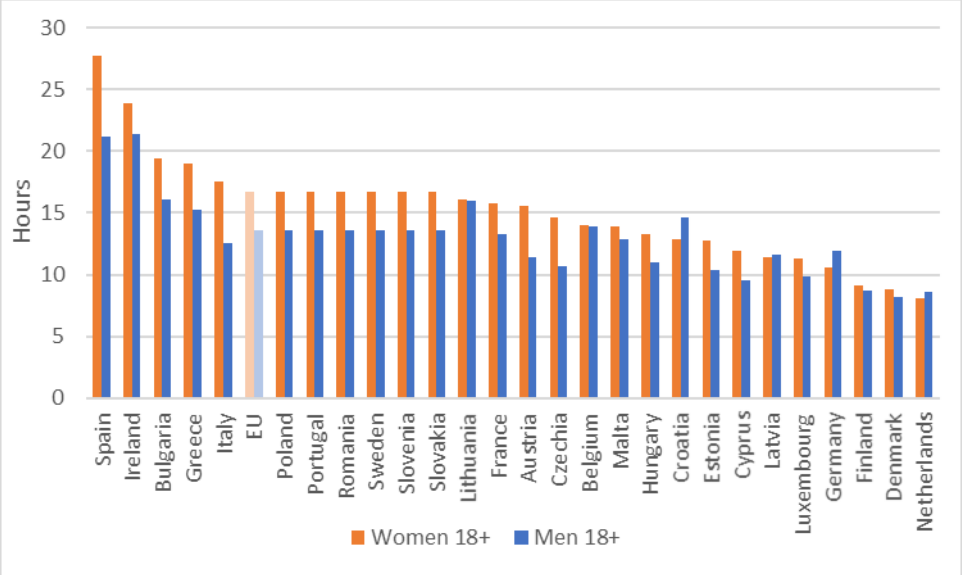
Intense informal care and gender imbalance

While an analysis of low-intensity informal care is useful to better understand the nature of informal care for more than half of the informal carers, it is high-intensity informal care that is likely to have the largest impacts on the care provider in terms of health and employment status. In this study, informal care for more than 40 hours per week is defined as intense care.

Earlier it was noted that low-intensity informal care is most predominant in the northwest of the EU. It is therefore not surprising that average weekly hours of informal care are lowest in countries such as the Netherlands, Denmark and Finland (Figure 36). The average weekly hours are highest in mostly Southern and Eastern European countries.

In the previous chapter it was noted that women provide care more often than men (Figure 20). In addition to the gender imbalance in the incidence, women also provide more intense care. Women spend on average 17 hours per week on providing informal care compared to 14 hours for men. The gender imbalance in intensity is even more pronounced in some countries such as Spain, where women providing informal care spend on average 28 hours per week on that, compared to 21 hours for men in that country. In Italy the gender difference is also at least five hours per week (18 hours for men, 13 hours for women).

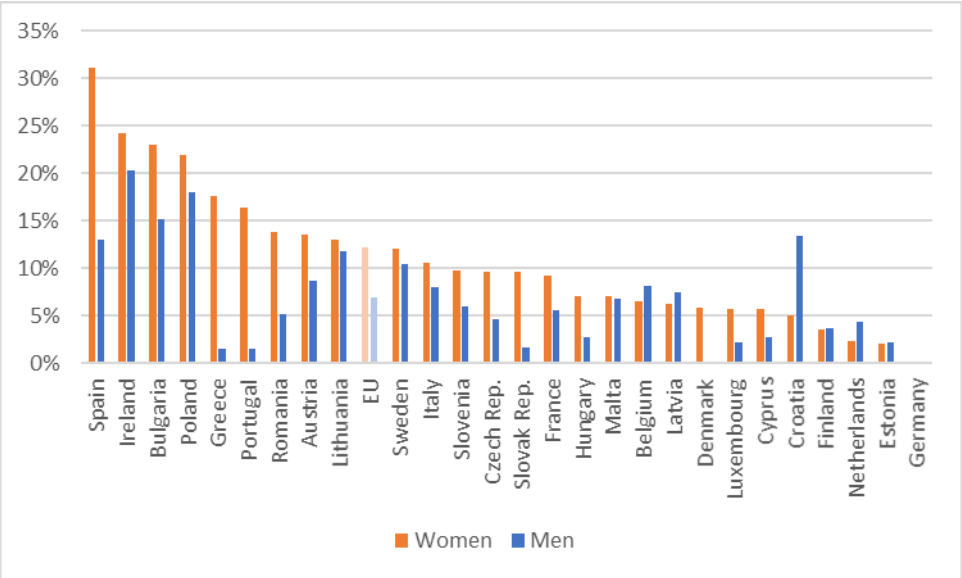
Figure 36 - Average hours per week of informal care provision, men and women aged 18+



Source: EQLS (2016) and EHIS 2013-2015.

Among women providing care, 12% provide intense care (for more than 40 hours per week), compared to 7% for men (Figure 37). In total 5.3 million people provide intense informal care in the EU, of which 3.8 million are women. Here again, the gender difference is largest in Spain (among women providing informal care, 31% spend more than 40 hours per week compared to 13% among men providing informal care), followed by Portugal and Greece (16-18% for women versus 2% for men).

Figure 37 - Share of the informal carers aged 18+ providing intense care (more than 40 hours per week), by gender and country



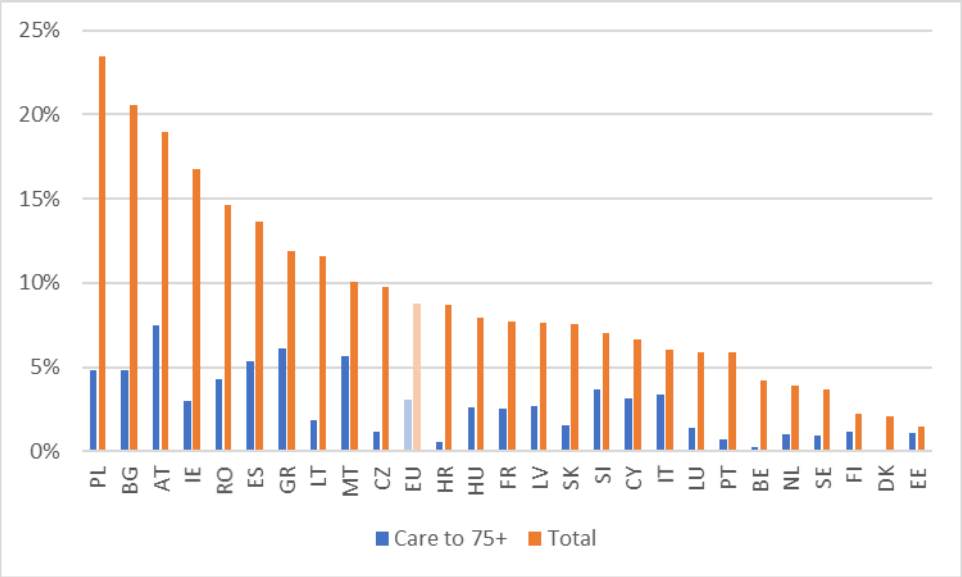
Source: EQLS (2016) and EHIS 2013-2015.

The number of intense informal carers is too small to show a significant relation with formal care provision as was done for informal care in general (Section 3.5).

As noted earlier, informal care provided to people aged 75+ is more often low intensity than in general (Figure 34 further above). The mirror side is that high-intensity informal care (40+

hours per week) is relatively rare among those providing informal care to people aged 75+. The rarity of high-intensity informal care to people aged 75+ is even much more pronounced than the ordinariness of low-intensity care to people aged 75+. At the EU level, according to EQLS 9% of all informal carers provide care more than 40 hours per week. However, among informal carers providing help to people aged 75+ this drops to merely 3% (Figure 38).

Figure 38 - Percentage of informal carers providing high-intensity care, care to people aged 75+ and total



Source: EQLS (2016) (excl. DE). Germany is not included because no answers of 40+ hours of informal are recorded for this country.

4.2. Duration of informal care

Most informal care is long-term. Data on duration of informal care is rare, but the available information indicate that if people provide informal care, they often do so over a longer time span. In Germany, about 90% of the persons receiving a nursing allowance (Pflegegeld - Geldleistung) receive this benefit for at least three months before dying and about 75% for at least one year.[77] [78] Since care receivers can spend Pflegegeld solely on informal care, this suggests that many informal carers provide help this long, under that assumption that care receivers do not usually switch between informal carers. In France in 2016, the average duration of the "personal autonomy benefit" was 3.5 years[79]. The only data source on duration of informal care provision (rather than duration of informal care receipt) is the Dutch

[77] Jacobs, K. Kuhlmey, A., Greß, S., Klauber, J., Schwinger, A. (2017). Die Versorgung der Pflegebedürftigen. In Pflegereport 2017. Retrieved from: https://www.wido.de/fileadmin/Dateien/Dokumente/Publikationen_Produkte/Buchreihen/Pflegereport/2017/Kapitel%20mit%20Deckblatt/wido_pr2017_kap21.pdf, Section 21.2.3, Figure 21.16. Note that only 38% of Pflegegeld is spent on informal care, according to Table 3.10 in https://www.bundesgesundheitsministerium.de/fileadmin/Dateien/3_Downloads/P/Pflegebeduerftigkeitsbegriff_Evaluierung/Abschlussbericht_Los_2_Evaluation_18c_SGB_XI.pdf.

[78] Please note that this 75% applies to all informal care, not to the 90% that is informal *long-term* care (lasting at least 3 consecutive months). As a percentage of informal long-term care, the 75% corresponds to 83% (= 75% / 90%).

[79] See https://drees.solidarites-sante.gouv.fr/IMG/pdf/infographie-apa.pdf.

IZG survey, according to which the average duration of informal care was 4.5 years in 2016.[80]

The Dutch IZG survey is a cross-section data (of one year only). This means there is no information on the ultimate duration of informal care but only on the duration of care provided so far at the moment of the interview: we do not know how long informal care has lasted before the interview, nor how long it will continue to last after the interview. Longitudinal data where respondents are interviewed in multiple years offer some more insight in the duration of informal care. Of the reviewed datasets, only EU-SILC and SHARE are longitudinal, and the SHARE data has the limitation that it is limited to respondents aged 50+, and that data on informal care is only available for a limited number of countries. Regular EU-SILC only covers informal care to household members (a roughly estimated 1/3 of total informal care), but is otherwise representative for the whole population and covers most EU Member States. In addition, EU-SILC registers the main activity for each month in the reference year. Therefore, besides the Dutch IZG data, durations are only analysed in-depth with EU-SILC.

Dutch IZG survey

The Dutch IZG questionnaire asks whether people have provided informal care in the past twelve months and if yes for how long (in years and months) and whether the respondent still provides informal care. Thus, for respondents who no longer provide informal care the exact duration is known, and for respondents who still provide care the duration from the start till the moment of the interview is known.

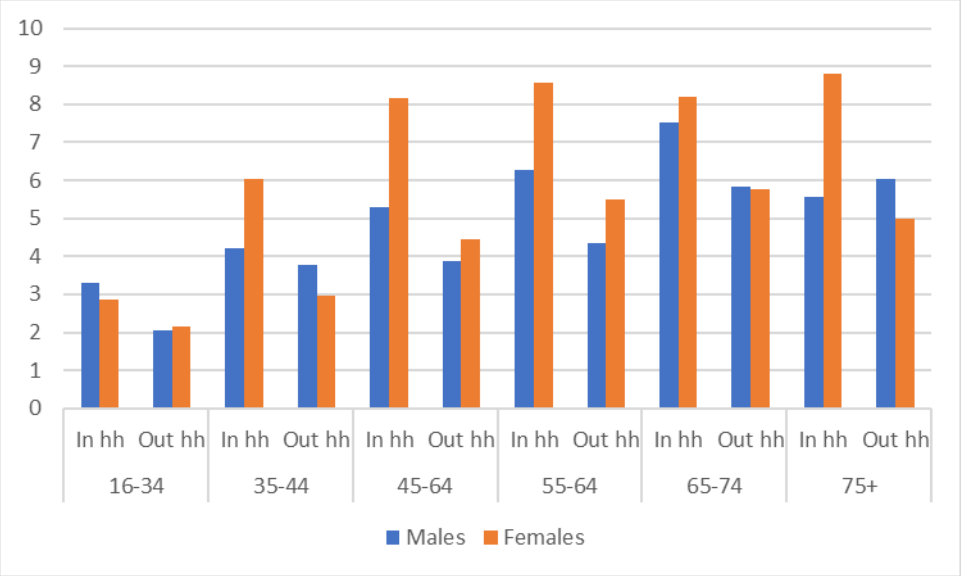
Unfortunately, even though the exact duration is known for some informal care providers, this does not help to estimate the average ultimate duration of informal care for the whole population of informal carers. The reason is that a cross-section includes people who started providing informal care many years earlier and still provide informal care, but it does not include the (presumably much larger) population of people who had started providing informal care as long ago and have stopped doing so at some time since then. Thus, compared to the population who provided informal care at any time during a long period before the interview, people who so far provided care for a long time are over-represented in a cross-section sample. Of course, the cross-section sample also includes people who have just started providing informal care and may continue to do so as many years in the future. Statistical software exists to estimate ultimate durations if the whole population of "spells" (informal care) over a long time is observed, but not to estimate ultimate durations from cross-section data.

What rests, is to present the reported durations of informal care so far, and assume that the effects of (1) missing short durations in the past and (2) not knowing how soon newly started informal care will end in the future, cancel each other out (Figure 39). Under this assumption, the distribution of reported informal care is the same as the ultimate distribution of informal care (measured from a far past to a far future). As noted earlier, the average reported duration of informal care was 4.5 years. However, in the age category 45+, Dutch women reported on average to have provided informal care for 8 to 9 years, compared to 6 to 7 years for men (Figure 39). Persons aged 16-34 reported on average shorter durations of two to three years, and in the category 35-44 years the reported average was about four

[80] Based on the Informele Zorg (IZG) 2016 survey, https://www.scp.nl/over-scp/data-en-methoden/onderzoeksbeschrijvingen/informele-zorg-izg.

years. There is no gender imbalance in the age category 65-74 years, which leads to the conclusion that the longer duration of women caring for their partner past the age of 75 can be attributed to life expectancy.

Figure 39 – Average reported years of informal care



Source: Dutch IZG (2016), estimates Ecorys.

Dutch people on average provide longer informal care to household members than to others outside the household: 6 years compared to 4 years. In the age between 35 and 64 years, this is more pronounced for Dutch women than for men, which suggests that women bear the greatest burden of caring for children with health problems.

For short spells (given that the duration is less than 12 months), the average duration varies between 1 and 6 months (Table 4). The longer durations of short spells may be simply a selectivity effect: if women providing informal care for several months are more likely to continue to provide help after the first year, those spells last long and are not included in the average of Table 4.

Table 4 - Average months of short spells lasting less than 12 months (IZG)

	To household members		To persons outside the household	
Age	**Men**	**Women**	**Men**	**Women**
16-34	2.6	3.0	2.2	2.9
35-44	---	2.4	3.7	2.5
45-54	6.2	1.2	3.5	2.9
55-64	4.9	2.3	3.1	2.1

65-74	2.8	2.3	3.4	2.6
75+	4.6	3.0	6.0	1.4

Source: Dutch IZG (2016), estimates Ecorys; --- means no observations were available.

EU-SILC

With EU-SILC, it is possible to combine the variables “domestic tasks and care” and “has limitations in daily activities due to health problems” (health limitations for short). The idea was to follow informal carers over multiple years to see when they started and stopped providing informal care. It seems reasonable to assume that if a household member has health limitations and a person’s main activity is “domestic tasks and care”, that the person provides informal care. Since the main activity is asked for each month of the reference year (in most countries, the calendar year before the year of the interview), this would allow to estimate the duration of informal care. This assumption was tested and refined with cross-section data (see text box).

Approximation of informal care within households with SILC data

The EU-SILC ad hoc module of 2016 cannot be matched with longitudinal EU-SILC data. The EU Survey of Income and Living Conditions (EU-SILC) is an annual survey that comes in two versions: cross-section and a longitudinal. The cross-section data contain data of one year, with a core part consisting of questions that are asked every year, and an ad hoc module with additional questions about a certain theme. The core part does not include questions about the provision of informal care, but the 2016 ad-hoc module on access to services (need and use) did. Thus, informal carers can be identified in EU-SILC in year 2016 only. Unfortunately, the respondents in the cross-section version cannot be matched with respondents in the longitudinal version, so the history of these informal carers before and after 2016 cannot be observed.

In the longitudinal EU-SILC data, informal care provision is not observed, but adult household members' need of care can be used as a proxy under certain assumptions. The longitudinal EU-SILC follows interviewees for four years, which allows an analysis of what happened to interviewees one year earlier or later. The longitudinal questionnaire however does not include a question about informal care. The longitudinal data nevertheless still covers all adults (aged 16+) in a household and includes a question about having strong difficulties with daily activities due to reasons of health or old age. Before it was discovered that the majority of informal carers in the working age are employed, it looked promising to combine the presence of another household member having strong difficulties with "domestic tasks and care" as main activity to identify informal carers. In the end, the additional criterion to identify potential informal carers was extended to include non-employed people in general and people working up to 16 hours per week. To summarize: informal care to adult household members was assumed if (a) the person lives with an adult having strong difficulties in performing daily tasks due to health problems or old age and (b) the person was not in employment or employed at most 16 hours per week. As noted below Figure 15, about 9% of the adult population provides informal care to household members according to this approximation, which is in between the percentage found using other data sources (SILC 2016 ad hoc module, SHARE and the Dutch IZG survey).

It was considered to also simply include anyone living with someone who has strong need of care, but then the incidence rate of informal care would be implausibly high. In practice, if someone in a household with multiple adults has strong need of care, typically one of them provides informal care according to the SILC 2016 ad hoc module, and the one working the least hours per week is the most likely to provide informal care.

A cross-check with EU-SILC 2016 ad hoc module revealed limitations of this approximation with the regular SILC. Less than half of those identified as potential informal carers with 2016 regular SILC data, actually provided care according to the 2016 ad hoc data,[81] implying an overestimation of informal care. By matching with longitudinal data of one year earlier or later, it is also possible to identify household members who needed care in the current year but not one year earlier or later. Informal care to, for example, parents living in a different household is still unobserved, leading to an underestimation of informal care. In practice, whenever longitudinal EU-SILC data is used in this report, it should be kept in mind that this only indirectly indicates in-house informal care. Since (logically) stronger effects are expected for intense care, the apparent under-reporting of many "light" informal carers in EU-SILC implies that using EU-SILC may result in overestimating the average effects of informal care on health

[81] Of course this likelihood that someone living with an adult with strong health limitation actually provides informal care is not 100% (then there would be no formal home care), but it is 29% according to the EU-SILC 2016 ad hoc module, as opposed to 3.3% of the population aged 18+ providing care to household members (according to the same EU-SILC 2016 ad hoc module). This likelihood is further increased to 34% by selecting people not in employment or working at most 16 hours per week.

status and re-employment likelihood. The percentage of informal carers in the EU-SILC 2016 ad hoc module is much lower than in EHIS/EQLS. To test an assumption that EU-SILC in particular underestimates "light" informal care consisting of only help with household tasks (because other questions in EU-SILC already cover that), employment rates of informal carers were compared between the EU-SILC 2016 ad hoc module and in EHIS/EQLS with the idea that a lower employment rate indicates the exclusion of "lighter" informal care. The EU-SILC employment rates were indeed lower, suggesting that effects for "light" carers may indeed be overestimated. Still, as the only source to compare developments over time between informal carers and other people at EU-level, the longitudinal EU-SILC data has proven to be very insightful.

In sum, longitudinal EU-SILC is not used as a source on the incidence of informal care, and is only used to explore dynamics of (potential) informal care givers.

With EU-SILC, it is also possible to analyse durations from the start by selecting respondents who provided informal care in multiple years in two steps:

- Define informal LTC providers as persons who had a household member with strong health limitations and whose main activity was non-employment or working at most 16 hours per week (as defined above) for at least three consecutive months in the reference year.

- Select persons who were not estimated to be informal LTC providers in the reference year of their first interview and were informal LTC providers in the reference year of the second interview in the consecutive year. These are persons who started providing informal care in the year before their second interview. The research question is whether they were estimated to still provide informal care in the year before their third interview.

Between two interview years, an inferred informal care spell can start or end due to one of two reasons:

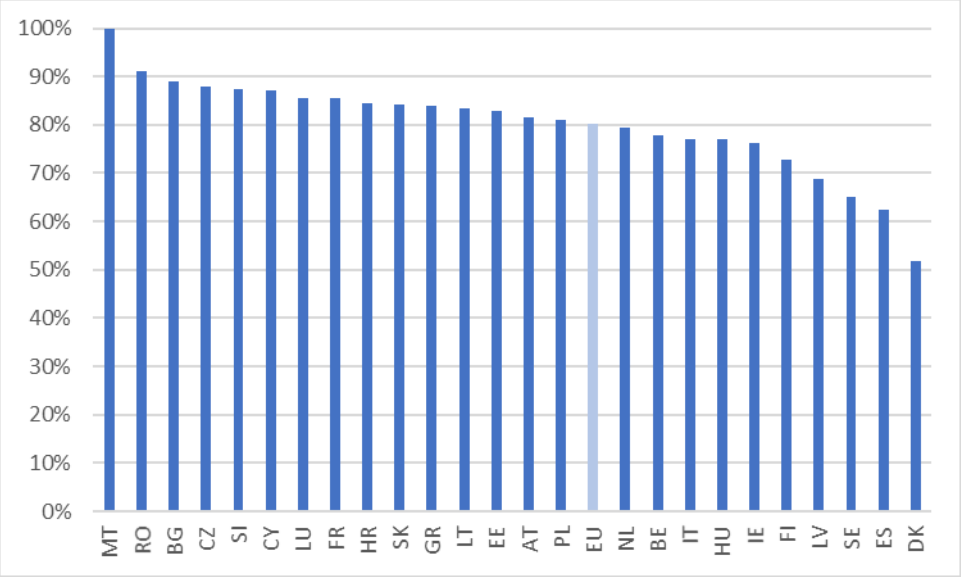
- A household member starts or ceases having strong health problems (if the person is non-employed or works at most 16 hours per week)

- The person in question starts or ceases being non-employed or working more than 16 hours per week (if a household member has strong health problems)

The above approach exploits the longitudinal aspect of the longitudinal SILC data. The outcome is that 80% of the assumed informal care spells that started in the year before the second interview, continued in the year before the third interview (Figure 40). In other words, 80% of informal care lasts longer than one year.

Between countries, informal care seems more likely to last less than a year in the northwest of Europe, in particular Denmark, Sweden and Finland although also in Spain. In some east European countries, about 90% of informal care is estimated to last at least one year, notably in Romania, Bulgaria, the Czech Republic and Slovenia but also in Malta.

Figure 40 – Percentage of estimated informal care spells lasting more than 1 year



Source: SILC longitudinal data, 2010-2017; no or insufficient data for Germany and Portugal; small sample size in Denmark (implying limited reliability).

Based on Dutch IZG data, between 80 and 90% of the informal LTC is reported to have lasted at least one year. As noted at the start of this section, according to WIDO[82], 90% of the personal care budget (Pflegegeld) is paid out for at least 3 months and 75% for at least one year. However, defining informal LTC as lasting at least 3 months, this 75% needs to be divided by 90%, resulting in 83% of informal LTC lasting at least one year. Thus, also for Germany it is indirectly confirmed that the great majority of informal LTC lasts longer than one year.

4.3. Conclusions

On average, informal carers provide care for 16 hours per week. However, more than 50% of informal care is provided at low intensity of less than 10 hours per week. Low-intensity informal care is particularly predominant at 80 to 90% of all informal care in the northwest of the EU. This may explain the high headcount incidence rates in the northwest of the EU that was noted in the previous chapter. At EU level, about 10% of all informal care is intense (at more than 40 hours per week).

A hypothesis that low-intensity care is caused by burden sharing between more people is rejected: there is no relation. For high-intensity care, the burden is more than proportionally born by women: care is intense for 12% of the women providing informal care and for 7% of the men providing informal care. Thus, women not only provide informal care more often than men, but they also provide intense informal care more often than men. The gender imbalance in intensity of informal care is strongest in Italy and Spain.

Survey data and point-in-time administrative data are little suited to an analysis of durations, because one can only ask after care provided so far until the moment of the interview and because survey data miss care spells that both started and ended before the interview.

[82] WIDO (2017), ibid.

However, if one assumes that effects of missing data on the past and future cancel each other, reported durations are indicative of ultimate durations of care spells. Under this assumption, informal care spells last on average between 3.5 and 4.5 years according to French and Dutch data.

The monthly main activity data in EU-SILC data to assess the impact of the three consecutive month criterion of long-term informal care proved to be of little use because inferred informal care in the reference year includes care spells that started before the reference year.

The longitudinal version of EU-SILC can be used to identify the start and end of care spells of people who participated in at least three consecutive interviews, although based on a quite imperfect approximation of informal care to household members only (see the methodology box in Section 4.2). Keeping these limitations in mind, this study found that about 80% of informal care spells last longer than one year. This is confirmed by Dutch and German data. These data also showed that about 90% of informal care lasts longer than 3 months (and thus is “long-term” according to the definition of this study).

As noted earlier in this section, informal care spells are more predominantly low-intensity in the northwest of the EU. In addition, only 60-70% of the informal care spells last longer than one year in this region, compared to 80-90% in some East European Member States.

5. Characteristics of informal carers

5.1. Characteristics considered

In the previous two chapters, gender and age differences in the provision of informal care have already been discussed. This chapter discusses other characteristics of informal carers, namely:

- Educational level
- Health
- Employment
- Household type
- Household income and risk of poverty

Across the board, the characteristics of informal carers providing help to people aged 75+ do not differ very much from informal carers in general. That is no surprise, because at the EU level two thirds of informal carers provide help to people aged 75+. With a lower age threshold such as 60 years, informal care to older people would be even more commonplace and the difference in characteristics even smaller. Differences by age of the informal care provider and intensity of informal care have been discussed in previous two chapters.

Specifically, there are no notable differences in educational level (Section 5.2), health (Section 5.3), most employment characteristics (Section 5.4) and household income (Section 5.6) between informal carers providing help to older and to younger recipients. However, differences exist in the occupations of informal carers providing help to younger and older recipients (end of Section 5.4) and in the household type (Section 5.5).

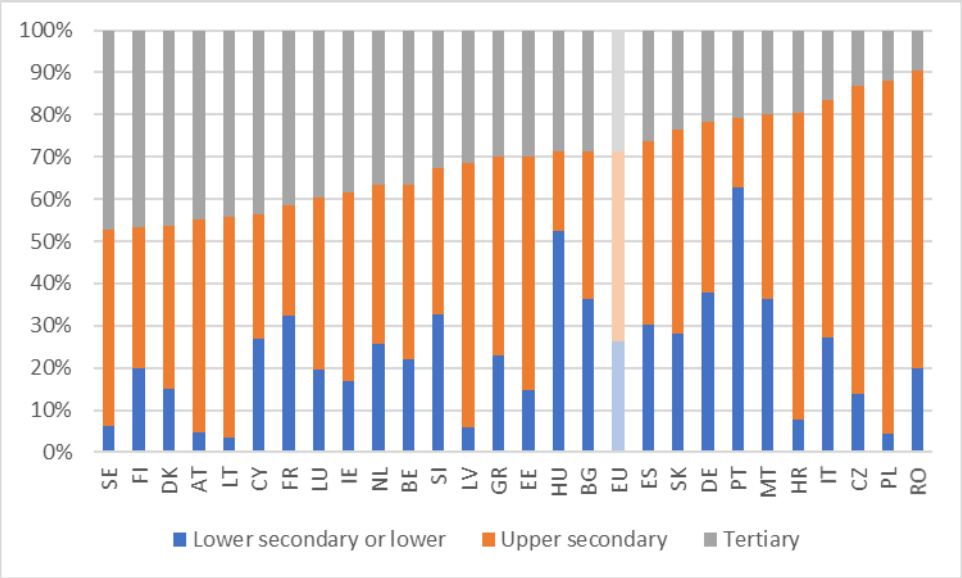
5.2. Educational level

About one third of the informal carers aged 18+ is lower educated (highest attained educational level corresponds to lower secondary level or less) and about one in four has a tertiary education (Figure 41). For education levels, it is common to limit the age group to 20-64. In this age bracket, 45% of both informal carers and the general population has upper secondary educational level based on EQLS. The share of lower educated people aged 20-64 is slightly lower among informal carers: 26% compared to 27% in the general population. The share of tertiarty educated people aged 20-64 is correspondingly slightly higher among informal carers: 29% compared to 28% in the general population. Despite these minor differences, it is fair to say that the educational profile of informal carers is similar to that of the general population in the working age. With regard to the educational profile, informal carers thus seem a random sub-sample of the general population aged 20-64.

The provision of informal care does not seem to correlate much with educational level. Remarkable differences exist per country which likely relate to the educational structure of

the whole population. For example, in Finland and Sweden a majority of both informal carers and the total population of adults have tertiary education; in Croatia, the Czech Republic and Poland a majority of both informal carers and the total adult population have upper secondary education, and in Portugal and Hungary a majority of both informal carers and the total adult population have not completed education beyond lower secondary level.

Figure 41 - Educational split of informal care providers

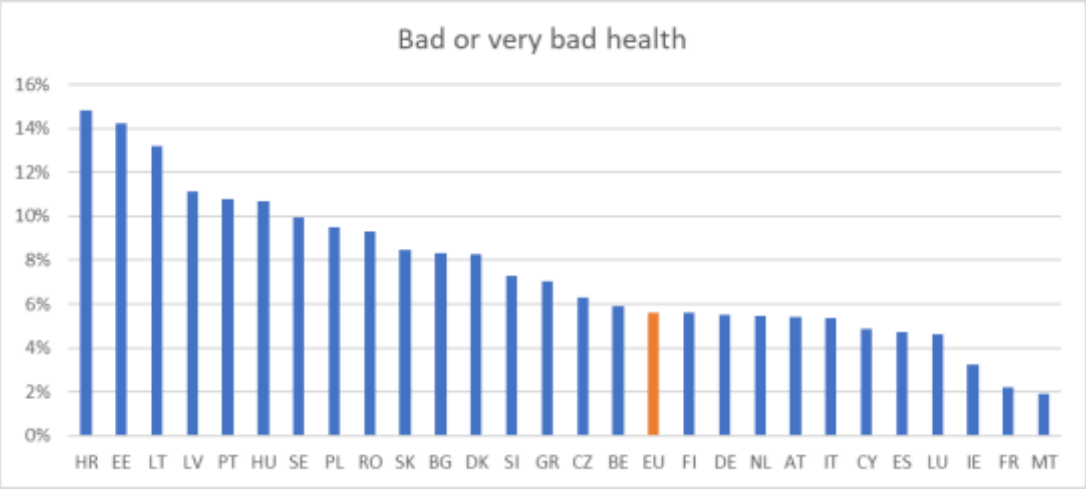


Source: EQLS (2016).

5.3. Health

At the EU level, according to EHIS 7% of the informal carers have bad or very bad health and according to EQLS this is 5%. Combining the two datasets, about 6% of the informal carers have bad or very bad health, ranging from 2% in France and Malta to 13-15% in Croatia, Estonia and Lithuania (Figure 42).

Figure 42 - Percentage of informal care providers with bad or very bad health



Source: EQLS (2016) and EHIS 2013-2015.

Since health problems can have effects on the supply of labour, a focused analysis of people in the working age is also relevant. In the working age, about 5% of both informal carers and the general population report bad or very bad health (compared to 6% across all ages as discussed above). In the working age, informal carers on average have less often health problems (5%) than non-employed people (where 9% report bad or very bad health), but more often than employed people (where 3% report bad or very bad health). Of course, people in the non-employed working age include persons with a disability. It could be argued that the comparison with employed people is more relevant. However, informal carers also include non-working people. Most literature that compares the health status between informal carers and the general population without controlling for characteristics, find that both bad mental health and bad physical health are more frequent among informal carers ([1], [3] and [14] in the studies listed in Annex B].

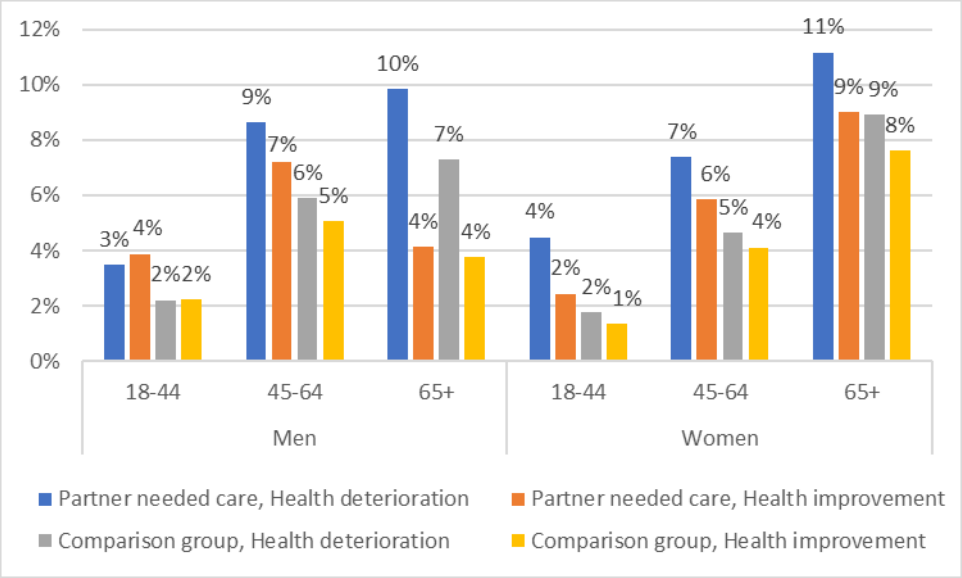
To make certain that differences in health status are caused by informal care activities rather than different characteristics of informal carers and the general population, it is important to run statistical regressions or to analyse changes in health status between informal carers and the general population.

With longitudinal EU-SILC data, it is possible to analyse the self-reported health status of people between their first interview and their second interview one year later. As a preliminary remark, health tends to deteriorate with age and Figure 43 shows this. For the overall population, the health status is more likely to change from moderate-good (or very good) to bad or very bad than the other way round. The effect of changes in health status increases with age, both regarding an improvement of health status (except for men aged 65+) and a deterioration of health status. It means they have health problems more often, and thus also have more health problems to recover from. However, overall the balance of health improvements and deteriorations worsen with age.

The relevant analysis for informal carers is therefore whether the balance of health improvements and deteriorations is worse than in the general population. Except for men aged 18-44, the balance of health changes (health improvement minus health deterioration) is more negative for informal carers than for the comparison group[83]. The negative balance is strongest for men providing informal care beyond the age of 65 (Figure 43). One reason why health effects are strongest beyond the age of 65 may be that in particular beyond the age of 75 informal care is mostly spousal care (see also Figure 12 in Section 3.2) and according to the literature negative health effects are strongest for spousal care (as discussed below the next figure).

[83] Given that the 5% of informal carers with bad or very bad health is less than the 9% of non-employed people (including persons with a disability) and more than the 3% among employed people (including full-time workers), a comparison group was created by excluding people with a disability (and students) and people working more than 16 hours per week. Specifically, the control group consists of people with self-reported economic status retired, “fulfilling domestic tasks and care responsibilities” or “other inactive person”, as well as those with self-reported part-time work status (as employee or self-employed) and working at most 16 hours per week.

Figure 43 - Change in health status if living with an adult needing care compared to people who fulfil domestic tasks or care, are retired, or work at most 16 hours per week



Note: The graph shows the % of people whose health changed to or from bad/very bad.
Source: SILC longitudinal version 2010-2017.

The conclusions from literature based on regressions and analyses of changes over time are (with numbers in square brackets referring to the literature listed in Annex B):

- Overall, informal care provision has a negative effect on mental health but not on physical health: [4], [6], [8], [10-13], [19], [21], [27], [29], [31]
- Informal care provision has a negative effect on mental and overall health for spousal care, but not for care to others outside the household: [16], [17], [29]
- Negative mental health effects of caring / informal care increase with the intensity of informal care: [7], [27]
- Negative health effects strongest in the south and east of the EU, less in the west and least in the north: [24]

The most interesting and recurrent finding from the literature is thus that informal care affects the health of informal care negatively and that in general, mental health rather than physical health is affected. However, spousal care seems to affect physical health as well according to three studies. The negative spousal care effect could be a hidden age effect, but since most studies also control for age, spousal care seems to have a separate negative effect of its own. Kaschowitz [16] refers to studies that indicate that spousal caregivers are more likely sole caregivers. Wagner [29] suggests that an important reason is that spousal caregivers feel less in control, although she compared with non-carers. There may be other reasons such as perhaps stress caused by seeing the partner suffer. However, potential reasons for specific health effects of spousal care have not been exhaustively investigated.

The finding that (mental) health effects increase with hours of informal care is confirmed by two studies: (Verbakel et al., [27] in Annex B and Estrada et al. ([7] in Annex B which uses the European Social Survey and thus includes care to healthy children). The regional differences found in Uccheddu et al. ([24] in Annex B) may be explained by regional differences in the intensity of informal care found in the previous chapter (Section 4.1).

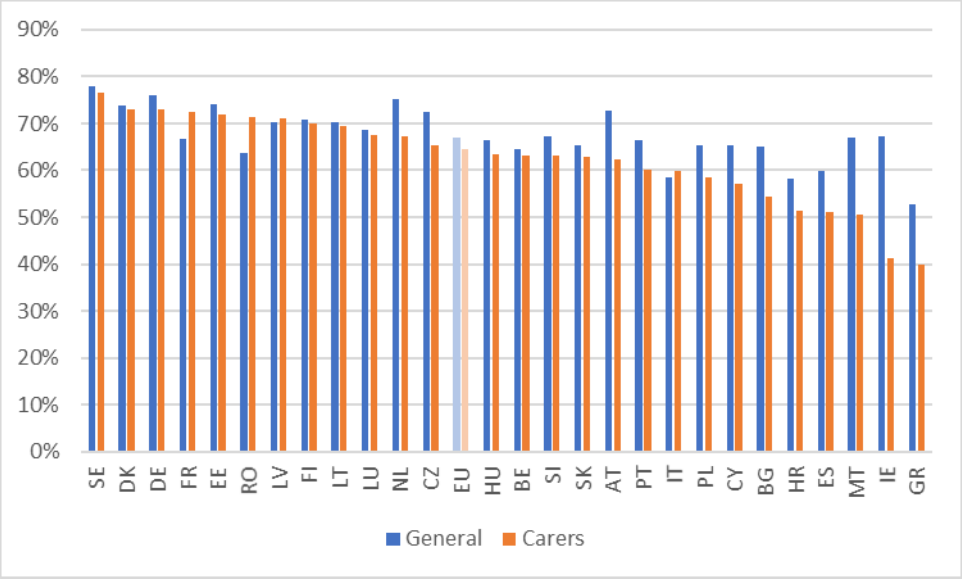
5.4. Employment

This section discusses the employment rate of informal carers, but also two other aspects of employment, namely working hours and the occupation in which employed informal carers work.

Employment rate

Among informal carers in the working age (18-64), the employment as a percentage of the total population is 64%, according to the combination of EQLS and EHIS. This is slightly less than the 67% employment level in the general population aged 18-64. Across countries, the employment rates of informal carers range from 40-41% in Greece and Ireland to 76% in Sweden. The employment rate of informal carers is typically higher if the general employment rate is higher. However, informal carers are particularly much less often employed than adults in the working age in general in Ireland (-26 ppt), Malta (-17 ppt) and Greece (-13 ppt). However, in France, Italy, Latvia and Romania informal carers are actually more often employed than in the general population (Figure 44).

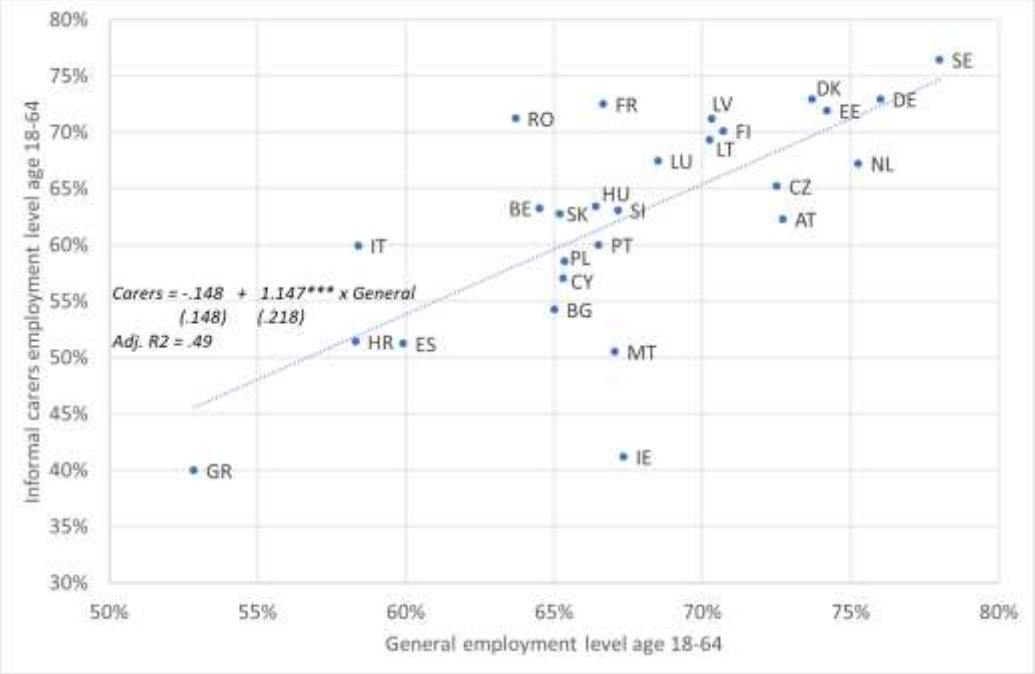
Figure 44 - Employment rates of general population and informal carers



Source: EQLS (2016) and EHIS (2013-2015), LFS (2015).

The employment rate among informal carers increases more than proportionally compared to the general employment rate according to the regression shown in Figure 45: 1.147 percent points increase among informal carers for every percent point increase in the general working age population. The more than proportional increase of employment of informal carers with the general employment rate suggests that the employment gap (the difference in employment rate between informal carers and the general population in the working age) decreases when the economy improves. If this is true, this would imply that the employment gap is not constant but changes over time.

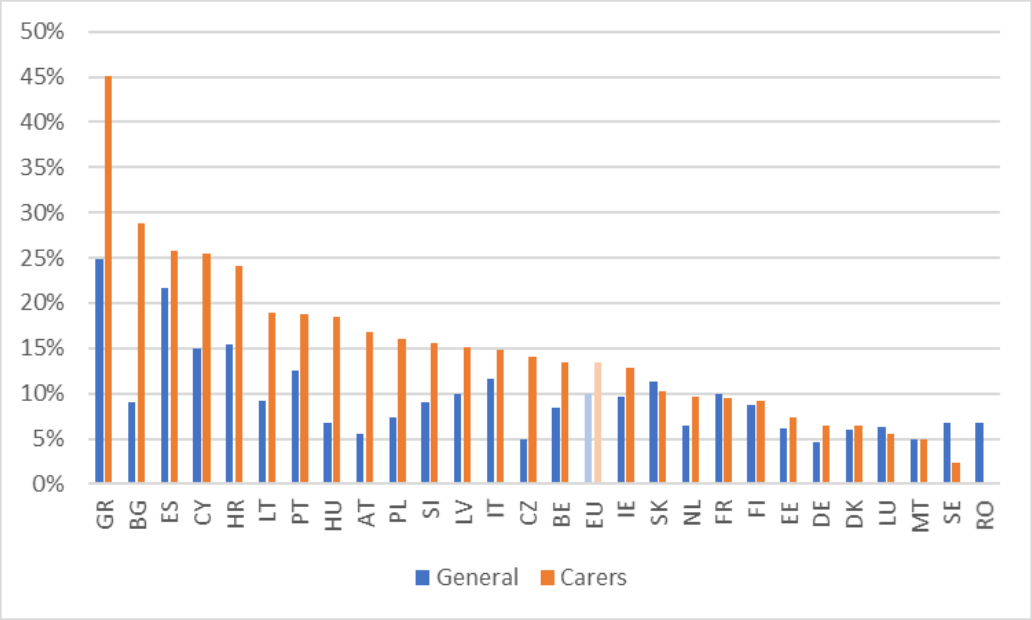
Figure 45 – Relation total and informal carers employment rates



Source: EQLS (2016) and EHIS (2013-2015), LFS (2015).

A low employment rate might mean either that many people are inactive (not employed but not searching for work either) or unemployed (not employed despite searching for work). This study follows the convention to express the number of unemployed as a percentage of the active population (excluding the inactive population). The unemployment among informal carers is 13% and somewhat higher than in the total population (10%), see Figure 46. Unemployment among informal carers is very low or virtually absent in Romania and Sweden, about 25% in Bulgaria, Croatia, Cyprus and Spain and even 45% in Greece. The countries with the highest unemployment rates naturally have low employment rates (Figure 44). However, Ireland and Malta have a combination of both low employment rates and low unemployment rates among informal carers, which points to a large inactive sub-population among informal carers.

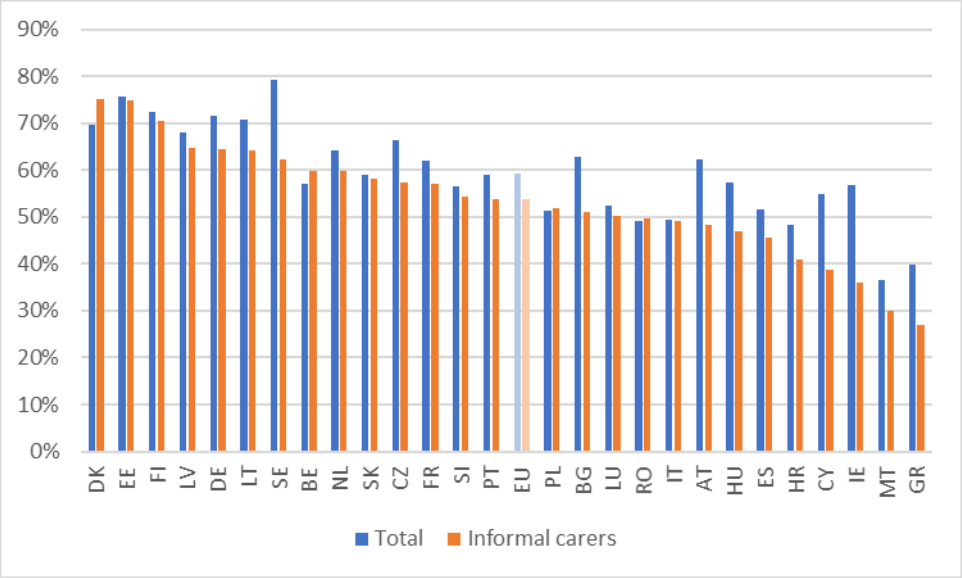
Figure 46 – Unemployment rates of general population and informal carers



Source: EQLS (2016) and EHIS (2013-2015), LFS (2015).

The previous two chapters showed that women aged 45-64 are more likely to provide informal care and on average also provide informal care for more hours per week than men of the same age or than younger informal carers. Thus, it comes perhaps as no surprise that women in this age group who provide informal care are less often employed (54%) than on average in this age group (59%); the actual difference is 5.6 percent points. In general, the employment rates among informal carers aged 45-64 is lower than the EU average in the East and South of Europe and higher in the North and West of Europe (Figure 47). The employment rate among informal carers aged 45-64 is particularly low in Greece and Malta (less than 30%), and particularly high in Denmark, Estonia and Finland (70% or more).

Figure 47 - Employment rates of women aged 45-64, total and informal carers



Source: EQLS (2016) and EHIS (2013-2015).

In this sub-population, the employment rate among informal carers increases one-on-one compared to the general employment rate (1.004 percent points among informal carers for every percent point in general) according to the regression shown in Figure 48. The same regression suggests an employment gap of 6.3 percent points for female informal carers aged 45-64.[84] This 6.3 percent points in Figure 48 is slightly higher than the 5.6 percent points in Figure 47. The reason for this difference is that the employment gap at the EU level is measured in slightly different ways: as just the difference in employment rate in the total population and among informal carers in Figure 47 and as a constant on top of the employment rate of Member States in Figure 48 (by means of a regression). The added value of the regression is that it shows that the employment gap at the EU level is not some random aggregate fact, but persists in different EU Member States. The next two chapters will assume an employment gap of 5.6 percent points.

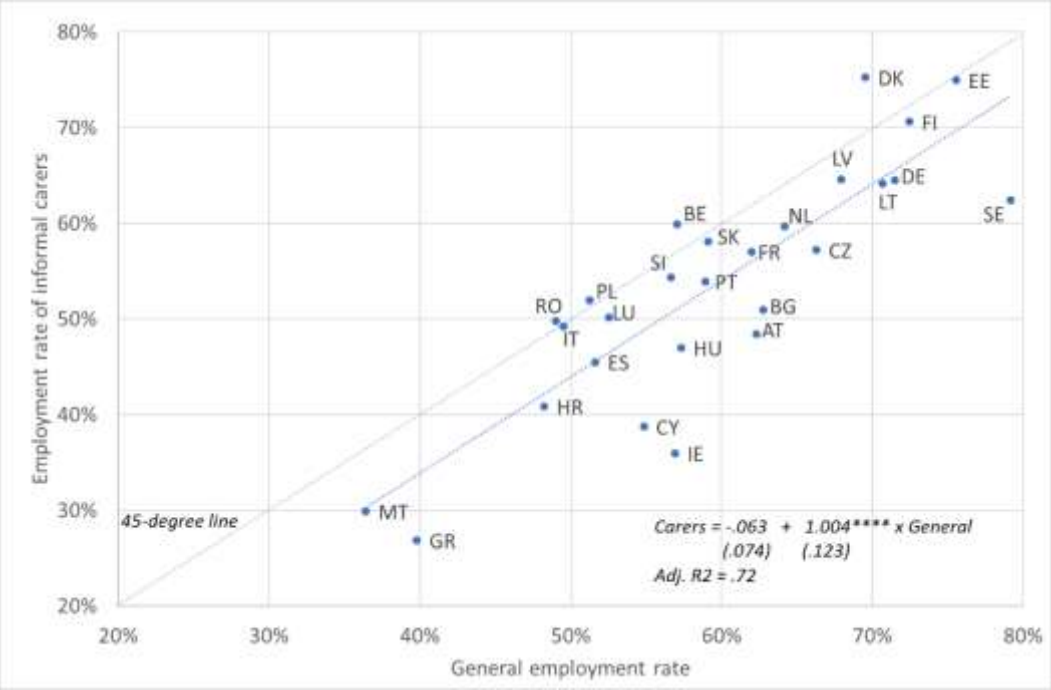
Figure 48 shows that in the age group 45-64 years, the vertically shown employment rate of informal carers ranges from 27% in Greece to 75% in Denmark and Estonia, compared to the horizontally shown general employment rate which ranges from 36% in Malta and Greece to 79% in Sweden. A point above the 45-degree line indicates that the employment rate of informal carers is actually higher than in the general population of women aged 45-

[84] The employment gap of 6.3% in the regression is not statistically significant (not even with 10% uncertainty), however a Pearson chi-squared test on 25,000 individual responses of women aged 45-64 indicates a statistically significant difference with a p-value of 0.0004.

64 years: notably Belgium and Denmark but also Poland and Romania. There is no literature about why informal carers could be more likely employed than non-carers and one can only speculate about possible reasons. Possible (*ad hoc*) explanations could be that employers in sectors such as healthcare and education value the informal care experience of women aged 45-64 (pull-factor), but another possibility could be that to the extent they provide care to their partner who lost his work, they may need to work to keep household income at an adequate level (push-factor).

Points below the 45-degree line indicate an employment gap: informal carers are less often employed than others, as is the case in most EU countries. The other line is the regression line which is 6 percent points below the 45-degree line. This indicates an average employment gap of 6 percent points for wormen providing informal care aged 45-64, compared to the general population of women in the same age group.

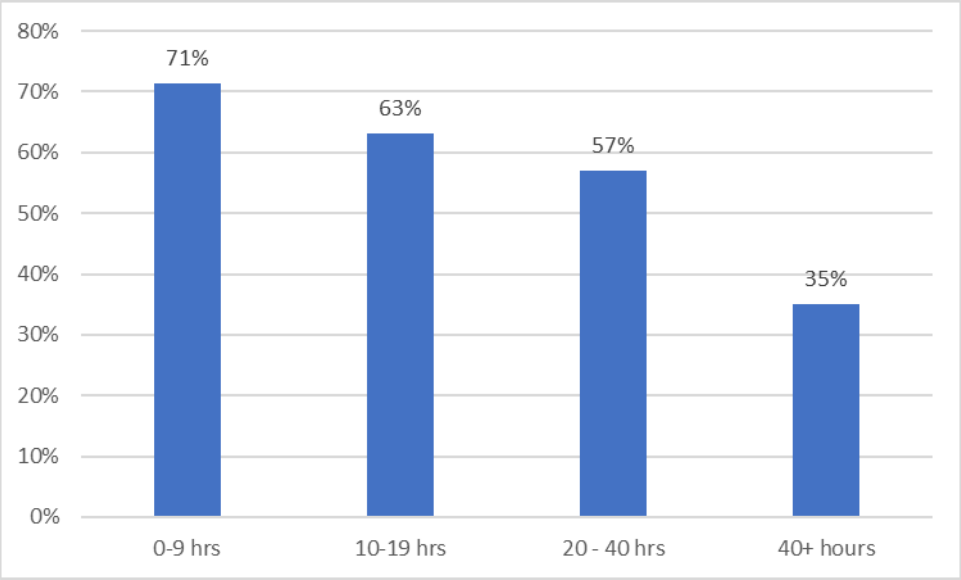
Figure 48 - Employment rates in general and of informal carers, women aged 45-64



Source: EQLS (2016) and EHIS (2013-2015).

According to both the EHIS and the EQLS database, the employment rate decreases with the number of hours that persons give informal care (Figure 49). Based on combined data, the employment rate is highest at 71% among low-intensity carers (less than 10 hours care per week). However, the employment rate decreases with the intensity of informal care and drops to 35% for intense carers (40+ hours care per week).

Figure 49 - Employment rate by hours per week of giving informal care (age 18-64)

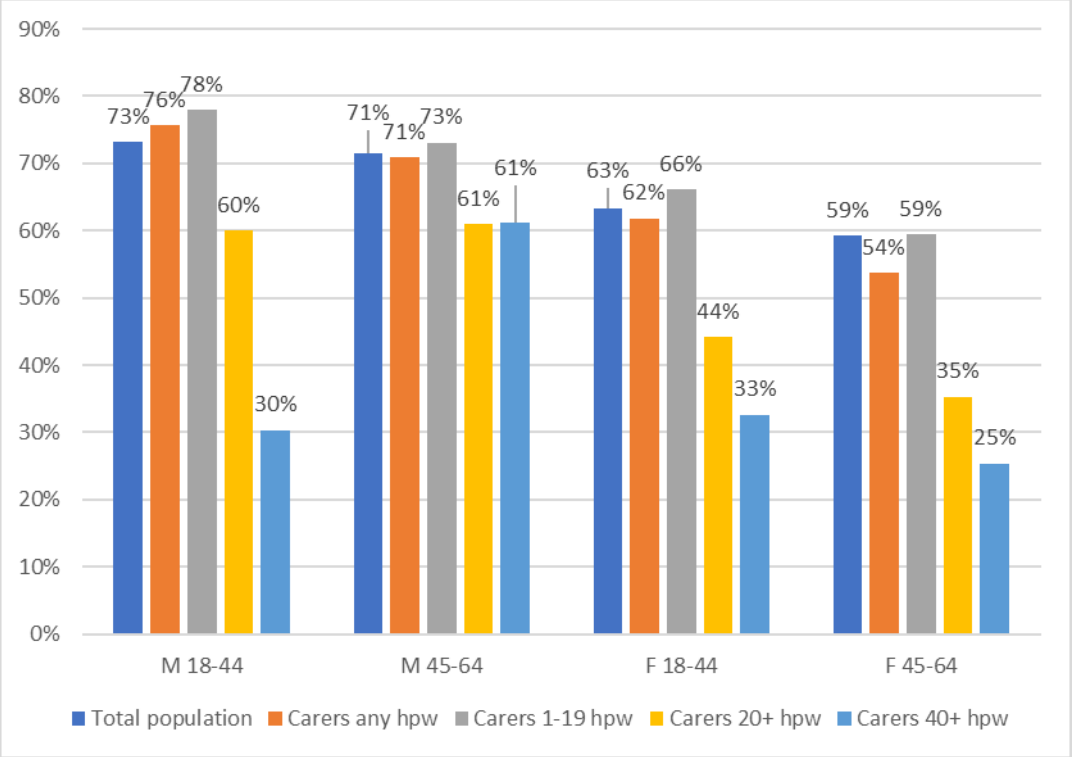


Source: EQLS (2016) and EHIS (2013-2015).

As Figure 49 shows, the employment rate is particularly low for intense care providers, although it should be noted that only a small part of about 10 % (7% for men, 12% for women) of informal carers provide intense care (more than 40 hours per week). Among the intense carers, the employment rate is below average of the total population in the working age, regardless of gender and age group (compare light and dark blue bars in Figure 50). In fact, the drop in employment rate is already noticeable from 20 hours per week of informal care. However, the group of intense carers is not large enough to affect the average employment rate much. [85] The employment rate among non-intense carers is at least as high as that of the total population (compare grey and dark blue bars in Figure 50) regardless of gender and age group.

[85] The number of respondents providing intense care is too small to compare their employment rates between countries, whether from 20+ or from 40+ hours of informal care per week.

Figure 50 - The employment rate by gender and age, total population and informal carers (total and by hours per week of informal care)



Note: Informal carers* assumes the employment of non-intense carers equals that in the total working age population and employment of intense carers is the observed value.
Source: EHIS (2013-2015) and EQLS (2016).

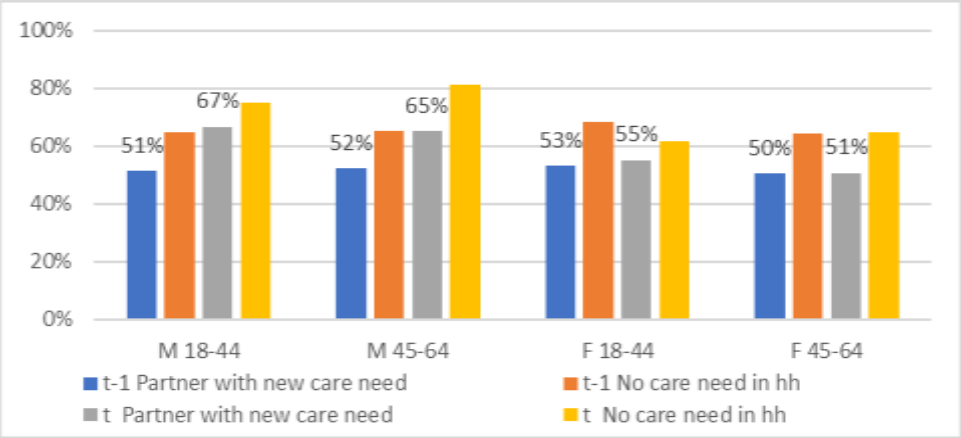
Most literature confirms that only high-intensity carers are significantly less often employed. Cicarelli and Van Soest ([15] in the literature list of Annex B) conclude this explicitly for people aged 50+ (based on SHARE data) and add that especially women providing high-intensity care are less likely employed. Schmitz and Westphal ([22] in Annex B) find a four percent points lower probability to work full-time and find a larger effect for high-intensity (3+ hours per day in their definition) or long-lasting informal care. Heger and ([13] and Kolodziej et al. [18] in Annex B) limit their analysis to people aged 50+ caring for parents and find that employment is only lower in countries that rely strongly on family care (Heger) or only in East and South Europe (Kolodziej et al.). As demonstrated in Section 4.1, these tend to be countries with more high-intensity care. Interestingly, Kolodziej et al. find no evidence that gender causes different employment rates. Stanfors et al. ([23] in Annex B) find for Sweden no difference in employment rates between informal carers and others in the working age. According to Kolodziej et al. the difference in employment likelihood above the age of 50 is 14 percent points less for informal carers than for others in the working age; however this difference in employment likelihood is not statistically significant at the usual 95% certainty level.

The employment gap of female informal carers aged 45-64 is partly explained by the provision of intense care, but not completely. When comparing employment level of informal carers before and after an adult in the household became dependent on care (see Figure 51)[86], analysis shows that around half of the women aged 45-64 had been inactive already

[86] The EU-SILC data (2010-2017 longitudinal version used) offers an indirect possibility to zoom in on people providing informal care to other adults in the household. Here, a "treatment" group can be defined where in the preceding (interview) year people lived with adults without health limitations and in the going (interview) year lived with an adult with health

before becoming an informal carer and the employment rate was not lower after the partner needed care for the first time than before (Figure 51). For men on the other hand, the employment levels actually increased once they started providing informal care. This could indicate that women often go from one caring activity to the other, starting with childcare to care of parents and partners, or even engage in several caring activities at the same. Caring activities over the life course are not equally distributed, resulting in gender inequalities and women participating less in the labour market. Overall, informal care provision reinforces gender inequalities in employment.

Figure 51 - Employment rate before and after another household member had for the first time health or old age problems compared to others, by gender and age



Note: Others means people who are not providing informal care.
Source: EU-SILC, longitudinal version 2010-2017.

To conclude, the employment rate among intense informal carers in all four gender-age groups is significantly lower than the general employment rate of that gender-age group. However, only for women aged 45-64 the proportion of intense informal carers in the population is large enough to cause the employment gap also to be significant for the whole group of informal carers (namely 6 percent points). By country, the employment rates of informal carers mainly reflects the general labour market situation. The employment gap is largest in the East of South of Europe which is likely related to the higher proportion of intense care in those countries. In most countries with a low employment rate of informal carers, the unemployment rate among them is high as well, with Ireland and Malta being the main exceptions where the unemployment rate is low as well, indicating a relatively large inactive sub-population among informal carers in the working age. It should however also be noted that the employment gap is not necessarily caused by informal care. Indeed, employment rates in the first year of informal care are not lower than in one year earlier in any of the four gender-age groups in the working age considere in this study.

Work hours

limitations. The “control” group is similar but in the going year still no adult household member had health limitations. The “treatment” group is likely highly correlated with the start of informal care provision to an adult household member (“partner” for short).

At the EU level, informal care is associated with slightly fewer hours worked on the formal labour market, because informal carers who in addition are employed are more likely to work part-time. At EU level, 65% of informal carers aged 18-64 in employment work full-time, compared to 75% of all employed people[87]. 30% of employed informal carers work in part-time jobs of between 20 and 36 hours per week, compared to 23% of all employed people. 7% of employed informal carers work less than 20 hours per week compared to 4% of all employed people[88]. The difference in full-time work is largest in Belgium and Germany, where just over 50% of informal carers aged 18-64 work at last 37 hours per week compared to 70% in the total working age population. Other countries where the share of full-time workers among informal carers is substantially lower than among others in the working age (8-10 percent points difference) are the Czech Republic, Greece, Luxembourg and the Netherlands. In all these countries informal carers work mostly 20-36 hours per week rather than less than 20 hours.[89]

The difference in average numbers of work hours is also small at the EU-level: 39.5 hours on average among informal carers and 40.6 hours in the total employed population aged 18-64 (Figure 52). Although intense carers work less often than others, if they work it is for similar working hours per week (39.2). As in the total population, women among informal carers work on average fewer hours per week than men: between 37 and 38 hours per week for women and between 43 and 44 hours per week for men. As in the total population, the difference between men and women is significant. However, both for men and for women the difference in work hours between informal carers and the general population is insignificant.

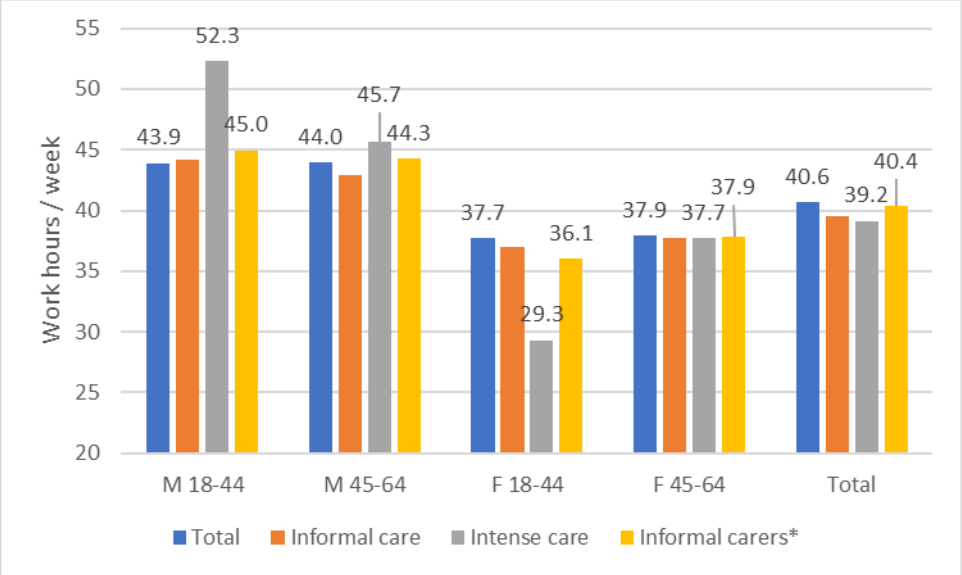
On the other side, among women aged 18-44, intense carers work significantly fewer hours per week at the EU level: 29.2 compared to 37.7 among the total population of employed women aged 18-44 (Figure 52). As for the total employment rate, the number of intense carers is too small to affect the average number of work hours much, and also too small to compare between countries.

[87] Based on European Quality of Life Survey (EQLS) (2016). This study defines full-time work as at least 37 hours per week. The cut-off of 37 hours is used because according to the Eurostat Labour Force Survey, the lowest average working hours in full-employment is between 36 and 37 hours in some professions and some countries.

[88] Ibid.

[89] Reasons for a greater proportion of substantial part-time work (20-36 hours per week) rather than small part-time work (less than 20 hours per week) are difficult to give for each country. For example the Netherlands are world champion in part-time work and much of part-time work and the substantial hours in part-time jobs is explained by the fact that employers allow workers to work less than full-time. In other countries part-time work is less often voluntary and perhaps employers wish to pay less than full-time salaries, or perhaps workers combine multiple part-time jobs to earn a living standard. An analysis of this goes beyond the scope of this study.

Figure 52 - Work hours by gender and age, total population, informal carers, intense carers and informal carers* with assumptions about work hours



Note: Informal carers* assumes work hours of non-intense carers equal those in the total working age population and work hours of intense carers are the observed values.
Source: EQLS (2016).

There is not much literature on work hours of informal carers, but the few studies that cover this, confirm the results of this study. Heger ([13] in the literature list of Annex B) found no effect of informal care on hours worked (age 50+, based on SHARE). Stanfors et al. ([23] in Annex B) found higher part-time work in Sweden. Schmitz and Westphal ([22] in Annex B) found that among Germans in their first year of providing informal care the proportion of full-time workers was 27% of the total sub-population (not only those employed) compared to 31% one year earlier, but the difference of four percent points was not statistically significant. They also found that average weekly work hours were 31 in the first year of providing informal care compared to 32 one year earlier, but again the difference was not statistically significant.

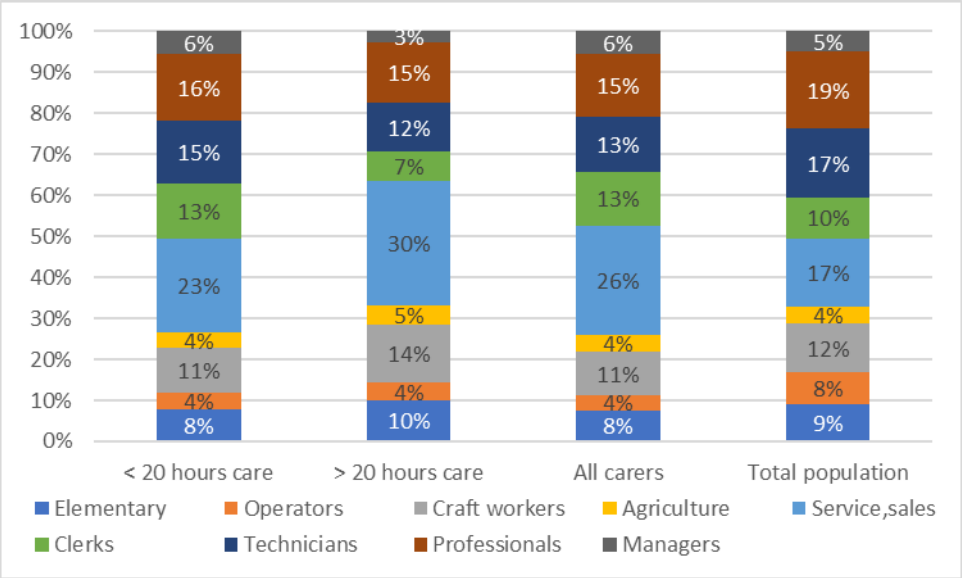
Thus, both the findings of more frequent part-time work among informal carers and the difference of only one hour in work weeks compared to the general population in the working age are confirmed by literature. There is a gender difference in work hours among informal carers but it is the same as in the general population.

Occupation of employment

Informal carers are more likely to work in service and sales (26%) compared to employed people in general (17%), especially if they provide informal care for more than 20 hours per week (30%). Informal carers are also less likely employed as machine operators and assemblers (4%) compared to employed people in general (8%) but this does not relate to the hours of informal care (Figure 53).

The difference in occupational split between employed informal carers and other employed people may seem surprising given that their educational profile does not differ so much. The occupational split of informal carers is partly affected by the gender-age profile of informal carers, and the dominance of service and sales workers among informal carers partly relates to the dominance of women aged 45-64 among informal carers.

Figure 53 - Occupational split of informal carers by hours of care, and total employment



Source: EQLS (2016) and EHIS (2013-2015); *elementary refers to elementary occupations*.

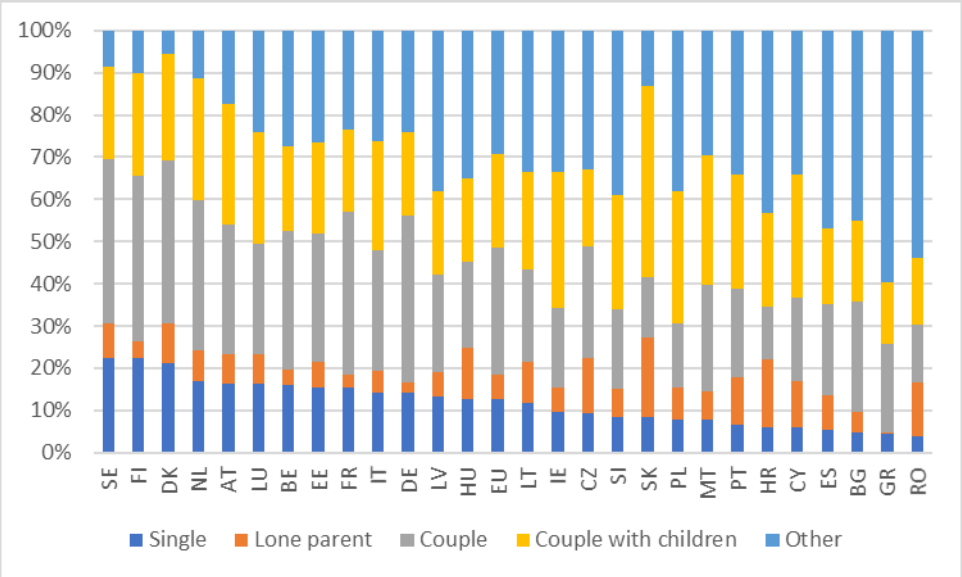
However, the difference in occupational split also partly points to difficulty to combine work in high-skilled occupations with informal care. Compared to employed people in general, informal carers are less often employed in high-skilled occupations (managers, professionals and technicians and associate professionals): 34% among employed informal carers compared to 41% among those employed in general. In particular, the data suggest that management positions at work are hard to combine with long hours of informal care, because 3% of those providing informal care for more than 20 hours per week are in management positions compared to 6% of informal carers on average.

The share of informal carers who provide help to people aged 75+ is much lower than average of 64% (Figure 28) for skilled agricultural workers (34%) and craft and related trades workers (48%). Likely explanations are that skilled agricultural workers make long hours in high season and that craft workers include construction workers who have to travel long hours to the construction site so frequent travels to take care of parents may be more difficult for them.

5.5. Household type

The household situation of informal carers does not seem very different from other people, although this characteristic has not been investigated in much detail due to the large number of “other” household types which makes results difficult to interpret or to compare with other data. Informal carers are most likely to live in single-person households in the north and central Europe as well as in Italy, and least likely in the east and south of Europe, as well as in Ireland (Figure 54). Lone parents are a relatively small group, and the dominant household type among informal carers consists of couples with or without children.

Figure 54 - Split of informal carers by household type



Source: EQLS (2016) and EHIS (2013-2015).

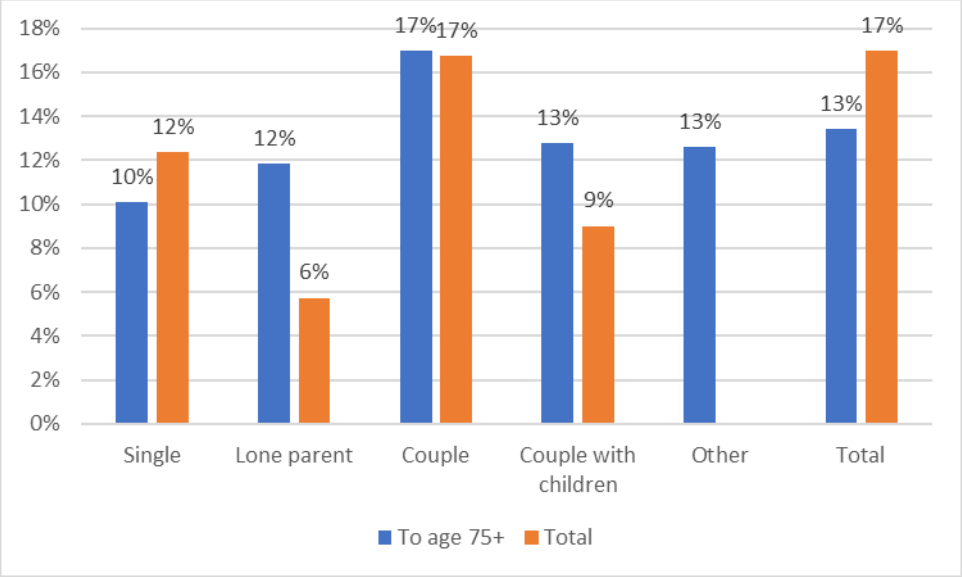
At the EU level, the proportion of informal carers providing help to people aged 75+ is slightly over half for households with children (55% for single parents and 57% for couples with children). The proportion of informal carers providing help to people aged 75+ is about 70% for households without children (69% for singles and 70% for couples without children). For the category "other households" the percentage is in between (65%). This finding raises the question whether adults in households with children provide more informal care to younger people, or less informal care to older people.

Unfortunately, the EQLS does not provide an unambiguous answer to this question because of the category "other type of household". Taken at face value, people in households with children are equally likely to provide informal care to people aged 75+ (Figure 55). Among singles, lone parents, couples with children and "other" types of households the percentage of people providing informal care to others aged 75+ varies between 10% and 13%. For couples without children this percentage increases to 17% but this includes older couples who provide informal care to their partner.

People in households with children are less likely to provide informal care in general (6% for lone parents, 9% for couples with children). However, if they do, combining the above two pieces of evidence on the incidence rate and the proportion of informal care to people aged 75+ implies that children in the household increases the likelihood of informal care to younger persons without decreasing the likelihood of informal care to people aged 75+.

The caveat to the above analysis is the rather large proportion of "other" types of households in the EQLS which includes people living with parents grandparents, in-laws (parents in law or children in law), brothers, other relatives or non-relatives in which case the likelihood of providing informal care is significantly higher (but not reported here because it is oddly high).

Figure 55 – Incidence of informal care by type of household of informal care provider



Source: EQLS (2016). The total incidence of informal care in "other" types of household is outside the range of the graph and is not presented.

5.6. Household income and risk of poverty

In general, larger families need more income because they have more mouths to feed. For this reason, it is customary to "equivalize" household income by calculating a weighted average household income per household member, where the first adult are assigned unit weight (weight = 1), subsequent adults are assigned weight 0.5 and children are assigned weight 0.3. This analysis requires household income to be exactly observed, however in EQLS and EHIS household income is classified in categories. For this reason, the analysis of household income is first based on actual income when the combination of EQLS and EHIS is used, and is subsequently based on equivalized income when the EU-SILC 2016 ad hoc module is used.

Actual household income

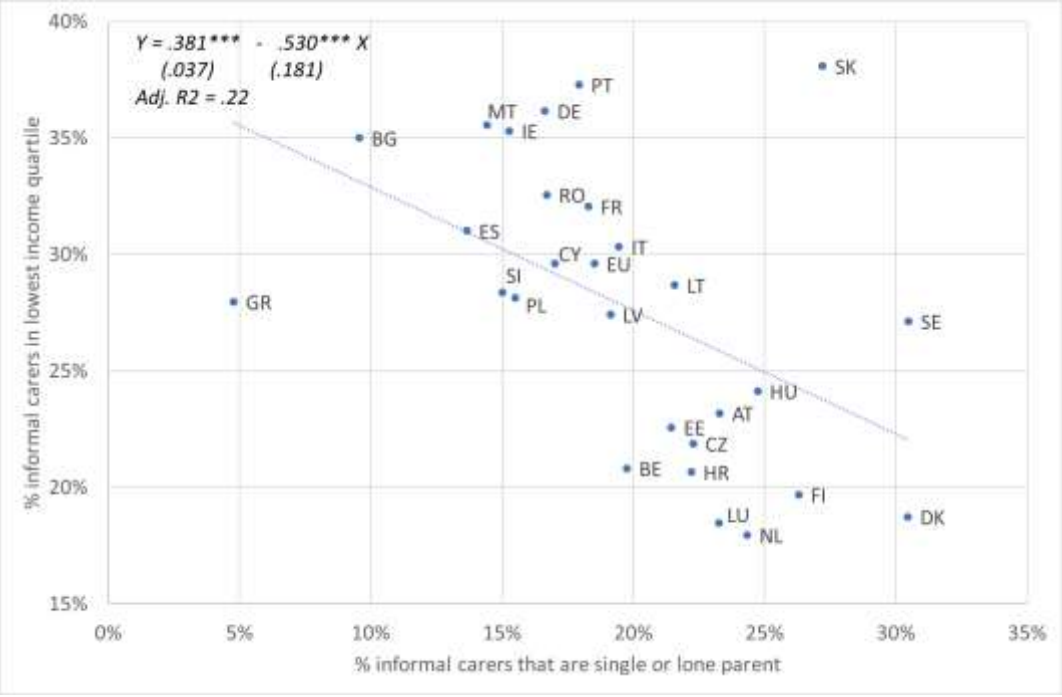
Despite similar educational levels, low-income earners are slightly over-represented among informal carers. In the EU, 46% of the informal carers aged 20 to 64 live in a household with above-median income compared to 52% of the general population in the same age bracket. Another finding is that 30% of informal carers aged 20-64 have a household income in the bottom quarter of the income distribution, compared to 26% in the general population in that age bracket. One possible reason is that a household member provides informal care instead of opting for formal care for the dependent due to financial reasons. Another possible reason is that part-time workers and non-employed people are more likely to start providing informal care. On the other hand, as discussed further down, (previously) employed people providing intense informal carers face a loss of income, as they cannot participate (fully) on the labour market. Therefore, since formal care is rarely free (or fully insured), households where intense care is needed, may face a trade-off between paying

for formal care but the family member remains employed, or providing informal care but losing income from work.

Singles and lone parent informal carers are more likely to face low-income situations. One might expect the employment rate of informal carers or the general income distribution (Gini coefficient) to be a major determinant of (household) income of informal carers, because in some aspects such as educational level informal carers seem a random sample of the population. However, these first two factors explain only five to six percent of the cross-country variation of the proportion of informal carers in the lowest income quartile (not corrected for household composition due to data limitations of EHIS and EQLS, however further below the poverty rate is discussed based on equivalized household income using the EU-SILC 2016 module data). One might also expect care allowances to be a major determinant, with low-income situations more likely in the absence of care allowances. However, the impact of the availability of care allowances is not always clear-cut. In both the Netherlands and Germany, people in need of care receive a nursing allowance, but in the Netherlands 19% of the informal carers aged 20-64 are in the bottom income bracket while in Germany 39% are. Finland, Ireland and Malta all have a carer allowance, but in Finland 20% of the informal carers aged 20-64 are in the bottom income bracket and in Ireland and Malta 38% and 36% respectively.

Informal carers who are singles or lone parents are significantly more likely to have a household income in the lowest quartile than other informal carers (Figure 56). This is partly trivial because households with more people tend to have a higher combined income (from work, pensions or benefits). However, this finding also underlines that singles and lone parents cannot rely on the income of another household member if they provide informal care.

Figure 56 - Relation between lowest income quartile and household type across the EU

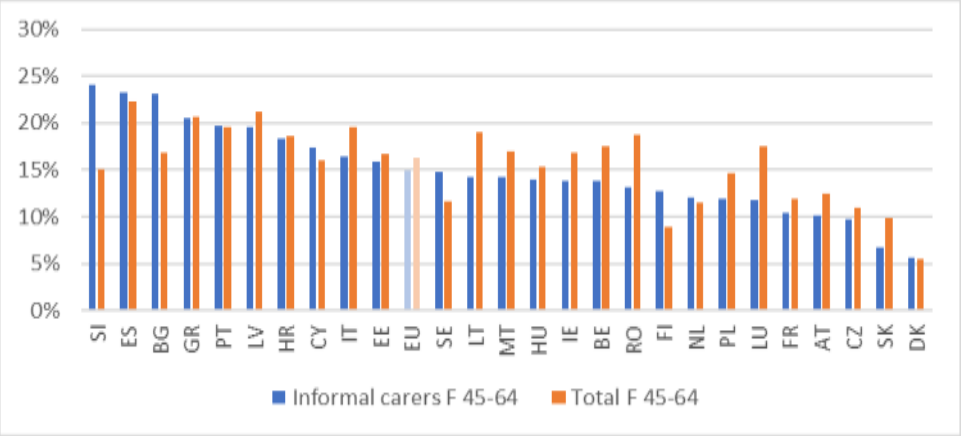


Source: EQLS (2016) and EHIS (2013-2015).

Risk of poverty

Like other women aged 45-64, female informal carers are at greater risk of poverty in some countries, based on a comparison of equivalised household income with the national risk-of-poverty threshold.[90] At EU-level, the poverty rate of female informal carers aged 45-64 is 15% and thus similar to the 16% of the total population of women aged 45-64, based on the EU-SILC 2016 ad hoc module (Figure 57). However, in two countries, Slovenia and Bulgaria, female informal carers at this age are at a particular risk of poverty compared to others. In addition, although in Finland and Sweden the risk of poverty is lower than the EU average, it is higher among informal carers than among others aged 45-64. In Spain, Greece and Portugal this group of informal carers also has a high risk of poverty, but not more than other women in this age category (the risk-of-poverty rate of women aged 45-64 is above EU average in these countries[91]). Lastly, there are also countries where informal carers have a lower risk of poverty than aged aged 45-64 such as Lithuania, Luxembourg and Romania.

Figure 57 - Risk-of-poverty rate among women aged 45-64, informal carers and total population



Source: EU-SILC 2016 ad hoc module.

Informal carers living in single-adult households are at greater risk of poverty than average: 22% compared to 15%. However, this risk is not greater for informal carers than for the average single-adult household (24%). In eight EU Member States in the east of Europe (BG, CZ, EE, HR, HU, LT, LV and SI) more than 30% of informal carers living in single-adult households are at risk of poverty, however only in the Czech Republic and Hungary is this risk greater for informal carers than for average single-adult households.

5.7. Conclusions

Close to 60% of the informal carers are women, however in other aspects informal carers seem a random sample from the population. The educational profile and the risk of poverty of informal carers are similar to the total population: close to half have upper secondary education, and slightly more than a quarter each have lower education and tertiary

[90] As national risk-of-poverty threshold, 60% of the median equivalised household income is used.

[91] The comparison is with Eurostat (2016). At-risk-of-poverty rate by poverty threshold, age and sex - EU-SILC and ECHP surveys (ilc_li02). Retrieved on 14.12.2020 from http://appsso.eurostat.ec.europa.eu/nui/submitViewTableAction.do.

education, respectively. Before correcting for household size, a slightly larger proportion of informal carers aged 20-64 has a household income in the bottom quarter compared to people aged 20-64 in general: 30% compared to 26%. However, larger families need more income to feed additional mouths, and low incomes of informal carers are predominantly in single-person households. After correcting for household size ("equivalizing"), the risk of poverty is the same for informal carers aged 20-64 and the rest of the population in that age bracket. Differences between countries in educational profile and the risk of poverty of informal carers reflect differences in educational systems and poverty in general.

The health status of informal carers is difficult to compare with the general population because informal carers are a selective group. For example, people with a disability are more likely to receive help than to provide help. The few studies that directly compare the health status of informal carers with a peer group offer mixed findings. Two ways to control for self-selectivity are statistical regressions controlling for other characteristics of people such as gender, age, education etcetera, and a comparison of changes in health status over time between informal carers and others. This study and previous literature then find:

- Informal care affects the mental health of the caregiver, especially between spouses
- If informal care affects the physical health of the caregiver, it is limited to intense informal care but evidence is mixed

Evidence on the employment of informal carers is mixed. This study found a slightly lower employment rate among informal carers than in general: 64% compared to 67%. However, only for women aged 45-64 this difference was significant: 6 percent points. The employment gap of women aged 45-64 providing informal care is largest in the South and East of Europe and is partly explained by the greater intensity of informal care in that region. Previous literature also found significant negative correlations between employment and intense informal care only.

Informal carers work less often full-time (at least 37 hours per week) than others in the working age: 65% compared to 75%. Nevertheless, the difference in average working hours per week is limited to one hour, mainly because informal carers who reduce their working hours, on average work more hours per week than part-timers in general. One Germany study found that informal carers on average reduce their working hours by one hour at the start of the care stint. A possible reason for the larger part-time jobs of informal carers is that slightly over half of the informal carers provide less than 10 hours of informal care per week. Thus, for a large part of the informal carers a small reduction in work hours seems to suffice.

Only among women aged 18-44 providing intense care a large and significant difference in work hours per week is observed: 29 hours compared to 38 hours among employed women aged 18-44 in general. Unfortunately, the number of intense informal carers is too small to analyse differences between countries. The previous literature confirms both findings in increased part-time work among informal carers and (although limited to Germany) a difference of only one work hour per week.

The occupational profile of informal carers in employment reflects gender differences rather than educational differences: informal carers are more likely to work in service and sales (26% compared to 17% in general) and less likely to work as machine operators and assemblers (4% compared to 8% in general). A further split by intensity of informal care suggests that high-skilled jobs and in particular management jobs are difficult to combine with informal care of more than 20 hours per week: 3% of people providing informal care for more than 20 hours per week are in management positions compared to 6% of informal carers in general.

6. Individual costs and benefits of informal care

6.1. Methodological notes

Using the framework from Table 1 in Chapter 1, the costs of providing informal care to the care provider consist of travel costs and mostly indirect costs:

- Less leisure.
- Lost wages.
- Lost future pensions.
- Skills loss.
- Caregiver burden.
- Adverse health outcomes.
- Risk of poverty.

The framework further classifies the following benefits of informal care:

- Sense of purpose.
- Care allowance.
- Income support, unemployment benefits.
- Affections, relations with the care recipient.

Travel costs are incurred if the care provider and care recipient live in different households, although if specific equipment is used, their cost should be included as well. However, such expenses are considered too minor and the lack of data is too severe to quantify them.

The indirect costs of less leisure and lost wages depend on the carer's missed opportunities. In the hypothetical situation that an informal carer does not have to provide care, would that person have enjoyed leisure or gained income from work? The most important thing to avoid here is to double-count the same hours as hours of lost leisure and lost income from work. One way of ensuring that hours are not double-counted, is to assume the leisure opportunity for all hours of informal care provided by people aged 65 and older and to assume the employment opportunity for all hours of informal care provided by people in the working age (18-64). This is a simplification because it would imply that full-time working informal carers would otherwise have worked more than full-time hours.

In reality, many non-carers in the working age are not employed and many informal carers in the working age are employed and even full-time employed. This chapter compares the employment rates and average work hours between informal carers and non-carers. Only where these values are lower for informal carers than for others, an employment gap is

identified and employment is assumed to be the missed opportunity.[92] Otherwise, leisure is assumed to be the missed opportunity. Contrary to the next chapter, leisure is not monetised in this chapter, because people do not receive money for watching TV or other leisure activities.

Actually, the employment opportunity could even apply to fewer persons than the employment gap indicates. For example, the previous chapter showed that the health status of informal carers is on average worse than for employed people on average. Figure 43 further showed that providing informal care has a detrimental effect on the health status. However, there is likely also some self-selection of healthy people into work. Indeed, Figure 51 indicates that the employment rate of women caring for an adult household member was roughly the same before and after their household member needed to be cared for, and that the employment rate of men even increased after their household member became in need of care. However, it can also be argued that informal care is just a continuation of care duties, first for children and then for older or sick relatives. One argument for this interpretation is that also in general, men are more often employed than women.

Therefore, costs of lost wages are calculated for the full employment gap (in terms of employment status and hours of work). In case the employment rate is higher among informal carers than among others, informal care is assumed to result in increased income from work. This may seem counter-intuitive, however as noted in Section 5.4, employers in healthcare and education may value their experience as informal carer (pull-factor) or people providing informal care to a partner who lost his work may need to work for an adequate household income (push-factor). Where informal carers are employed at a greater rate than others, the calculated cost of the employment difference is negative and should be interpreted as benefits.

For individual non-employed informal carers, the relevant lost wage is the income net of taxes and social security contributions. Without paying those contributions, the informal carer is not insured for future lost income in case of unemployment, sickness, disability or maternity. Of course, for non-employed informal carers the current labour market status is already one of those (unemployment, sickness, etcetera). If hypothetically someone has a disability benefit there is generally no risk that the benefit will be lower in the future. Unemployment benefit levels do decrease over time in some countries, but the maximum duration of unemployment benefits is generally less than the average duration of care stints (3.5 to 4.5 years in the Netherlands and France). Sickness benefits are generally also short-term and in addition stable over time. Hence, this study does not analyse the risk of lower disability, unemployment or sickness benefits after the care stint. However, old age is one particular risk that everyone needs to be insured for regardless of their labour market status, and in some countries informal carers are not insured against this risk. Therefore, the loss of future pension income is considered to be a separate cost of informal care, contrary to unemployment, sickness, disability and maternity benefits. The loss of future pension is only calculated for the employment gap in terms of employment status. If informal carers reduce their hours of work, this assumed to have a negligible impact on future pensions.

Non-employed informal carers may experience difficulties finding employment after their care stint. For the number of informal carers in the employment gap, the total probability of not re-entering employment is used to calculate the associated lost income. For other informal carers, only the difference in probability of re-entering employment compared to other “similar” non-employed people searching for work is used.

The caregiver burden and the analogous benefit “sense of purpose” are interpreted as emotional costs and benefits, and are only briefly discussed qualitatively in this chapter.

[92] Note that the missed opportunity is not necessarily caused by the informal care provision. As is evident from Figure 51, most non-employed informal carers were already non-employed before the start of the informal care spell. However, one could still say that informal care causes a continuation of missed opportunities, that before the informal care spell perhaps were caused by childcare (care of healthy offspring).

The risk of poverty was already discussed in the previous chapter in relation to household income. Since the outcome was that the risk of poverty does not significantly relate to informal care, it is not further discussed in this chapter.

6.2. Wage loss due to non-employment

The previous chapter explored the difference in employment rate between informal carers and the total population by gender and binary age group (18-44 and 45-64 years old). As Figure 50 showed, an employment gap of more than one percent point was identified for women aged 45-64. For this specific group, Figure 48 showed that the magnitude of the employment gap varies widely between Member States, and in four countries women aged 45-64 who provide informal care are even more often employed than women in this age group in general: in Poland and Romania (slightly) and in Belgium and Denmark (more substantially). For these four countries the employment "gap" is negative and associated costs are actually benefits of higher employment.

The difficulty to assess the wage loss is to determine the applicable income aspects for women aged 45-64. From Eurostat, average gross earnings of a full-time worker (annually or per hour) is available by country, gender, age and occupation, from the most recent Structural Earnings Survey (SES 2018).[93] All data were collected by occupation to get data on the spread of income. This is important because tax rates are progressive: higher income is in most Member States taxed at a higher rate. For a full coverage of Member States, data on companies with at least ten employees were used. This slightly overestimates earnings because micro-enterprises (with less than 10 employees) pay at lower wage rates than average.

Of course, not everyone works full-time and women aged 45-64 are even more likely to work part-time than men or younger persons. Therefore, Labour Force Survey (LFS) data of 2019 (the most recent available annual data at the time of this analysis) were used to collect data on the numbers of women aged 50-64 working part-time and full-time respectively, by country and occupation, under the assumption that for women aged 45-64 the same percentage is working part-time.[94] The LFS 2019 was also used to collect data on average hours of women working part-time and full-time respectively, by country and occupation (regardless of age, since Eurostat does not publish average working hours by this fourth-dimensional breakdown).

Average annual gross earnings of women aged 45-64 were calculated per country and occupation by multiplying the hourly wage rate with the average work hours per week for part-time and full-time workers respectively, and then further multiplied with the percentages of part-time and full-time workers respectively. The sum of these results were lastly multiplied with 52 (the number of weeks in a year). In formula:

$$Annual\_wage_{ij} = 52 \cdot Hourly\_pay_{ij} \cdot (\%FT_{ij} \cdot Hours\_FT_{ij} + \%PT_{ij} \cdot Hours\_PT_{ij})$$

Where i stands for one of the 27 EU Member States and j stands for one of the nine main ISCO categories of occupations. For each country and occupation, the net earnings were calculated by applying the tax rates and employee social security contribution rates from OECD data, for annual gross incomes at respectively 67%, 100%, 133% and 167% of the

[93] Eurostat code: EARN_SES18_28.

[94] Eurostat code LFS_EPGAIS. The age breakdown in this study is 45-64 but the Eurostat website presents only detailed data for the age group 50-64.

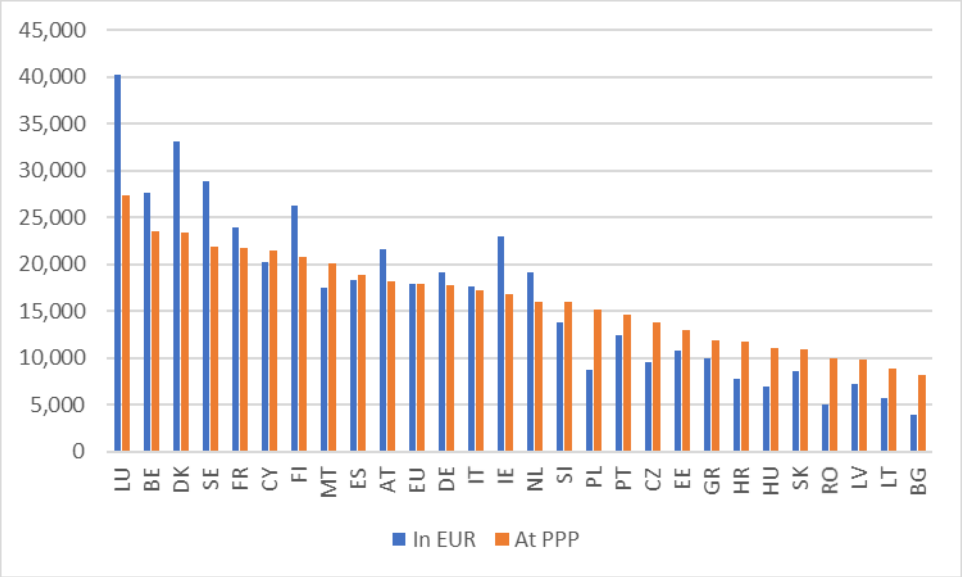
average gross annual wage. For the five countries where these data were not available,[95] PwC data on tax and social security rates were used.[96] For both OECD and PwC data, the rates include health insurance contributions.

For occupations where the average annual gross wage of women aged 45-64 is less than 67% of the national gross average, the tax rate at 67% is used, and for occupations where it is above 167%, the tax rate at 167% is used. For occupations where the gross annual wage is in between, the tax rate is assumed to progress linearly within the income bracket.[97]

Lastly, the net wages were averaged across the occupations for each country after weighting with the headcount share of women aged 45-64 working in those occupations. A further refinement could have been to calculate the net wages for full-time and part-time workers and then average the net wage with full-time and part-time weights as well but this was not done.

Lost income by non-employment of informal carers is expressed in Euros and in addition corrected for differences in purchasing power parity for actual consumption. In euros, non-employed informal carers could have earned a gross annual wage EUR 25,800 and an average net wage of EUR 17,900 at the EU level. After further correcting for differences in purchasing power (EU = 1), lost income remains highest in Luxembourg, and above EU average in most countries in the north and west of Europe, and below EU average in most countries in the east and south of Europe (Figure 58).

Figure 58 – Annual net wage, women F 45-64, in EUR and corrected for purchasing power



Source: SES (2018), LFS (2019) and Eurostat PPP and exchange rates 2019.

Men and younger workers are less likely to provide intense informal care (more than 40 hours per week). However for those few that do provide intense care and drop out of work,

[95] OECD tax and social security rates are not available for Bulgaria, Croatia, Cyprus, Malta and Romania. PwC only publishes average tax rates (at 100% of average gross annual wage). In the five countries for which PwC data was used, the average tax rates are quite low and similar to Poland, and hence the same progression of tax rates was assumed as for Poland. For social contribution rates no assumptions were needed: they are levied at flat rates in Bulgaria, Croatia, Cyprus and Romania. And in Malta the social security contributions seem to be fixed amounts.

[96] See https://taxsummaries.pwc.com/bulgaria/individual/other-taxes for Bulgaria and similar for other countries.

[97] Graphically, this is equivalent to drawing successive lines between successive dots.

their gross income loss at the EU level is respectively EUR 27,000 (men 45-64), EUR 23,200 (women 18-44) and EUR 30,700 (men 18-44).[98]

6.3. Wage loss due to reduced work hours

In the previous chapter, women aged 18-44 providing intense informal care (40+ hours per week) were shown not only to be less often employed (Figure 50), but also to work less hours per week compared to other women in that age category (Figure 52). It should be noted that the numbers of intense informal carers (who in addition are employed) are too small to affect the overall average number of working hours by more than one hour per week, even among women aged 18-44. Nevertheless, if women aged 18-44 provide intense informal care and reduce their work hours, they work on average 8 hours per week less at the EU level (20% of the "standard" work week of 40 hours). Unfortunately, the number of respondents who report to provide intense informal care is too small to meaningfully estimate their hours reduction per country. Assuming that the average hours reduction of women aged 18-44 and providing intense informal care is 8 hours per week in all EU countries, their income loss is between 20 and 25% for almost all EU countries.[99]

For employed women aged 18-44 providing intense care and reducing their work hours, it is likely that they return to usual work hours after the care stint has ended. After all, they have remained employed the whole time and the hours reduction is likely caused by the care stint.

6.4. Informal care allowances and other benefits

Most EU countries compensate informal carers for a loss of income during their care stint, but often under conditions of the severity of care needs or the intensity of informal care. Some countries pay these benefits directly to informal carers, while other countries pay benefits to people with care needs specifically to pay for care services, whether from formal care service providers or from informal carers.[100]

MISSOC provides a general overview of care allowances.[101] Other sources on relevant benefits are the website of the European Commission[102] and ESSPROS[103]. Some work

[98] Men aged 45-64 earn less per hour than women aged 45-64 but work more often full-time. Men aged 18-44 earn less per hour than men aged 45-64 but work more often fulltime in high-wage occupations.

[99] Only in the Netherlands, where about 75% of employed women across all ages work part-time, a reduction of 8 work hours per week would result in a larger gross wage loss (30%). However, people who already work part-time may have less need to reduce working hours even further, so the 30% loss of income likely applies to fewer intense carers in the Netherlands.

[100] The benefits for care provision paid to people needing care are distinct from income replacement benefits for people with health problems such as a sickness or disability benefit.

[101] See https://www.missoc.org/missoc-database/comparative-tables/.

[102] See https://ec.europa.eu/social/main.jsp?catId=858&langId=en (but information on informal care allowances is missing for many countries).

[103] See https://ec.europa.eu/eurostat/web/social-protection/data/qualitative-information, however informal schemes are sometimes part of more general schemes including formal care, so the full expenditures may include expenditures on formal care.

papers provide more detailed information on the conditions for informal care benefits,[104] but overall information on informal care allowance schemes is fragmented, and results in this section are mostly based on desk research of national sources.

Since the purpose of this study is only to provide insights in the incidence and costs of informal care, this section only provides an overview of the relevant informal care allowances, the number of benefiting informal carers and the expenditure per benefiting informal carer and not on other aspects of care allowance schemes such as eligibility criteria or the combination with other benefits. Of the 27 EU Member States, thirteen pay care allowances directly to informal carers, nine pay a "care budget" to people needing care which they may spend on formal or informal care, Belgium has a mix of these schemes, and five Member States do not have a specific care allowance scheme (Table 5).

Table 5 - Care allowance schemes in the EU

MS	Schemes	Paid to
AT	Pflegegeld + Pflegekarenz + Pflegeteilzeit	Care receiver
BE	Vervangingsinkomen verlof voor medische bijstand ; palliatief verlof ; Allocation pour Personnes Agées ; Persoonlijk zorgbudget (Flanders + Wallonia); zorgbudget voor zwaar hulpbehoevenden (Flanders)	Carer [1-2], Care receiver [3-5]
BG	Предоставяне на грижи в домашна среда	Carer
CY	--	--
CZ	Příspěvek na péči	Care receiver
DE	Pflegegeld + Pflegezeit + Pflegeunterstützungsgeld	Care receiver
DK	Employment by municipality, Plejevederlag	Carer
EE	Hooldajatoetus	Carer
ES	Dependencia	Care receiver
FI	Omaishoidon tuki	Carer
FR	Allocation personnalisée d'autonomie	Care receiver
GR	--	--
HR	Naknada roditelja njegovatelja/njegovatelja	Carer
HU	Ápolási díj	Carer
IE	Carers allowance + Carer's support grant + Carer's benefit	Carer
IT	Paid leave (congedo per cure, 3 days per month)	Carer
LT	--	--

[104] See for example https://kce.fgov.be/sites/default/files/atoms/files/KCE_223_support_informal_caregivers_Report.pdf and https://www.researchgate.net/publication/242673212_Informal_Carers_Who_Takes_Care_of_Them (Table 1.1) on informal care allowances and the conditions for some countries.

LU	Social security ; assurance-dépendance	Care receiver
LV	--	--
MT	Allowance għall-Carers	Carer
NL	Persoonsgebonden budget	Care receiver
PL	Świadczenia opiekuńcze / Zasiłek opiekuńczy, excluding child nursing	Carer
PT	Subsídio por assistência de 3ª pessoa (adultos)	Care receiver
RO	Allowances paid to the personal assistant of handicapped persons (indemnizatii paltite personalului asistent al persoanelor cu handicap)	Apparently to carer
SE	Municipal support / anställda anhörige stöd	Carer
SI	Pomoč na domu / družinski pomočnik : LTC social part, private sector	Care receiver
SK	Peňažný príspevok na opatrovanie	Carer

Source: MISSOC, July 2020; --- = no specific informal care allowance scheme.

For the eight of the nine countries paying a benefit to the care receiver, information was collected on the estimated share of benefits paid to informal care (Table 6); here no distinction is made between contracts concluded with informal and formal carers and the value of those contracts. Thus, the expenditure on informal care allowances paid via the people needing care may be overestimated, because people with heavy care needs tend to use more formal services, and in addition formal services may be paid at a higher rate.

Table 6 - Share of "care budget" spent on informal carers

MS	Source	%
AT	https://www.ig-pflege.at/hintergrund/datenundfakten.php ; BMASGK, PFIF-Pflegegeldinformation des HV der SV-Träger, Pflegedienstleistungsstatistik Dez. 2018	71%
CZ	Data on expenditures on people not using the service of registered providers were used	100 %
DE	https://www.bundesgesundheitsministerium.de/fileadmin/Dateien/3_Downloads/P/Pflegebeduerftigkeitsbegriff_Evaluierung/Abschlussbericht_Los_2_Evaluation_18c_SGB_XI.pdf	64%
ES	https://www.imserso.es/imserso_01/documentacion/estadisticas/info_d/estadisticas/est_inf/ datos_estadisticos_saad/index.htm, category "P.E. Cuidados Familiares"	32%
FR	https://drees.solidarites-sante.gouv.fr/IMG/pdf/infographie-apa.pdf	80%
LU	Based on https://igss.gouvernement.lu/fr/statistiques/assurance-dependance/serie-statistique.html	12%
NL	https://www.rijksoverheid.nl/binaries/rijksoverheid/documenten/rapporten/2020/09/04/rapportage-onderzoek-onderzoekfinanciering-informele-zorgeen/rapportage-onderzoek-	57%

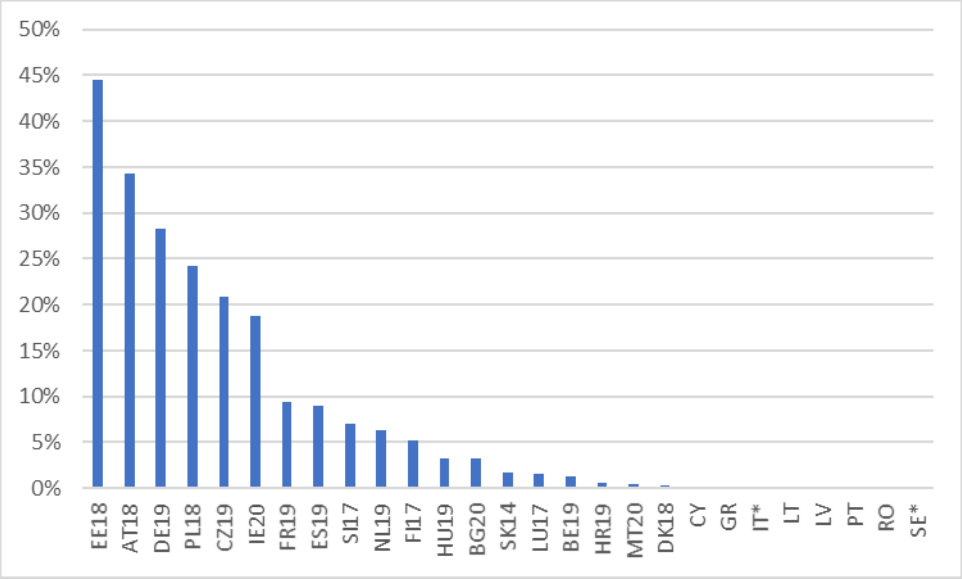
	onderzoekfinanciering-informele-zorgeen.pdf ; information from the Dutch ministry of healthcare	
PT	No data was found	---
SI	Data on long-term care, social part and from the private sector were used	100 %

Source: desk research Ecorys.

Data on the numbers of informal carers benefiting from a care allowance is collected directly for the countries that pay these allowances directly to informal carers, and is calculated as the number of beneficiaries or contracts times the share spent on informal care for the countries that pay the persons needing care to spend on care services as they wish. For a comparison between countries, these numbers of benefiting informal carers are divided by the number of informal carers estimated on the basis of the EQLS and EHIS surveys.

The low percentages of informal carers that benefit from a care allowance in most countries (Figure 59) reflect that more than half of the informal carers provide care for less than 10 hours per week, and in all likelihood would not qualify. However, it also reflects the sometimes strict conditions for an informal care allowance in the identified schemes. For instance, in Denmark carers qualify for a care allowance only if they care for terminal patients, while in Malta only those who provide full-time care qualifiy and in Croatia only those caring for children with a disability.

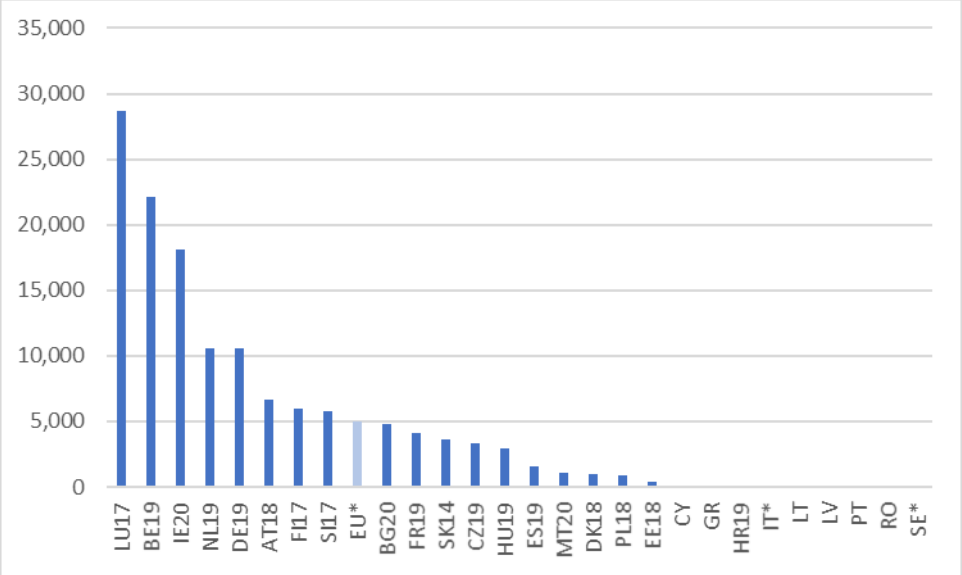
Figure 59 - Percentage of informal carers benefiting from a care allowance



Note: the reference year is indicated after the country abbreviation, for example 2018 for Estonia;
* indicates that no data was found (for Italy and Sweden).
Source: desk research Ecorys.

Perhaps not surprisingly, the annual expenditure per benefiting informal carer is less than the average (net) wage in all EU countries. The highest benefit amounts per year (corrected for differences in purchasing power) are typically found in central Europe, but also in Ireland, Finland, Slovenia and Bulgaria (Figure 60).

Figure 60 - Average annual expenditure on care allowances per benefiting informal carer, in purchasing power parities (EU = 1)



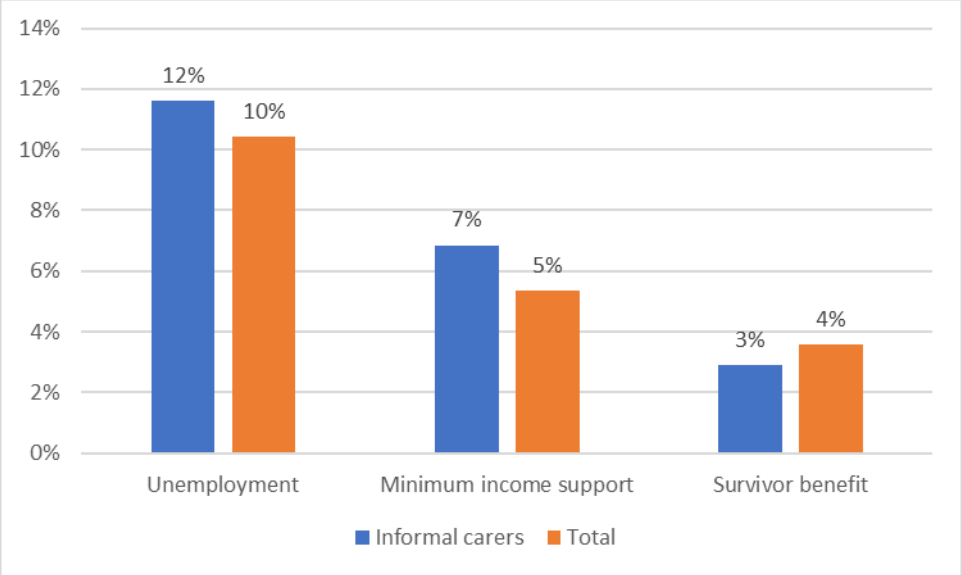
Note: the reference year is indicated after the country abbreviation, for example 2018 for Estonia;
* indicates that no data was found (for Italy and Sweden). For Belgium, the data on expenditures includes both formal home care and informal care; 50% expenditures on informal care was assumed but this may be an overestimate.
Source: desk research Ecorys.

If non-employed informal carers do not qualify for a care allowance, they may still qualify for an unemployment benefit or minimum income support (if the partner has insufficient income as well). Of course, non-employed non-carers also receive these benefits, and for this reason unemployment and minimum income support are only considered to be relevant for the number of informal carers in the employment gap, specifically women aged 45-64.

No administrative data was found on unemployment benefits or minimum income support to informal carers. As an alternative, the EU-SILC ad hoc module of 2016 was used. The regular EU-SILC data covers data on unemployment benefits and benefits to fight “social exclusion not elsewhere classified” which for shorthand is interpreted as minimum income support. Unfortunately, EU-SILC does not include care allowances as a separate income category, and it is unknown how respondents would classify such a benefit. Comparing average annual amounts between informal carers and the rest of the population in the working age for unemployment benefits, minimum income support, survivor benefits and family benefits, the difference was by far the largest for family benefits. Hence, it is assumed that care allowances are generally classified as a family benefit.

Most family benefits are of course for childcare and not related to informal care. Since data on care allowances are already collected from administrative data, only the percentages of the informal carers receiving unemployment benefits, minimum income support and survivor benefits are compared with the total population in the working age. Among women aged 45-64, the percentage of informal carers receiving an unemployment benefit or minimum income support (12% and 7% respectively, adding up to 19%) is four percent points higher than in the total population (10 and 5% respectively, adding up to 15%), see Figure 61. This difference in proportion of the population receiving these benefits is in line with the employment gap of 5.6 percent points for female informal carers in this age group (Figure 47). Informal carers are less likely than average to receive survivor benefits, which makes sense as long as they provide informal care.

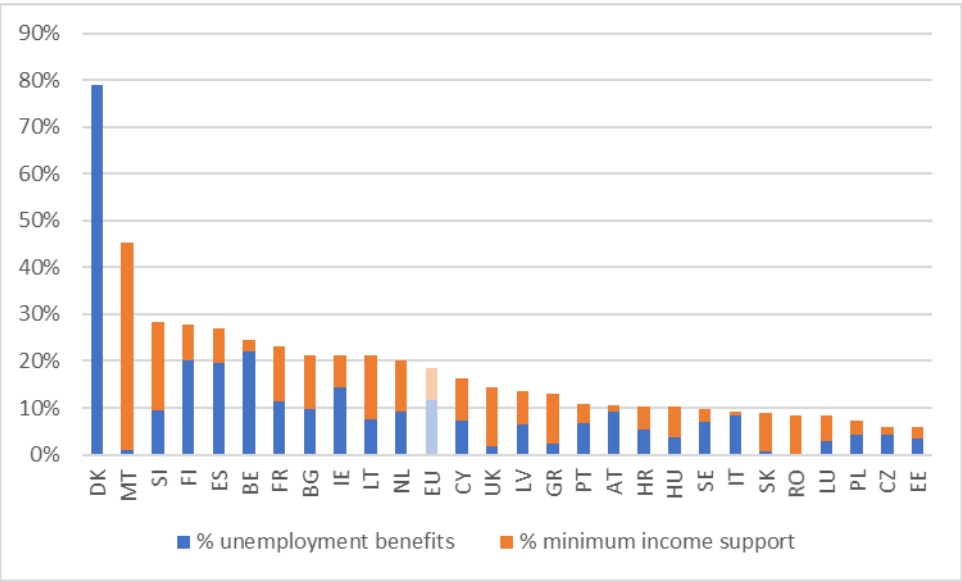
Figure 61 - Percentage receiving certain benefits, women 45-64, informal carers and total population (EU average)



Source: EU-SILC ad hoc module 2016.

The proportion of receiving an unemployment benefit or minimum income support among women aged 45-64 who provide informal care is highest in Denmark (79%) and Malta (45%), which are the two countries where the lowest proportions of informal carers receive a specific care allowance, as is evident from comparing Figure 59 above with Figure 62 below. The percentage for Denmark is extremely high given that close to 80% of the women aged 45-64 providing informal care in that country is employed. In Denmark one can claim a partial unemployment benefit if one needs to work at reduced hours. Still, the high percentage for Denmark might be a statistical outlier. In the other countries, between 6 and 28% of the female informal carers aged 45-64 receive one of the two benefits.

Figure 62 - Percentage of female informal carers 45-64 receiving UB or MIS

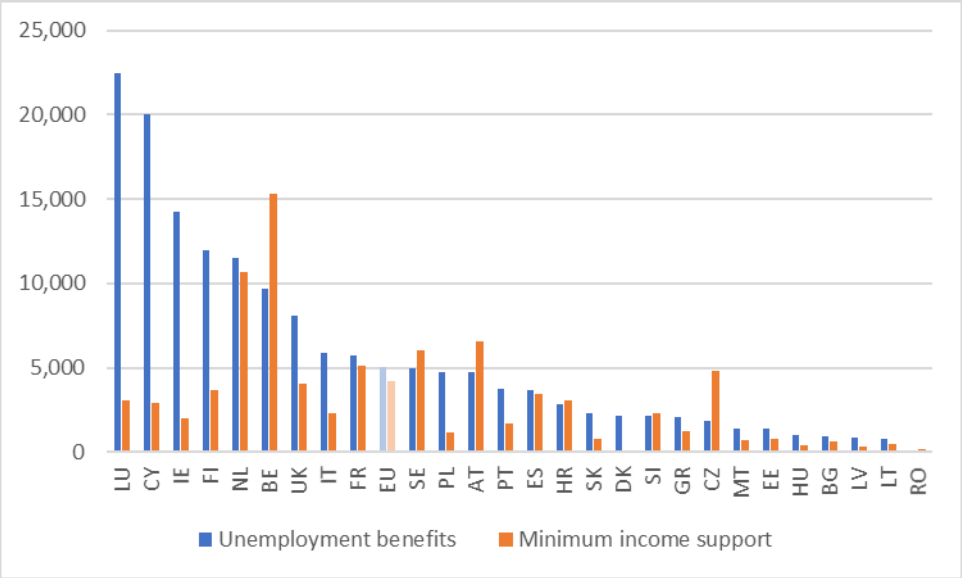


Source: EU-SILC ad hoc module 2016.

The benefit amounts that women aged 45-64 providing informal care receive, vary substantially between countries (Figure 63). First of all, it should be noted that not everyone

receives the benefit during the whole year. In particular minimum income support is often received for only a few months, until someone in the household has a sufficient income to provide for the household. However, it can be concluded that the lowest benefit amounts are observed in the east of Europe, even correcting for differences in purchasing power.

Figure 63 - Average annual amounts of unemployment benefits and minimum income support of female informal carers aged 45-64, in purchasing power parities (EU=1)



Source: EU-SILC ad hoc module 2016.

All in all, income support for informal carers seems less developed in the east of Europe. Apart from this, it is difficult to say which country has the most generous provisions for informal carers. Much depends on whether they qualify for a care allowance, whether they lost their job during their care provision, and whether their partner has sufficient income.

6.5. Wage loss due to re-employment difficulties

Non-employed informal carers may not only face a loss of income during their care stint, especially if they provide intense care (40+ hours per week), but also after their care stint. During the care stint, the peer group consists of employed people for the number of informal carers in the employment gap (who stopped working), and of non-employed people for the number of informal carers not in the employment gap (who already were not employed before the care stint). It makes sense to use the same peer groups for the period after the care stint.

Thus, for the number of informal carers in the employment gap (specifically women aged 45-64), the peer group consists of employed people and the employment “likelihood” remains 100%. For the informal carers who already were not employed before the care stint, the peer group are non-employed people in general and the relevant benchmark is the probability that non-employed people in general (re-) enter employment.

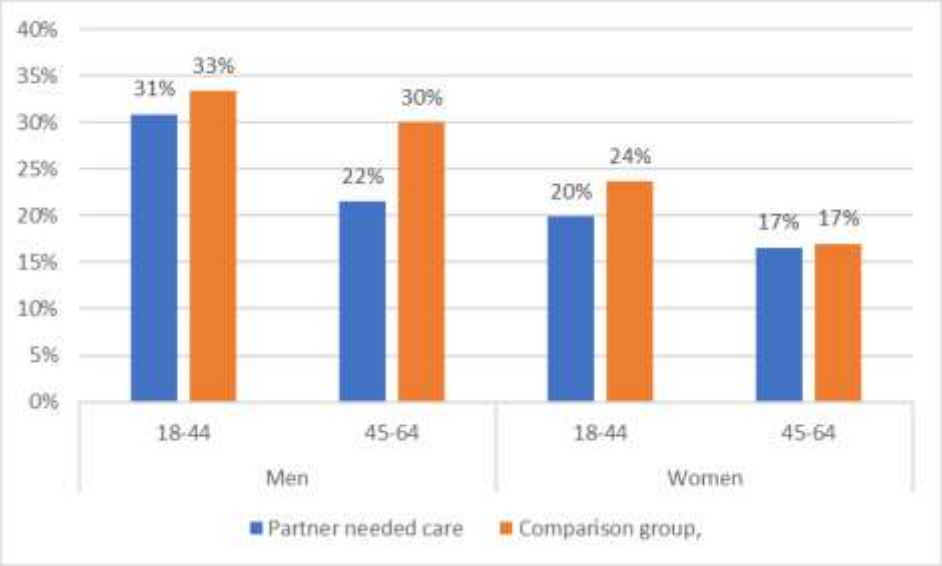
It is not straightforward to compare the likelihood of entering work between informal carers and others. The main reason is that informal carers may simply not search for work during their care stint, but may do so again after their care stint. Furthermore, it is important to exclude people with a disability, since they are less likely to enter employment than the

average population. For these reasons, informal carers and others are compared within the group of people whose main activity is fulfilling domestic tasks or "other inactivity" or who work at most 16 hours per week[105], and who in addition search for work. Estimating the likelihood of informal carers and others within this group to enter employment in the next year requires longitudinal data for based on EU-SILC data.

Within this subgroup of non-employed or small-time employed job searchers, people living with an adult needing care are less likely to enter employment than people not living with an adult needing care (Figure 64). This is particularly the case for men aged 45-64, where 22% of those living with an adult needing care enter employment in the next year compared to 30% of the comparison group, and to a lesser extent for women aged 18-44 (20% compared to 24%). Men aged 18-44 also have a lower probability of re-entering work, but for them the difference is small (31% compared to 33%). For women aged 45-64, there is no difference in re-employment likelihood (17% for both informal carers and the comparison group).

It is perhaps not surprising that the greatest difference in re-employment likelihood exists for older men, since they are less often employed in sectors where informal caring skills are valued and are more often employed in sectors such as industry and construction. Thus, specifically for male informal carers aged 45-64 it seems that the lower re-employment likelihood can be attributed to a loss of skills. A loss of skills may also explain the lower re-employment likelihood of younger informal carers, but if so the impact is more limited.

Figure 64 – Re-employment probability of job searchers fulfilling domestic tasks or care or working at most 16 hours a week, if living with an adult needing care and comparison group



Source: (EU-SILC), longitudinal version 2010-2017*. Comparison group : (a) main activity is « fulfilling domestic tasks or care responsibilities », « other inactivity » or employed but working at most 16 hours per week and (b) searching for employment.*

To estimate the loss of future income from work, it is assumed that the care stint starts at the mid-way point of 31 years in the age group of 18-44. Informal carers in the age group 45-64 may have started their care stint before the age of 45 and the assumed average age of starting the care stint is assumed to be 52 years in this category.[106] The average duration

[105] But not other main activities such as retirement or student or disability.

[106] With an estimated average duration of the care stint of six years in the age group 45-64, someone providing informal care at the age of 45 may have just started the care stint or may have been providing it for up to 6 years. On average, someone providing informal care at the age of 45 has provided the help for 3 years, hence starting at the age of 42.

of the care stint also differs by gender and age, and based on Dutch IZG data (Figure 39) the care stints are assumed to end at age 34 (men and women 18-44), age 57 (men 45-64) and age 58 (women 45-64).

The loss of future income from work also depends on whether the difference in re-employment likelihood lasts only one year after the care stint, whether the difference is permanent or anything in between. In this section, lost future income is evaluated for the two extreme cases. For men and younger persons providing informal care, the differences in re-employment likelihood are those in Figure 64. For the number of female informal carers aged 45-64 in the employment gap, the comparison group consists of employed women and the relevant benchmark is 100% employment.

The valuation of the loss of future income further depends on the rate at which future values are discounted. In this section, calculations are done with assumed discount rates of 2% and 4% per year, respectively. A discount rate of 2% per year means that one euro in the next year is valued as 0.98 euro today, one euro two years from now is valued as 0.96 euro today, and for example one euro ten years from now is valued as 0.82 euro today. At a discount rate of 4% per year, one euro ten years from now is valued as 0.66 euro today.

The lost future income is calculated as the sum of all lost wages in all years from the end of the care stint. In a minimum scenario, the difference in re-employment likelihood is assumed temporary and only a wage loss in the first year after the care stint is included. In a maximum scenario, the difference in re-employment likelihood is assumed permanent and all wage losses to the assumed retirement age of 65 are included. All the future wage losses in the respective scenarios (just one year in the minimum scenario) are discounted to the year at which the care stint starts. For easier comparison with other components of income losses, which are calculated as an amount per year, the discounted sum of future wage losses is recalculated as an equivalent annual amount, the so-called annuity. Annex D provides the technical details of these financial calculations. Table 7 presents the results of these calculations. Women in the age group 45-64 on average provide care for one year longer than men aged 45-64. Hence after their care stint, they have one year less to go the assumed retirement at age 65.

At a 2% discount rate per year and assuming the re-employment difference is permanent, the lost income is largest for the number of women aged 45-64 in the employment gap, because the women in the comparison group are employed.[107] Specifically, the value of lost future income from work is 100% of the annual net wage (Table 7). The value of lost future income from work is also substantial for men 45-64 providing informal care due to their relatively large skills loss, and for women 18-44 providing informal care due to their long time until the retirement age. For men 18-44, the difference in re-employment likelihood is too small to make a huge impact on the value of lost future income from work.

Table 7 - Annuity of lost future income from work as a percentage of annual net wage, simulation of permanent re-employment difference

Gender, age, in employment gap (Yes/No)	Years to retirement	*P1*	*P2*	Annuity at 2% discount rate	Annuity at 4% discount rate

Likewise, someone providing informal care at the age of 64 has thus on average started providing three years earlier, at the age of 61. The mid-point value of age 42 and 61 is 52.

[107] Note that for women aged 45-64 providing informal care and not in the employment gap, the re-employment likelihood is the same as in the peer group.

M 18-44, No	30	0.31	0.33	6%	6%
M 45-64, No	7	0.22	0.30	42%	36%
F 18-44, No	30	0.20	0.24	25%	22%
F 45-64, No	6	0.17	0.17	0%	0%
F 45-64, Yes	6	0.17	1	100%	94%

In Table 7, P1 is the annual probability that non-employed or small-time employed informal carers searching for work re-enter employment, and P2 is the annual re-employment likelihood in the comparison group. The sum of lost future incomes after the care stint is expressed as an equivalent annual amount during the care stint, as a percentage of the net wage that the informal carer could have earned during the care stint.

The value of future lost income from work due to skills losses is of course much less if it is assumed that the difference in re-employment likelihood only applies to the first year after the care stint (Table 8). Under this assumption, the value of future lost income from work varies from 2% for men 18-44 and 6% for men 45-64 and women 18-44. This assumption has a huge impact, however no data is available about the persistence of the difference in re-employment likelihoods after the care stint between informal carers and the comparison group, hence the results of two extremes are shown (for permanent persistence in Table 7 and zero persistence in Table 8). For female informal carers aged 45-64 in the employment gap the benchmark employment likelihood is permanently 100% in both simulations, and for female informal carers not in the employment gap the re-employment likelihood is the same 17% as in the benchmark and the annuity thus remains 0%.

Table 8 - Annuity of lost future income from work as a percentage of annual net income, simulation of re-employment difference lasting only one year

Gender, age, in employment gap (Yes/No)	Years to retirement	*P1*	*P2*	Annuity at 2% discount rate	Annuity at 4% discount rate
M 18-44, No	30	0.31	0.33	2%	2%
M 45-64, No	7	0.22	0.30	6%	6%
F 18-44, No	30	0.2	0.24	6%	6%
F 45-64, No	6	0.17	0.17	0%	0%
F 45-64, Yes	6	0.17	1	100%	94%

See footnote to the previous table.

The above calculations do not include additional pension losses due to non-employment after the care stint. Since full income loss leads to a pension reduction of 8% as discussed in the next section, the additional pension losses from lost income after the care stint amount to 8% of the income losses presented in this section.

6.6. Future pension losses during care stint

Employed people and their employers pay contributions for an old-age benefit past the retirement age. Many EU countries also grant pension credits to non-employed people, but not indefinitely and/or for a lower future pension. Some EU countries even grant pension credits during the entire period of the informal care stint, but this is often conditional on the severity of the care needs or the intensity of informal care. This means that only part of the informal carers are covered by specific pension credits for informal care provision.

In this section, in countries where people who took career breaks to act as informal carers are covered by specific pension credits, it is assumed that their pension would be the same as if they had been working throughout. In reality, even with pension credits the future pension might not be 100% of what it would be if informal carers who stopped working had continued to work at the same hours. In other countries, the future old-age pension level of informal carers is assumed the same as for people with a career break of several years (the average duration of informal care provision) in general.

Of the 27 EU Member States, 17 grant specific pension credits to informal carers, under various conditions (Table 9). As noted earlier, countries that do not have specific pension credits for informal carers, may still have pension credits for non-employed people in general. For example in the Netherlands, all residents are credited for the State old age pension.

Table 9 - Pension credits for informal carers in the EU

MS	Condition for pension credit	% of informal carers receiving care allowance	Estimated % of informal carers assumed to be covered by a pension credit (in all countries less than 100% since conditions apply)
AT	---	34%	0%
BE	---	1%	0%
BG	Fully dependent spouse or child only	3%	5%
CY	---	0%	0%
CZ	Only for care to persons with at least 75% disability	21%	21%
DE	All informal care but carer pays half of the contributions	28%	28%
DK	Only 6 months	0%	0%
EE	Care for disabled persons only	44%	44%
ES	---	9%	9%
FI	---	5%	0%
FR	Care for disabled relatives only	9%	50%
GR	---	0%	0%
HR	Restricted to full dependency	1%	1%
HU	---	3%	0%
IE	All informal care, work < 18.5 hours per week	19%	19%
IT	Care for disabled relatives only (50% disability)	0%	5%
LT	All informal care	0%	100%
LU	All informal care	2%	100%
LV	Care for disabled children only	0%	10%
MT	Constant care to fully dependent household member	0%	5%

MS	Condition for pension credit	% of informal carers receiving care allowance	Estimated % of informal carers assumed to be covered by a pension credit (in all countries less than 100% since conditions apply)
NL	---	6%	0%
PL	Care for disabled children only	24%	24%
PT	---	0%	0%
RO	---	0%	0%
SE	---	0%	0%
SI	Credited non-contributory periods no longer exist.	7%	7%
SK	Severely disabled child or caring for at least 140 hours monthly	2%	2%

Note: % receiving care allowance is taken from Figure 59, % granted pension credits is an estimate by Ecorys based on the % receiving care allowance in countries where this is a requirement for the pension credit, and based on conditions for pension credits in other countries.
Source: MISSOC, July 2020; --- = no specific pension credit for informal carers.

For non-employed informal carers who are not credited for their employment loss, the pension replacement rates for a career break lasting respectively 5 and 10 years according to the OECD Pension at a Glance are used, for people with an income at 50% and 100% of the average national wage, respectively.[108]

The average duration of informal care provision by women aged 45-64 is estimated as the average duration of 5 years care provided to persons outside the household[109], plus the difference in duration of 3 years between care provided to persons in and outside the household (8-5=3) times the share of care provided to household members in that country. For an annual wage above the national average, the pension replacement rate at 100% of the average wage is used, for an annual wage below 50% of the national average, the pension replacement rate at 50% of the national average is used, and for annual wages in between, the replacement rate is assumed to decrease linearly.

For non-employed female informal carers aged 45-64, the pension losses are largest in various countries in the east of Europe and in Italy (Figure 65). In most countries, the majority of informal carers would not have lost much more pension entitlements without specific credits for informal carers, comparing the blue and orange bars in the figure below. The most notable exceptions are Lithuania and Luxembourg where all informal carers are estimated to receive pension credits, Estonia where almost half of the informal carers is

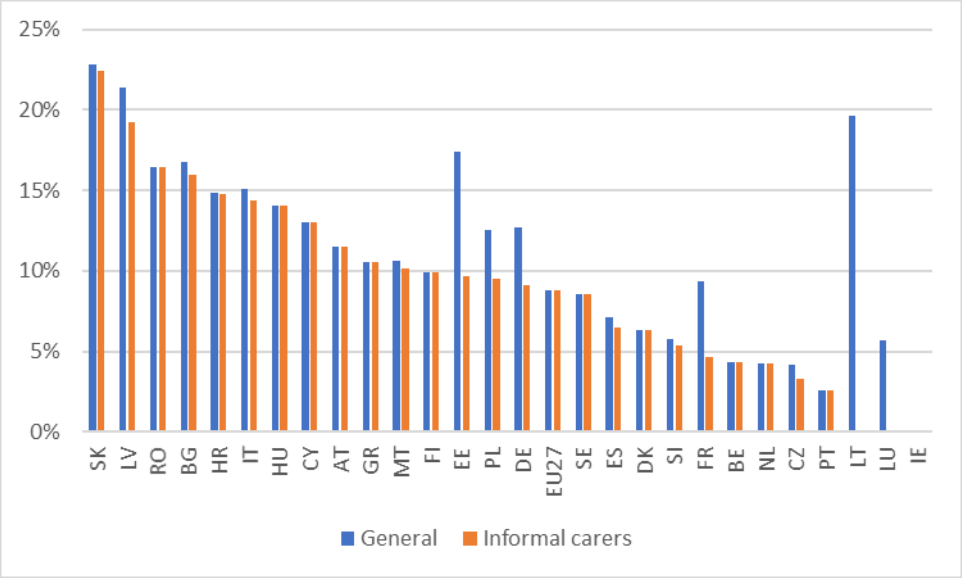
[108] See Source: https://www.oecd-ilibrary.org/docserver/678dadc6-en.pdf?expires=1605087620&id=id&accname=guest&checksum=3E98FF2F72FFF664F93CDF793E3FA57C

It should be noted that the OECD assumes the start of the career break at age 31, and the pension loss for this group is applied to the loss of pension entitlements for women aged 45-64. Since an earlier career break implies less interest on interest until the retirement age, the pension loss for women aged 45-64 is likely smaller than according to the calculations in this section.

[109] The average duration of 5 years provided to persons outside the household is from the Dutch IZG data and assumed for all EU countries.

estimated to receive pension credits, and to a lesser extent France, Germany and Poland. In Ireland (and the UK) non-employed people do not lose old-age pension entitlements in general.

Figure 65 - Average old-age pension loss, career break in general and specifically for informal carers, women aged 45-64



Source: OECD 2019, MISSOC, EHIS 2013-2015, EQLS 2016, SES 2018, LFS 2019.

All in all, women aged 45-64 providing informal care may lose up to 22 and 19% of their old-age pension entitlements in Slovakia and Latvia respectively, lose 3 to 5% of their old-age pension entitlements in Portugal, the Czech Republic, Netherlands, Belgium, France and Slovenia, and are estimated to lose no pension entitlements at all in Ireland, Lithuania and Luxembourg. The underlying estimated average durations of informal care vary from 5 years in the Netherlands to 7 years in most countries, but differences between countries are mainly caused by differences in eligibility criteria for pension credits and differences in general replacement rates.

6.7. Caregiver burden and sense of purpose

People providing informal care find what they do in life slightly more worthwhile than others but lack of time and freedom make them less happy overall. According to the EQLS 2016, of all informal carers in the EU 79% agree or strongly agree that what they do in life is worthwhile, compared to 77% in the total adult population. Of the informal carers, 73% feel they are free to decide how to live their life, compared to 75% in the total adult population. In addition, 39% of informal carers have some time to really enjoy life compared to 43% in the total adult population[110]. Overall, 82% of informal carers would rate their happiness a 6 or higher on a scale from 1 to 10, compared to 84% of the total adult population.

[110] The statement was “In my daily life, I seldom have time to do the things I really enjoy” and 39% and 43% disagree or strongly disagree.

6.8. Conclusions

For individual carers, the major potential effect of informal carers is the loss of income from work, in particular if providing intense care for more than 40 hours per week. Informal carers who stop working lose 100% of their income from work. Of course, they would receive unemployment insurance benefits at first, and may receive minimum income support later if their partner has insufficient income as well. This study only found for women aged 45-64 providing informal care that they are significantly less often employed than their peers. For this reason, loss of income from work during the care stint is only analysed for this group. On average, the loss is EUR 18,000 in the EU for people in this gender-age group who stop working. The loss of income from work, even in terms of purchasing power parity, is less than the EU average in all countries in the east and south Europe (Cyprus excepted) and above the EU average in all countries in the west of Europe. This suggests that informal carers in the east and south of the EU are less likely to have lost well-paid work.

A smaller loss of income from work is associated with reduced work hours. The percentage loss of net income is similar the percentage hours reduction. For women aged 18-44 providing intense informal care, the average hours reduction from 38 to 29 hours causes a net income reduction of between 20 and 25% in all EU countries.

Of the 27 Member States, 13 pay informal care allowances directly to informal care providers and 9 to the person needing care to spend on either formal or informal care, with 5 Member States not having an informal care allowance scheme. In all countries, further conditions apply regarding for example the care needs / degree of disability, the relationship between care provider and receiver (family only), and/or intensity of informal care. As a result, the percentage of informal carers receiving a care allowance varies from about one percent in Croatia Denmark, Malta to slightly less than 50% in Estonia. Benefit levels also vary strongly, from about EUR 29,000 per year in purchasing power parity in Luxembourg to EUR 900 per year in Denmark and Poland and even EUR 375 per year in Estonia. Here it should be remarked that the benefit in Luxembourg is subject to income tax, and that the benefit in Denmark is typically given for only a few weeks.

Informal carers who do not qualify for an informal care allowance may still receive an unemployment benefit or minimum income support, of about EUR 5,000 per year on EU average but varying from EUR 1,000 or less per year in various east European countries (Bulgaria, Hungary, Latvia, Lithuania, Romania) to about EUR 20,000 per year for unemployment benefits in Cyprus and Luxembourg. However, it should be noted that these benefits are not always received the whole year because in general, a large minority of minimum income beneficiaries move constantly into and out of work.

Informal carers who stopped working, also risk a loss of income after their care stint, if they do not immediately re-enter employment. For the number of informal carers in the employment gap (in reality only determined with statistical significance for women aged 45-64), the benchmark employment probability is 100% (the peer group is employed). Women aged 45-64 providing informal care only have a probability of 17% to enter employment when they search for work – just like other non-employed women in that age bracket. Thus the difference in (re-) employment likelihood is 83% for the number of female informal carers aged 45-64 in the employment gap and 0% for the number of female informal carers not in the employment gap. The loss of future income from work after the care stint until the age of 65 can be expressed as a percentage of the annual income that the informal carer would have earned if fully employed. For female informal carers aged 45-64, the result turns out to be 100%.

For the other informal carers who are not employed but not in the employment gap, the peer group is also non-employed but the likelihood of re-employment turns out to be smaller for informal carers. Assuming that former informal carers are permanently less likely to re-enter employment, the future loss varies from 6% for men aged 18-44, 25% for women aged 18-44 and 42% for men aged 45-64, corresponding mostly to differences in re-employment likelihoods.

Informal carers may also lose future pensions. Many countries grant pension credits to informal carers, but as for care allowances often additional conditions apply. If an informal carer qualifies for pension credits, the pension entitlement is assumed 100% of the old-age pension although this is not always the case. If the status of informal carer does not qualify for pension credits, their pension entitlements can still be covered through their unemployment benefit or minimum income support benefit. The OECD has estimated their pension entitlement rates which unsurprisingly are less than 100% in almost all EU countries, Ireland being the exception. On average in the EU, the pension loss of informal carers with a career break during their informal care stint but hypothetically returning to work immediately after the care stint, is 9% of the pension they would be entitled to without a career break. The loss varies from 0% in Ireland, Lithuania and Luxembourg to 19% in Latvia and 22% in Slovakia. The variation in pension losses between countries is mainly caused by differences in entitlement criteria of pension credits for informal carers such as the degree of incapacity of the care receiver, the intensity of informal care or a family relation between the care provider and care receiver.

Informal carers rate their life similar as people in general. The largest difference is found with regard to having sufficient time to enjoy life, which 39% of the informal carers report compared to 43% in general.

7. Hours valuation of informal care

7.1. Aim and approach

In the evaluation of, and decision-making about, interventions in long-term care, the costs of informal care are often neglected. From the LTC budget perspective these costs may seem irrelevant, but from a societal perspective the resources informal caregivers supply are certainly relevant, particularly in the context of LTC. Studies have shown that considering the costs of informal care can have a considerable effect on the outcomes of economic evaluations of interventions. This impact of incorporating informal care in economic evaluations can differ from study to study. For example, an intervention, that frees up some caregiver time, might become more cost-effective when the value of these informal care hours are incorporated, whereas the opposite might hold for interventions that require additional care hours by the informal caregiver. Such changes in the cost-effectiveness measurements could affect the policy recommendations following from such studies.[111,112]

The aim of this chapter is to value informal LTC in terms of the time invested in providing care. These costs will be computed in nominal terms (in euro) on an annual basis, per Member State, and also expressed as a share of GDP. For comparison, we also present expenditures on formal long-term care in Member States as percentage of GDP.[113]

Two main approaches have been identified in the literature for valuing the time investment of informal caregivers: the proxy-good method and the opportunity costs method.[114,115,116] Both approaches concern partial approaches, as they focus on the valuation of time only, and ignore potential other effects of caregiving for informal caregivers such as the negative impact of informal care provision on (mental) health. The time valuations could therefore be seen as lower bound valuations of the cost of informal care. In the current study, these two approaches are selected because they are the most frequently applied internationally,[117] and it is more likely that the valuation parameters required for implementing the proxy-good and opportunity costs methods can be obtained for most Member States. In addition, the interpretation of the results of the proxy-good and opportunity costs methods are fairly straightforward, and more easily comparable (and transferable) between Member States.

[111] Krol M, Papenburg J, van Exel J. Does including informal care in economic evaluations matter? A systematic review of inclusion and impact of informal care in cost-effectiveness studies. Pharmacoeconomics. 2015 Feb;33(2):123-35.

[112] Goodrich K, Kaambwa B, Al-Janabi H. The inclusion of informal care in applied economic evaluation: a review. Value Health. 2012 Sep-Oct;15(6):975-81.

[113] Using LTC expenditures on health for 2018 from Eurostat.

[114] Hoefman RJ, van Exel J, Brouwer W.How to include informal care in economic evaluations. Pharmacoeconomics. 2013 Dec;31(12):1105-19.

[115] Koopmanschap MA, van Exel JN, van den Berg B, Brouwer WB. An overview of methods and applications to value informal care in economic evaluations of healthcare. Pharmacoeconomics. 2008;26(4):269-80.

[116] Van den Berg B, Brouwer WB, Koopmanschap MA. Economic valuation of informal care. An overview of methods and applications. Eur J Health Econ. 2004 Feb;5(1):36-45.

[117] Oliva-Moreno J, Trapero-Bertran M, Pena-Longobardo LM, del Pozo-Rubio R. The valuation of informal care in cost-of-illness studies: a systematic review. PharmacoEconomics 2017;35: 331-345.

7.2. Hours of informal care provision

To value the hours of informal LTC in the EU-27, an estimate is needed for the hours of informal care provision that are provided yearly in each EU Member State. These data used for the valuation of hours are the average hours of informal care provision per week based on averaged data from the EQLS 2016 and the EHIS wave 2 (2013-2015) datasets.

The average reported number of hours of informal care provision per week are subdivided into five time intervals. Individuals indicate to provide either: 0-9; 10-19; 20-40; 40-70 or 70+ hours of care per week. These categories are used to define a minimum, average and maximum time scenario. In all time scenarios individuals indicating to provide 0-9 hrs, 10-19 hours or 20-40 hrs of care per week are assumed to provide 4.5; 14.5 or 30 hrs of care per week, respectively; which corresponds to the mid-point values of the time intervals (Table 10).

In the *minimum time scenario* individuals reporting to provide 40 hrs or more are all capped at 40 hrs of care per week, which corresponds to a full-time working week. In the *maximum time scenario* individuals providing between 40-70 hrs of care are assumed to provide 55 hrs of care per week, which corresponds to the middle of the time interval, and individuals indicating to provide more than 70 hrs of care are assumed to provide 80 hrs of care per week. As the base case, we use an average time scenario in which hours of informal care per week are based on the average of the minimum and maximum time scenarios.

Table 10 - Minimum and maximum scenario for calculating hours of informal care provision

Hours category	Assumed hours minimum scenario	Assumed hours maximum scenario
0-9 hours	4.5	4.5
10-19 hours	14.5	14.5
20-40 hours	30	30
40-70 hours	40	55
70+ hours	40	80

To estimate yearly hours of informal care provision, a distinction needs to be made between individuals indicating to provide care the entire year or only a part of the year. For those individuals who indicate to have been providing care the entire year (i.e., on average 84% of the sample in the EU-27), weekly care hours are multiplied by the number of weeks per year (i.e., 52). For individuals who indicate to have provided care for less than a year, care hours are multiplied by the average number of weeks of care provision (i.e., on average about 19 weeks in the EU-27).[118]

[118] The average of 19 weeks (or 4.5 months) for informal care lasting less than one year is based on Dutch IZG data.

The resulting total volume of informal care provision differs strongly between the EU Member States. Table 11 provides an overview of the total number of informal care hours in all EU-27 countries using the minimum, average and maximum time scenario. Based on the average scenario, we estimate that 36 billion hours (sensitivity range: 33-39 billion hours) of informal care are provided yearly in the EU-27. The country with the largest volume of informal care provision is France with more than 9 billion hours of informal care, followed by Italy and Spain reporting respectively 5.6 and 5.4 billion hours of informal care.

Table 11 - Hours of informal care by Member State (billions per year, ranked by total hours)

Country	Base case	Minimum time scenario	Maximum time scenario
EU-27	36.23	33.05	39.41
FR	9.34	8.77	9.90
IT	5.58	5.09	6.06
ES	5.41	4.71	6.12
PL	3.39	2.83	3.95
DE	2.39	2.39	2.39
RO	1.29	1.17	1.41
GR	0.99	0.91	1.07
BE	0.95	0.88	1.03
NL	0.90	0.87	0.94
CZ	0.74	0.67	0.81
PT	0.59	0.56	0.62
AT	0.56	0.49	0.63
HU	0.55	0.52	0.59
BG	0.51	0.46	0.57
SE	0.48	0.43	0.53
IE	0.43	0.37	0.49
SK	0.35	0.32	0.38
FI	0.34	0.32	0.35
HR	0.32	0.29	0.35
DK	0.31	0.28	0.34

Country	Base case	Minimum time scenario	Maximum time scenario
LT	0.25	0.23	0.28
LV	0.18	0.17	0.20
SI	0.16	0.14	0.18
EE	0.07	0.07	0.08
CY	0.04	0.04	0.04
MT	0.04	0.04	0.04
LU	0.04	0.03	0.04

Source: EQLS (2016) and EHIS (2013-2015).

7.3. Valuation of an hour of informal care: Proxy good method

The proxy-good method values the time of informal caregivers by the market price of substitutes for specific caregiving tasks. For example, for household tasks this could be the wage of a housekeeper, and for personal care tasks the wage of a nurse or home care professional.[119] In other words, by applying wages of formal caregivers for each task, the proxy good method approximates the costs of replacing informal care with formal long-term care. It should be noted that this approach does not account for potential differences in efficiency and quality of care between formal and informal care providers. In addition, as mentioned above, these valuations represent lower bound valuations.

In the main analysis -the base case valuation scenario- substitutes were identified in the market for performing each type of caregiving task identified using SHARE data (care tasks, household chores and paperwork). On average in the EU-27, 57% of informal care hours are spent on household tasks, 27% on paper work and 15% on personal care tasks (= help with ADL). Hours of informal care spent on care tasks are valued at the gross wage rate of formal LTC workers (OECD, 2020)[120], hours spent on household tasks are valued at the wage rate of Service and Sales workers (ISCO 5) and hours spent on paper work are valued at the wage rate of Clerical support workers (ISCO 4). All average wage rates per Member State are taken from reference data provided by the International Labour Organization (ILO).[121] While LTC workers might perform some household tasks as well, a distinction is made between care tasks and household tasks as the definition of formal LTC workers used by the OECD focuses on personal care and assistance with activities of daily living (e.g.

[119] Van den Berg B, Brouwer W, van Exel J, Koopmanschap M, van den Bos GA, Rutten F. Economic valuation of informal care: lessons from the application of the opportunity costs and proxy good methods. Soc Sci Med. 2006 Feb;62(4):835-45.

[120] OECD (2020) Who Cares? Attracting and Retaining Care Workers for the Elderly. Missing values are imputed based on PPP corrected GDP per capita.

[121] ILOSTAT database. For all data the latest available latest available value is used and transformed to 2018 Euros (range 2014-2018). Accessed from https://ilostat.ilo.org/data/.

bathing, showing, dressing), and hence excludes instrumental activities of daily living (e.g. cooking, cleaning, shopping).

Approximation of hours per care activity using SHARE data

The SHARE survey asks people (aged 50+) about how frequently they provide informal care to up to three people and which types of care activities they provide for these up to three people. People can provide multiple care activities to one care recipient, so the proportions of activities can add up to more than 100%. However, hours spent on multiple activities must always add up to 100%. Unfortunately, SHARE does not ask about hours spent on informal care.

Only the Dutch IZG survey asks both about hours of informal per week and types of care activities (in separate questions). Based on cross-sections with IZG data of hours by type of care, the base assumption for all types of care activities is that the hours of informal care relate to the frequency as follows:

Daily care: on average 30 hours per week

Weekly care: on average 15 hours per week

Monthly care: on average 7 hours per week

In countries where the proportion of daily care was extremely high according to SHARE (between 27% for personal care to 34% for household tasks in Spain), lower hours per week of daily care were assumed (22 hours for personal care in Spain and 14 hours for household tasks in Spain) and in countries where the proportion of daily care was extremely low according to SHARE (from 0% for personal care to 2% for household tasks in Sweden), higher hours per week of daily care were assumed (35 hours for both personal care and household tasks in Sweden), to account for potential selectivity effects (and to avoid extremes in estimates of hours).

The above estimates were used to convert the distribution of activities (which may add up to above 100%) to a distribution of hours (which add up to 100%). The SHARE survey covers only 10 countries with questions about informal care. For the other countries, the distribution of hours per type of activity is assumed to be similar as in other countries with a similar distribution of total hours (across all activities) according to the EHIS-EQLS combo. Specifically, the following hours breakdown per activity are assumed to be the same as in other countries:

Bulgaria, Ireland and Lithuania: same as in Spain

Cyprus, Estonia and Luxembourg: same as in Germany

Finland: same as in the Netherlands

Slovakia: same as in the Czech Republic

Croatia, Hungary, Latvia, Malta, Portugal, Romania, Slovenia: same as the average of Austria, Belgium, the Czech Republic, France and Sweden.

To assess the sensitivity of the results to the chosen wage rates an *alternative valuation scenario* is used in which the value of informal care is estimated using reference wage rate information from only one source, the wages from ILO. In this case the wage rate of

Professionals (ISCO 2) is used instead of wage rates of specifically formal LTC workers for those informal care hours that are dedicated to care activities. The ISCO 2 Professionals classification however is quite broad (also including for example doctors and technicians), therefore assigning a higher valuation (i.e., hourly wage rate) to these care tasks. In addition, a minimum and maximum valuation scenario based on this alternative valuation are used. In the *minimum valuation scenario*, all care hours are valued at the (lowest) wage rate of Service and Sales workers (ISCO 5). In the *maximum valuation scenario*, all care hours are valued at the (highest) wage rate of Professionals (ISCO 2).

7.4. Valuation of an hour of informal care: Opportunity costs method

The opportunity costs method values the time of informal caregivers by the value of the foregone alternative spending of that time. Depending on the caregiving situation, this may concern the wage rate of the informal carer on the labour market, the wage rate of peers (in terms of age, level of education), or the value of (leisure) time.[122] Like the proxy good method, this approach does not account for potential differences in efficiency and quality of care between formal and informal care providers.

For implementing this method, the employment status of informal caregivers in the EU Member States was determined using EQLS and EHIS data. In these two datasets, no exact wage levels are observed. Hence, for employed individuals, in the base case valuation scenario, informal care hours are valued at the average wage rate corresponding to the ISCO classification of their occupational group. Hours of informal caregivers who are retired or currently not in employment[123] are valued at an average value for leisure time.

To explore the sensitivity of the results to the valuation of non-working hours at the value of leisure time, a minimum and maximum valuation scenario are used as well as a base case that corresponds to the average of the minimum and maximum scenarios. In the minimum valuation scenario, the time of people not in employment or retired is valued at zero, in the maximum valuation scenario their time is valued at the estimated Dutch value of leisure time derived from the study by Verbooy et al. (2018) They estimate the value people would need to receive informal care at 16 euro per hour, and the value people would pay for not providing informal care at about 9.50 euro per hour. In this study, the higher value is used and imputed for all other EU Member States using PPP corrected GDP per capita.

7.5. Value of informal care in the EU

The value of informal LTC in the EU-27 and across individual Member States differs considerably by valuation method and is sensitive to uncertainty in the estimations. Figure 66 depicts the estimated value of informal LTC provision (calculated via the proxy good

[122] Sendi PP, Brouwer WBF. Leisure time in economic evaluation: Theoretical and practical considerations. Expert Review of Pharmacoeconomics & Outcomes Research 2004;4(1), 1–3.

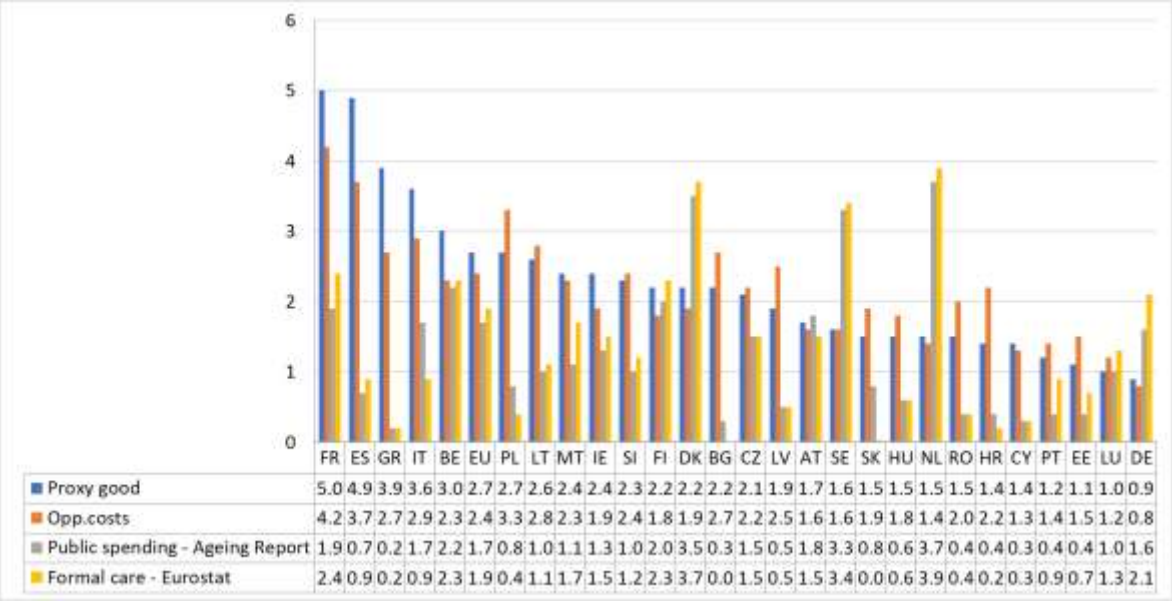
[123] Anyone aged 65+ is in this calculation assumed to be a pensioner.

method and opportunity costs method). For these estimates, the base case time scenario and the base case valuation scenarios are used. Using these base case scenarios, the yearly value of the time spent on informal care provision in the EU-27 is estimated at 2.4% - 2.7% of GDP in 2018.

For comparison Figure 7.1 also depicts formal LTC expenditures as share of GDP, for EU-27 and per Member State. As formal LTC expenditures may differ based on the exact definition used, the figure presents data from two sources: 2019 values of public LTC spending from the 2021 Ageing Report[124] and Eurostat, System of Health Accounts 2018 data which relates to data from all financing resources. The Eurostat SHA data includes data on the so-called "social component", consisting of services such as home-help, meals on wheels, transportation and other help with instrumental activities of daily life in 15 Member States. For the other 12 Member States, (AT, BE, BG, CY, DE, GR, HR, IE, IT, MT, PL, and SK). The Ageing Report has more complete data on the "social component'. On the other hand, the Ageing Report includes cash benefits that can be given to informal carers for all Member States that have care allowances, while the Eurostat SHA only includes such benefits in Member States where care allowances could not be isolated from "outpatient" long-term care.

The value of the time investment in informal LTC provision measured via either of the two methods exceeds the value of formal LTC expenditures in the majority of Member States, except for Austria, Denmark, Germany, Luxemburg, Belgium, Finland, the Netherlands and Sweden. For the EU-27, expenditures on formal LTC amounted to 1.9% of GDP (1.7% when using data on public expenditure from the Ageing report), which is approximately 20-30% (30-40%) lower than the value of the time spent on informal LTC. This emphasizes the strong reliance of health care systems across the EU on informal care.

Figure 66 - Time valuations of informal care and formal LTC expenditures as % of GDP per MS



	FR	ES	GR	IT	BE	EU	PL	LT	MT	IE	SI	FI	DK	BG	CZ	LV	AT	SE	SK	HU	NL	RO	HR	CY	PT	EE	LU	DE
Proxy good	5.0	4.9	3.9	3.6	3.0	2.7	2.7	2.6	2.4	2.4	2.3	2.2	2.2	2.2	2.1	1.9	1.7	1.6	1.5	1.5	1.5	1.5	1.4	1.4	1.2	1.1	1.0	0.9
Opp.costs	4.2	3.7	2.7	2.9	2.3	2.4	3.3	2.8	2.3	1.9	2.4	1.8	1.9	2.7	2.2	2.5	1.6	1.6	1.9	1.8	1.4	2.0	2.2	1.3	1.4	1.5	1.2	0.8
Public spending - Ageing Report	1.9	0.7	0.2	1.7	2.2	1.7	0.8	1.0	1.1	1.3	1.0	2.0	3.5	0.3	1.5	0.5	1.8	3.3	0.8	0.6	3.7	0.4	0.4	0.3	0.4	0.4	1.0	1.6
Formal care - Eurostat	2.4	0.9	0.2	0.9	2.3	1.9	0.4	1.1	1.7	1.5	1.2	2.3	3.7	0.0	1.5	0.5	1.5	3.4	0.0	0.6	3.9	0.4	0.2	0.3	0.9	0.7	1.3	2.1

Note: Time is valued using the proxy good method and opportunity cost method. Time is valued using the proxy good method and opportunity cost method. Two different sources are used for the expenditures on formal care. Data from Ageing report refers to 2019 data on public LTC spending from the 2021 Ageing Report. Formal care

[124] The 2021 Ageing Report – Economic and budgetary projections for the 27 EU Member States (2019-2070)", European Commission (DG ECFIN) and Economic Policy Committee (AWG), 2021.

– Eurostat, refers to data from Eurostat, System of Health Accounts 2018, hlth_sha11_hc, data for long-term care (health = help with ADL and social = help with IADL) (HC3), all financing schemes. Data on the social component is missing for AT, BE, BG, CY, DE, GR, HR, IE, IT, MT, PL, and SK. The formal care value of the social component of the other countries is included in the Eurostat EU 27 total.

Uncertainty in the estimates can arise from the two main components of the calculation: (1) the yearly number of hours of informal LTC provision and (2) the value attached to an hour of informal LTC. Using minimum and maximum time and valuation scenarios to explore the sensitivity of the estimates to the hours and values, the estimates show to be particularly sensitive to variations in the latter. Using the proxy good method, the value of time spent on informal LTC is estimated at 368 billion Euros per year, with a range based on the minimum and maximum valuation scenarios of 352-698. Using the opportunity cost method, the value of time spent on informal LTC is estimated at 320 billion Euros per year, with a range based on the minimum and maximum valuation scenarios of 190-449.

Values of informal LTC provision differ strongly between Member States. For example, using the opportunity cost method, the estimated value of informal LTC is lowest in Germany with 0.8% of GDP (sensitivity range: 0.5% – 1.1%) and highest in France with 4.2% of GDP (sensitivity range: 2.9% – 5.6%). These differences originate in part from differences between Member States in employment and wage rates, but are chiefly the result of differences in the average total yearly hours of informal LTC provision. As presented in Table 11 above: in France, on average 9.3 billion hours of informal care provision are reported yearly, compared to 2.4 billion hours in Germany.

Table 12 and Table 13 on the next pages provide overviews of the different valuations including the base case and sensitivity scenarios.

Table 12 - Value of time spent on informal LTC using the proxy good method (in billion Euro per year, ranked by total value) in 2018

Member States	Base case value of informal LTC		2019 Public spending on LTC (Ageing Report)	Value of formal LTC (Eurostat)	Sensitivity to hours		Sensitivity to valuation		
	in billion €	as % GDP	as % GDP	as % GDP	minimum time scenario as % GDP	maximum time scenario as % GDP	alternative scenario as % GDP	minimum valuation using alternative scenario as % GDP	maximum valuation using alternative scenario as % GDP
EU-27	**€ 368.1**	**2.7%**	1.7%	**1.9%**	**2.5%**	**2.9%**	**3.2%**	**2.6%**	**5.2%**
FR	€ 118.5	5.0%	1.9%	2.4%	4.7%	5.3%	5.5%	5.0%	8.7%
IT	€ 62.6	3.6%	1.7%	0.9%	3.3%	3.9%	4.5%	3.3%	7.9%
ES	€ 58.8	4.9%	0.7%	0.9%	4.2%	5.5%	6.5%	4.9%	9.9%
DE	€ 30.1	0.9%	1.6%	2.1%	0.9%	0.9%	1.0%	0.8%	1.8%
BE	€ 13.4	3.0%	2.2%	2.3%	2.7%	3.2%	3.2%	2.8%	5.2%
PL	€ 13.3	2.7%	0.8%	0.4%	2.2%	3.1%	2.9%	2.1%	5.4%
NL	€ 11.7	1.5%	3.7%	3.9%	1.4%	1.6%	1.8%	1.4%	2.6%
SE	€ 7.7	1.6%	3.3%	3.4%	1.5%	1.8%	1.7%	1.6%	2.3%
IE	€ 7.6	2.4%	1.3%	1.5%	2.0%	2.7%	3.0%	2.2%	4.6%

Member States	Base case value of informal LTC		2019 Public spending on LTC (Ageing Report)	Value of formal LTC (Eurostat)	Sensitivity to hours		Sensitivity to valuation		
	in billion €	as % GDP	as % GDP	as % GDP	minimum time scenario as % GDP	maximum time scenario as % GDP	alternative scenario as % GDP	minimum valuation using alternative scenario as % GDP	maximum valuation using alternative scenario as % GDP
GR	€ 7.2	3.9%	0.2%	0.2%	3.6%	4.2%	4.4%	3.5%	7.0%
AT	€ 6.5	1.7%	1.8%	1.5%	1.5%	1.9%	1.9%	1.5%	3.2%
DK	€ 6.5	2.2%	3.5%	3.7%	2.0%	2.4%	2.3%	2.1%	3.3%
FI	€ 5.1	2.2%	2.0%	2.3%	2.1%	2.3%	2.6%	2.1%	3.8%
CZ	€ 4.3	2.1%	1.5%	1.5%	1.9%	2.3%	2.3%	1.8%	3.8%
RO	€ 2.9	1.5%	0.4%	0.4%	1.3%	1.6%	1.3%	1.0%	2.7%
PT	€ 2.4	1.2%	0.4%	0.9%	1.1%	1.2%	1.3%	1.2%	2.3%
HU	€ 2.0	1.5%	0.6%	0.6%	1.4%	1.6%	1.5%	1.2%	2.7%
SK	€ 1.4	1.5%	0.8%	0.0%	1.4%	1.7%	1.9%	1.6%	2.9%
BG	€ 1.2	2.2%	0.3%	0.0%	1.9%	2.4%	1.9%	1.3%	3.0%

Member States	Base case value of informal LTC		2019 Public spending on LTC (Ageing Report)	Value of formal LTC (Eurostat)	Sensitivity to hours		Sensitivity to valuation		
	in billion €	as % GDP	as % GDP	as % GDP	minimum time scenario as % GDP	maximum time scenario as % GDP	alternative scenario as % GDP	minimum valuation using alternative scenario as % GDP	maximum valuation using alternative scenario as % GDP
LT	€ 1.2	2.6%	1.0%	1.1%	2.3%	2.8%	2.5%	1.9%	3.7%
SI	€ 1.0	2.3%	1.0%	1.2%	2.0%	2.5%	2.4%	2.0%	4.2%
HR	€ 0.7	1.4%	0.4%	0.2%	1.3%	1.5%	1.3%	1.0%	2.6%
LU	€ 0.6	1.0%	1.0%	1.3%	1.0%	1.1%	1.1%	0.9%	1.9%
LV	€ 0.6	1.9%	0.5%	0.5%	1.7%	2.1%	2.0%	1.7%	3.3%
MT	€ 0.3	2.4%	1.1%	1.7%	2.2%	2.6%	2.7%	2.4%	4.1%
CY	€ 0.3	1.4%	0.3%	0.3%	1.3%	1.5%	1.6%	1.3%	3.3%
EE	€ 0.3	1.1%	0.4%	0.7%	1.0%	1.1%	1.2%	1.0%	2.1%

Note: In all time scenarios individuals indicating to provide 0-9 hrs, 10-19 hours or 20-40 hrs of care per week are assumed to provide 4.5; 14.5 or 30 hrs of care per week, respectively. In the minimum time scenario individuals reporting to provide 40 hrs or more are capped at 40 hrs of care a week (a full-time working week). In the maximum time scenario individuals providing between 40-70 hrs of care are assumed to provide 55 hrs of care, individuals indicating to provide more than 70 hrs of care are assumed to provide 80 hrs of care a week. As the base case, we use an average time scenario in which hours of informal care per week are based on the average of the minimum and maximum time scenarios. In the alternative valuation scenario informal care hours are valued based on ISCO 2, 4 & 5. In the related minimum and maximum valuation scenarios, care hours are all valued at ISCO 5 (minimum scenario) or ISCO 2 (maximum scenario).

Table 13 - Value of time spent on informal LTC using the opportunity cost method (in billion Euro per year, ranked by total value) in 2018

Member States	Base case value of informal LTC		2019 Public spending on LTC (Ageing Report)	Value of formal LTC (Eurostat)	Sensitivity to hours		Sensitivity to valuation	
	in billion €	as % GDP	as % GDP	as % GDP	minimum time scenario as % GDP	maximum time scenario as % GDP	minimum valuation scenario as % GDP	maximum valuation scenario as % GDP
EU-27	**€ 319.5**	**2.4%**	1.7%	**1.9%**	**2.2%**	**2.5%**	**1.4%**	**3.3%**
FR	€ 99.6	4.2%	1.9%	2.4%	4.0%	4.5%	2.9%	5.6%
IT	€ 51.8	2.9%	1.7%	0.9%	2.8%	3.1%	1.7%	4.2%
ES	€ 45.2	3.7%	0.7%	0.9%	3.4%	4.1%	1.9%	5.5%
DE	€ 27.7	0.8%	1.6%	2.1%	0.8%	0.8%	0.5%	1.1%
PL	€ 16.3	3.3%	0.8%	0.4%	2.7%	3.8%	1.4%	5.2%
NL	€ 11.0	1.4%	3.7%	3.9%	1.4%	1.5%	0.9%	1.9%
BE	€ 10.2	2.3%	2.2%	2.3%	2.1%	2.4%	1.3%	3.2%
SE	€ 7.4	1.6%	3.3%	3.4%	1.4%	1.8%	1.3%	1.9%
IE	€ 6.1	1.9%	1.3%	1.5%	1.7%	2.1%	0.7%	3.1%
AT	€ 6.0	1.6%	1.8%	1.5%	1.4%	1.7%	0.8%	2.3%

Member States	Base case value of informal LTC		2019 Public spending on LTC (Ageing Report)	Value of formal LTC (Eurostat)	Sensitivity to hours		Sensitivity to valuation	
	in billion €	as % GDP	as % GDP	as % GDP	minimum time scenario as % GDP	maximum time scenario as % GDP	minimum valuation scenario as % GDP	maximum valuation scenario as % GDP
DK	€ 5.8	1.9%	3.5%	3.7%	1.8%	2.1%	1.5%	2.4%
GR	€ 5.1	2.7%	0.2%	0.2%	2.6%	2.9%	0.9%	4.6%
CZ	€ 4.6	2.2%	1.5%	1.5%	2.0%	2.4%	1.0%	3.3%
FI	€ 4.2	1.8%	2.0%	2.3%	1.7%	1.9%	1.3%	2.4%
RO	€ 4.1	2.0%	0.4%	0.4%	1.8%	2.2%	0.8%	3.3%
PT	€ 2.9	1.4%	0.4%	0.9%	1.4%	1.5%	0.5%	2.3%
HU	€ 2.4	1.8%	0.6%	0.6%	1.7%	1.9%	0.8%	2.8%
SK	€ 1.7	1.9%	0.8%	0.0%	1.7%	2.0%	0.9%	2.9%
BG	€ 1.5	2.7%	0.3%	0.0%	2.4%	3.0%	0.4%	5.0%
LT	€ 1.3	2.8%	1.0%	1.1%	2.6%	3.1%	1.4%	4.3%
HR	€ 1.1	2.2%	0.4%	0.2%	2.0%	2.5%	0.6%	3.8%
SI	€ 1.1	2.4%	1.0%	1.2%	2.1%	2.7%	1.4%	3.4%

Member States	Base case value of informal LTC		2019 Public spending on LTC (Ageing Report)	Value of formal LTC (Eurostat)	Sensitivity to hours		Sensitivity to valuation	
	in billion €	as % GDP	as % GDP	as % GDP	minimum time scenario as % GDP	maximum time scenario as % GDP	minimum valuation scenario as % GDP	maximum valuation scenario as % GDP
LV	€ 0.7	2.5%	0.5%	0.5%	2.3%	2.7%	1.2%	3.9%
LU	€ 0.7	1.2%	1.0%	1.3%	1.1%	1.3%	0.7%	1.7%
EE	€ 0.4	1.5%	0.4%	0.7%	1.5%	1.6%	0.7%	2.3%
MT	€ 0.3	2.3%	1.1%	1.7%	2.2%	2.5%	1.0%	3.7%
CY	€ 0.3	1.3%	0.3%	0.3%	1.3%	1.4%	0.7%	1.9%

Note: In all time scenarios individuals indicating to provide 0-9 hrs, 10-19 hours or 20-40 hrs of care per week are assumed to provide 4.5; 14.5 or 30 hrs of care per week, respectively. In the minimum time scenario individuals reporting to provide 40 hrs or more are capped at 40 hrs of care a week (a full-time working week). In the maximum time scenario individuals providing between 40-70 hrs of care are assumed to provide 55 hrs of care, individuals indicating to provide more than 70 hrs of care are assumed to provide 80 hrs of care a week. As the base case, we use an average time scenario in which hours of informal care per week are based on the average of the minimum and maximum time scenarios. In the minimum valuation scenario, the time of people not in employment or retired is valued at zero, in the maximum valuation scenario their time is valued at the estimated Dutch value of leisure time derived from the study by Verbooy et al. (2018), imputed for all other EU Member States using PPP corrected GDP per capita.

7.6. Conclusions

At the EU level, informal carers spend 33 to 39 billion hours per year on informal care, depending on assumptions about the average hours of high-intensity informal care providers (40+). These hours represent a certain value, even if those hours are unpaid. One method is to value those hours with the gross wages of professionals providing similar care activities (proxy-good method) while another method is to value those hours with the gross wage rate of what informal carers could have earned in their “real” professions, and the value of leisure for people past the age of 65 (opportunity cost method).

The value of the hours of informal care is 2.7% of 2018 EU GDP according to the proxy good method and 2.4% of EU GDP according to the opportunity cost method, in the base scenario assumptions. For the proxy good method, the value varies from 2.5% to 5.2% of EU GDP depending on scenarios for the number and valuation of hours, and for the opportunity cost the value varies from 1.4% to 3.3% depending on the valuation of hours.

The value of the hours of informal care exceed the cost of public expenditure on LTC, which is 1.7% of 2019 EU GDP according to the 2021 Ageing Report. Only in the northwest of Europe (excluding Ireland) does the cost of public expenditure on LTC exceed the hours valuation of informal care.

8. Public costs of informal care

8.1. Methodological notes

Using the framework from Table 1 in Chapter 1, public costs of informal care include:

- Expenditures on care allowances and other benefits.
- Lost tax and social security contribution revenues.
- Additional health care expenditures on informal carers.
- Gender inequality.

The framework further classifies two public benefits of informal care:

- Less or different expenditures on formal long-term care.
- Caring society.

The public costs of informal care do not include the hours valuation of informal care, because these do not involve an income transfer or lost revenues – at least not for the hours of informal care where leisure would have been the alternative option.

This chapter quantifies the expenditures on benefits and lost revenues. Although the provision of informal care has a detrimental effect on the health of informal care providers (Figure 43), no data are available to monetize the associated cost. Gender inequality has already been discussed in Chapters 3 and 4 on the incidence and intensity of informal care.

The general approach in this chapter is to aggregate the average expenditures or lost revenues per person over the relevant population, and to express the result as a percentage of GDP.

8.2. Lost revenues due to employment gap

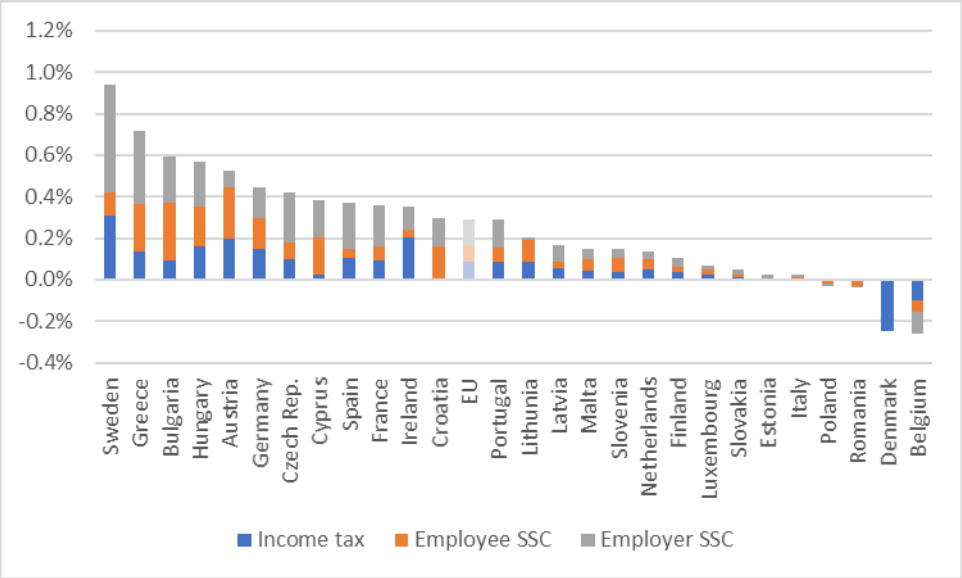
Most costs of informal care are associated with the employment gap, which was only identified with confidence for women aged 45-64 (Figure 50). The associated cost is estimated at 0.29% of the EU GDP of 2019. The costs of informal care related to the employment gap is (almost by default) zero beyond the age of 65. Below the age of 45 and for men aged 45-64, an employment gap was only identified for intense carers, but their numbers are too small to affect the average employment rate of informal carers in those groups.[125]

[125] The small numbers prevented the employment gap of intense carers to be identified with the usually required 95% statistical significance at Member State level.

As shown earlier in Figure 48, the estimated employment gap is negative for four countries: Belgium, Denmark, Poland and Romania: among women aged 45-64, the employment rate of informal carers is higher than average in those four countries. Accordingly, the estimated revenue losses are negative for these four countries (i.e. revenue gains).

The estimated annual lost tax and social security revenues related to the care employment gap as defined above amount to 0.29% of GDP at the EU27 level and even 0.9% of GDP in Sweden in 2019 (Figure 67). The high revenue loss in Sweden is related to the large employment gap caused by the high average employment rate of 79% for women aged 45-64, which is the highest across the EU.

Figure 67 - Lost tax and social security revenue due the employment gap of informal carers during their care stint (observed for women 45-64 alone)



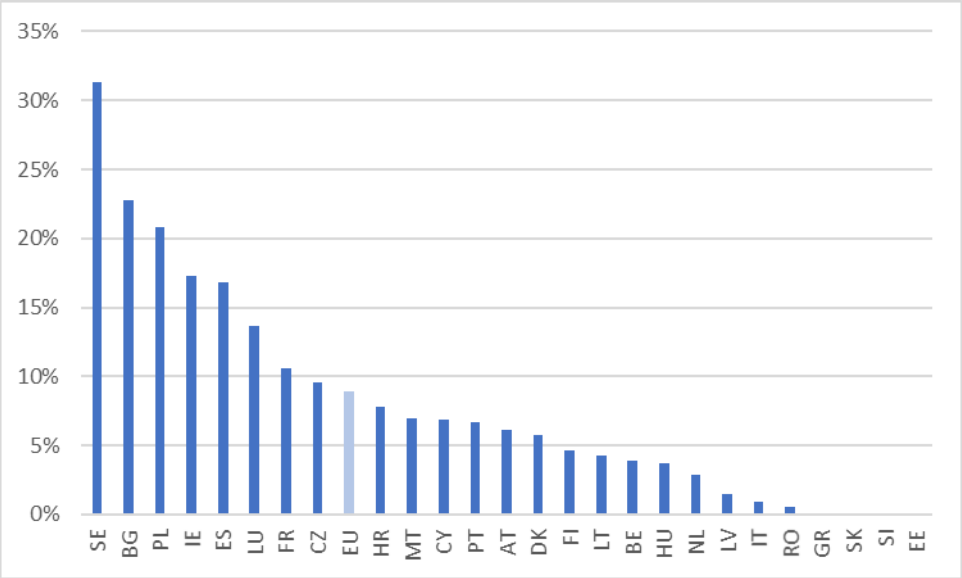
Source: EHIS (2013-2015), EQLS (2016), EARN SES (2018), LFS (2019), OECD-PwC tax rates (2019).

8.3. Lost revenues due to reduced work hours

The reduced working hours of female informal carers aged 18-44 cause a further revenue loss of an estimated 0.02% of GDP at the EU level (EUR 2.5 billion). At EU level, women aged 18-44 who provide intense informal care work on average 8 hours per week less than average. Numbers of respondents are too small to reliably determine the reduced working hours per country for this sub-group. Thus, a reduction of 8 work hours per week for female informal care providers in this age group is assumed for all countries and occupations. Under this assumption, the income loss per female informal carer aged 18-44 was estimated for the main occupational groups. These income losses were then for each country and main occupational group multiplied with the tax and social security rates (employee and employer contributions) that apply to the full wage. For a hypothetical example, if annual income at the average working hours is EUR 20,000 per year and the income lost due to reduced working hours is EUR 5,000 per year, the tax rate at EUR 20,000 is applied to the income loss of EUR 5,000.

As noted earlier, only a minority of informal carers provide intense care. For women aged 18-44, the percentage of informal carers providing intense care is 9% at the EU level (Figure 68). This means that the reduction of 8 work hours per week is aggregated over a relatively small group of 840,000 women aged 18-44 providing intense informal care in the EU, and another 36,000 women if it is assumed that in Germany also 9% of the female informal carers aged 18-44 provide intense care.[126]

Figure 68 - Share of informal carers providing intense care, women 18-44

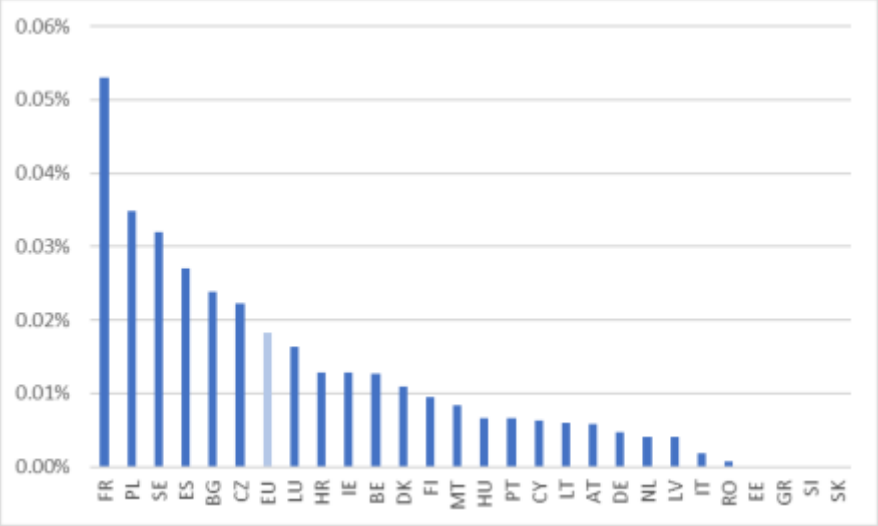


Source: EQLS (2016) and EHIS (2013-2015). No data available for Germany.
Note: as in the rest of the report, informal care does not include childcare for healthy children.

At the EU average, this results in a revenue loss of an estimated 0.02% of GDP. In four countries where no women aged 18-44 provide intense informal care according to both EHIS and EQLS: Estonia, Greece, Slovenia and Slovakia. In these four countries, no tax revenue is estimated to be lost due to reduced work hours. For the other countries, the tax revenue loss is estimated to vary from 0.001% of GDP in Romania to 0.053% of GDP in France (Figure 69).

[126] For Germany, no EHIS data was made available, and in EQLS 0 informal carers provide intense care across all ages, gender and other characteristics, and it is assumed that hours of informal care have been truncated at 40 hours per week.

Figure 69 - Lost tax revenues due to reduced working hours of women aged 18-44 providing intense informal care



Source: EHIS (2013-2015), EQLS (2016), EARN SES (2018), LFS (2019), OECD-PwC tax rates (2019).

8.4. Lost revenues due to skills losses

The lost tax and social security revenues due to a lower re-employment likelihood is estimated at 0.46% of the EU GDP of 2019. This is the sum of two effects: a lower re-employment probability for all informal carers (0.16% of GDP) and the same re-employment probability for the number of informal carers in the employment gap (0.30% of GDP).[127] In addition to lost revenues, the lower re-employment likelihood may also lead to benefit dependency. If the care stint was short, the informal carer might still be eligible for an unemployment benefit after the care stint, but after a few years only minimum income support will be available. However, minimum income support is only available if the household income the national minimum income level which is usually not the case if the partner is employed. Because of the complications of estimating the benefit entitlement after failing to re-enter employment, no calculations on this were done. The cost associated with skills losses during the care stint are therefore underestimated.

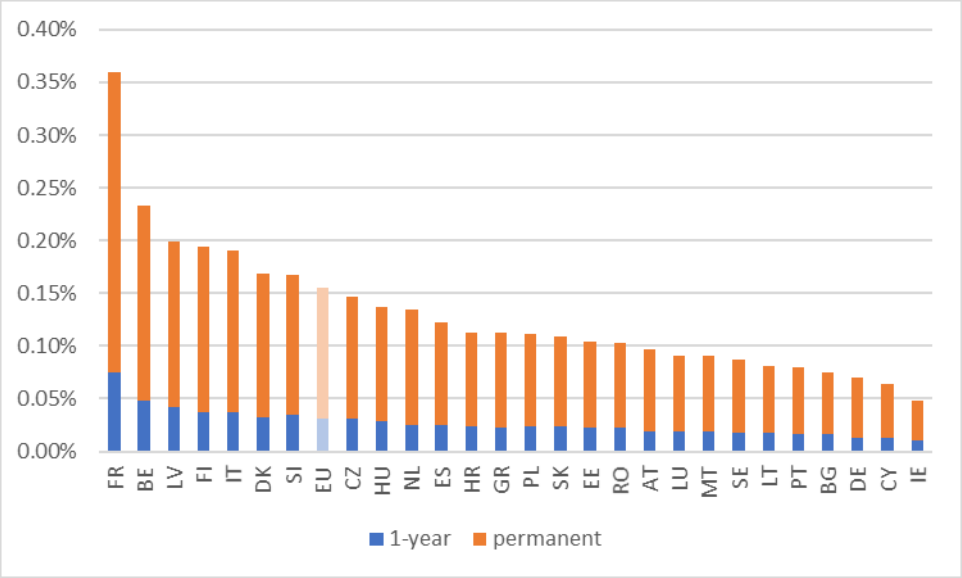
The lost revenues due to skills losses were calculated as an annual amount per informal carer during the care stint (Table 7 and Table 8). Multiplying these annuities over the numbers of respectively women 18-44, men 18-44 and men 45-64 providing informal care[128] and applying the tax and social security contribution rates by gender, age, occupation and country as described in Section 8.2 gives the aggregate annual revenue loss due to a lower re-employment likelihood. Under the assumption that the re-employment likelihood is only lower compared to a comparison group in the first year after the care stint and using a 2% discount rate per year, the revenue loss would be limited to an estimated 0.03% of EU GDP (Figure 70). However, if the re-employment likelihood of informal carers is assumed to be

[127] Mathematically, the revenues "Y" is the revenue "y" per informal carer times the number of informal carers "N" times the-employment likelihood "P". Then the lost revenues dY are y times (dN x P + N x dP), where dN is the number of informal carers in the employment gap, and dP is the difference in re-employment likelihood compared to other non-employed job searchers.

[128] For women aged 45-64, the re-employment likelihood of informal carers was the same as in their peer group implying zero lost revenues due to skills losses for this gender-age group.

permanently lower after the care stint, the revenue losses increase to 0.16% of EU GDP. This latter assumption is used in the rest of this section. The estimated revenue loss due to skills losses varies from 0.05% of GDP in Ireland to 0.36% in France.

Figure 70 - Lost tax revenues due to skills losses of informal carers



Source: EHIS (2013-2015), EQLS (2016), SILC longitudinal 2010-2017, EARN SES (2018), LFS (2019), OECD-PwC tax rates (2019).

In addition, the employment gap of women 45-64 providing informal care affects not only income from work during the care stint, but also after the care stint because the re-employment likelihood searching for work is limited at 17% per year (the same as for other inactive women 45-64 searching for work). In Section 6.5, the loss of future income per informal carer in the employment gap was estimated at 100% of annual income from work.

The associated public revenue loss associated with future income losses of the number of female informal carers aged 45-64 in the employment gap can therefore be estimated at 100% of the public revenue loss of the employment gap during the care stint. The result is the same as in Figure 67 and the resulting 0.29% of GDP is to be added to the lost revenues due to skills losses.

8.5. Expenditures on care allowances and other benefits

The expenditures on care allowances and other benefits are estimated at 0.21% of the EU GDP of 2019: 0.19% on care allowances and 0.02% on unemployment benefits and minimum income benefits.

Ecorys has collected data on expenditures on care allowances and estimated the share of informal care for those countries that pay the care allowances to persons needing care, to spend on formal or informal care as they wish (Section 6.4).[129] Eurostat collects similar data in the System of Health Accounts (SHA), namely expenditures on long-term care provided by households. Although the two sources agree roughly on expenditures on care

[129] For some countries, the desk research has benefited from input of a SPC committee on LTC.

allowances for some countries (Austria, Bulgaria, Germany, Ireland, Luxembourg, Spain), for most countries the differences are substantial.

One reason is the difficulty to separate expenditures on formal and informal carers. In the Eurostat SHA, if no separation of expenditures on informal care and formal care is possible and formal care is assessed to cause the main part of the expenditure, the whole expenditures on a measure is allocated to formal long-term care. It should be noted that in the Eurostat System on Social Protection (ESSPROS) expenditures are available per measure, and no further distinction is made if the measure includes expenditures on both formal and informal care.[130] Other notable differences between SHA and ESSPROS are:

- SHA includes the own share of persons needing care for the payment of care services as opposed to ESSPROS.
- SHA includes private insurance as opposed to ESSPROS, however private insurance for informal LTC seems limited (but for example the Belgian railway sector has such an insurance).
- ESSPROS aggregates combine public and private expenditures. However, individual measures are typically either private or public, and private insurance of informal care is rare anyway.

Mainly due to ESSPROS not separating expenditures on formal and informal care, only SHA data were used to compare the results of desk research with. The fact that in the SHA expenditures where formal and informal care cannot be separated are fully allocated to formal care if that is assessed to be the main component, explains why the SHA estimates expenditures on households providing informal care is zero or almost zero for some countries such as Belgium and the Netherlands. For Finland, France and Malta, Eurostat classified data as missing but desk research enabled estimates for these countries (for Malta the expenditures are negligible as a percentage of GDP due to the low number of eligible informal carers).

For Slovenia, the closest possible approximation based on desk research was on LTC social expenditures on the private sector, which is likely to overestimate the expenditures on households. The Eurostat figure is likely more accurate for this country. For Belgium, the closest information from desk research included not only expenditures on care allowances for informal care, but also for professional home care. For Figure 60, the assumption was that half of the expenditures were for informal care. For Figure 71, the expenditures have been allocated fully to informal care, with a note that this certainly overestimates the amount spent on informal care.

For four countries, the Eurostat figure is much higher than the figure based on desk research of this study and the difference is explored in further detail: Poland, Lithuania, Portugal and Romania.

For Poland, the difference between the desk research of this study and Eurostat is likely that this study excludes the care allowance (Zasiłek opiekuńczy) for child nursing. This allowance is meant for both disabled children (in scope) and illness and emergency

[130] The aggregate statistics in ESSPROS do not distinguish long-term care as a separate function, but the data by scheme includes LTC schemes: https://ec.europa.eu/eurostat/web/social-protection/data/data-by-scheme

situations (not in scope).[131] Excluding this benefit as in this study underestimates the relevant care allowances, including them would overestimate them.

In Lithuania, municipalities provide social services which includes home help services for elderly people. According to ESSPROS, these are usually provided in kind, but sometimes the person receives care money to look for the provider of services himself. This study excludes this benefit because it seems primarily intended for formal care.

For Portugal, the relevant benefit is tertiary care allowance, but unfortunately no separate numbers of beneficiaries or expenditures are published in either ESSPROS or the social security institute.[132] For this country, the Eurostat System of Health Accounts figure is therefore the relevant figure.

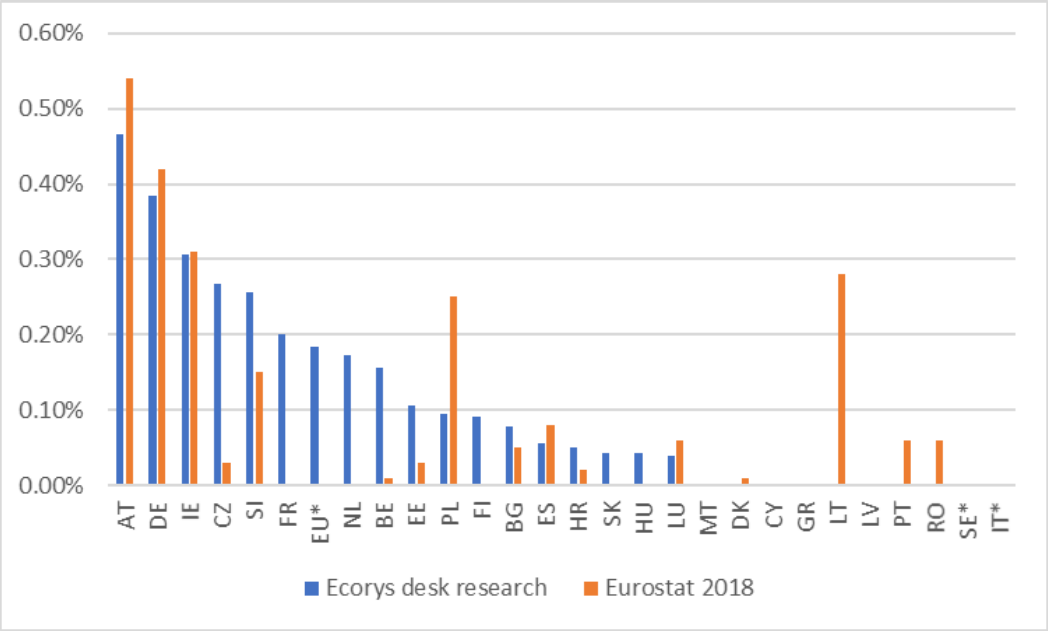
For Romania, the relevant scheme is the Scheme concerning social protection of the disabled persons: PSHAND (Schema privind protectia sociala si ocuparea persoanelor cu handicap) and the relevant benefit is the allowance paid to the personal assistant of handicapped persons (indemnizatii paltite personalului asistent al persoanelor cu handicap). The scheme includes various other benefits (free transport, accommodation, food, telecom), so the ESSPROS figure would overestimate the expenditures and the Eurostat System of Health Accounts figure is therefore the relevant figure.

Based on own desk research (excluding Cyprus, Greece and Latvia where no care allowance exists and excluding Denmark, Lithuania, Portugal, Romania, Italy and Sweden where no data was found), the care allowances amount to an estimated 0.18% of the EU GDP of 2019. Including the Eurostat SHA data for Portugal and Romania, the care allowances amount to an estimated 0.19% of EU GDP.

[131] For the conditions of this benefit see https://www.zus.pl/swiadczenia/zasilki/zasilek-opiekunczy/prawo-do-zasilku-i-okres-przyslugiwania

[132] Portuguese name: Subsídio por assistência de 3ª pessoa. See http://www.seg-social.pt/estatisticas : there are no separate data for the category “dependencia”. There may be good reasons for this. For example, if benefits are combined and the combined benefit is capped, then allocation of expenditures to individual schemes is a bit arbitrary.

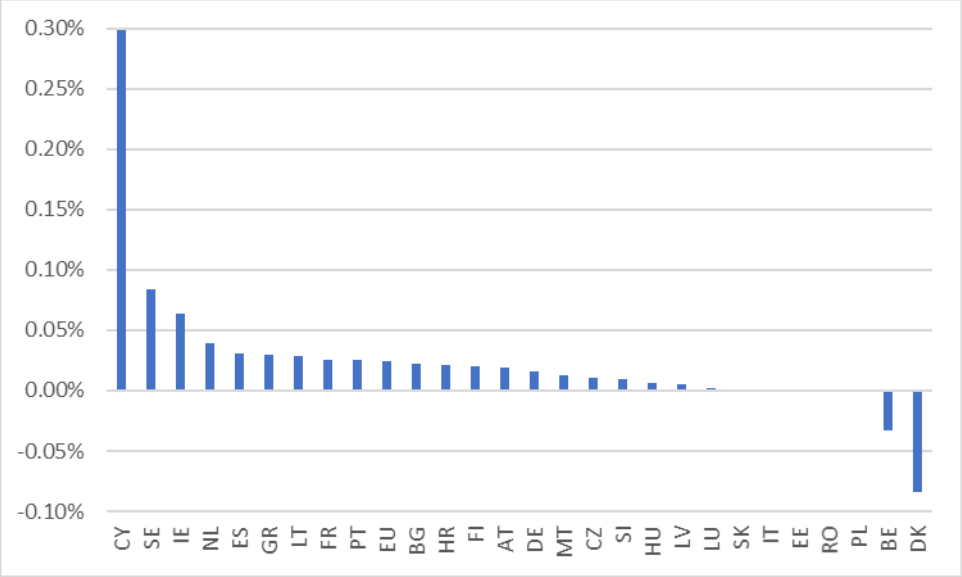
Figure 71 - Expenditures on care allowances as a % of 2019 GDP



Note: expenditures Belgium include formal home care. Sweden and Italy: no data available.
Source: desk research Ecorys, Eurostat SHA, expenditures on LTC provided by households (HP.8.1 in the SHA classification). For Portugal and Romania, the Eurostat SHA data will be used in the total.

If non-employed informal carers do not receive a care allowance, they may still receive an unemployment benefit or minimum income support. Contrary to care allowances, which no-one not providing informal care receives, unemployment benefits and minimum income support is only included for the number of informal carers in the employment gap (of women aged 45-64). At the EU level, these expenditures are 0.02% of GDP. Expenditures on unemployment insurance benefits and minimum income support are highest for two countries that do not have a national informal care allowance scheme, Cyprus and Sweden (Figure 72). The expenditures are negative in the two countries where the employment rate of women aged 45-64 providing informal care is higher than for other women in that age group: Belgium and Denmark. For the other countries, the expenditures on unemployment or minimum income benefits varies between an estimated 0 and 0.06% of 2019 GDP.

Figure 72 - Expenditures on unemployment benefits and minimum income support of informal carers in the employment gap (women 45-64) as a % of 2019 GDP



Source: EU-SILC 2016 ad hoc module, EHIS 2013-2015, EQLS 2016.

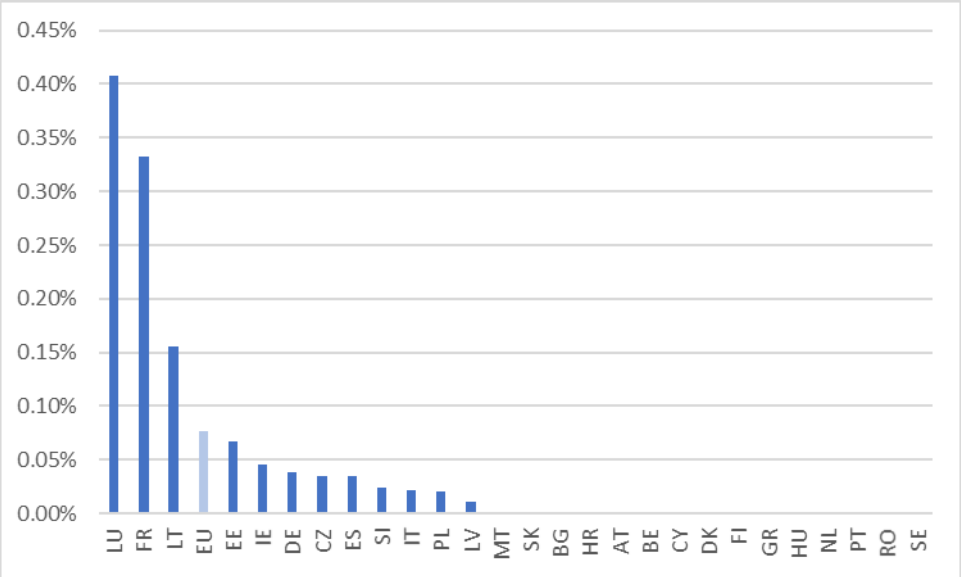
8.6. Valuation of pension credits

The equivalent annual amount of pension credits for informal carers is estimated at 0.08% of the 2019 EU GDP. The percentage of informal carers receiving pension credits during their care stint is already given in Table 9 in Section 6.6 above. In addition, many informal carers in the employment gap who do not qualify for the informal care pension credits are likely to receive pension credits on the basis of unemployment or minimum income support. However, we do not know their number and for simplicity, informal carers in the employment gap (women aged 45-64) are assumed to already receive the specific informal care pension credits.

Somewhere in the future, the State will have to pay the credited pensions to the (former) informal carers. The associated cost is hard to value, since it also depends on the family situation of the informal care, the return on investment of pension savings, etc. To value the pension credits, it is assumed that only the basic State pension is credited. As a rule of the thumb, the contribution for the old-age pension is 20% of the wage sum. For non-employed informal carers, the pension credit is therefore valued at 20% of the national minimum income support level for a single person.

Under the above assumptions, the aggregated value of pension credits is estimated at 0.08% of 2019 at the EU level. This percentage is highest in Luxembourg and Lithuania (100% of informal carers estimated to receive pension credits) and France and Estonia (about half of informal carers estimated to receive pension credits). As noted before, the old age pension of informal carers can still be covered in countries that do not have specific pension credits for informal carers, such as in for example the Netherlands where every resident is credited for the State old age pension – it is just not included as a cost of informal care if the credit entitlement is not based on informal care provision.

Figure 73 - Valuation of pension credits of informal carers as a % of 2019 GDP



Source: MISSOC, EHIS 2013-2015, EQLS 2016.

8.7. Total monetarised public costs of informal care

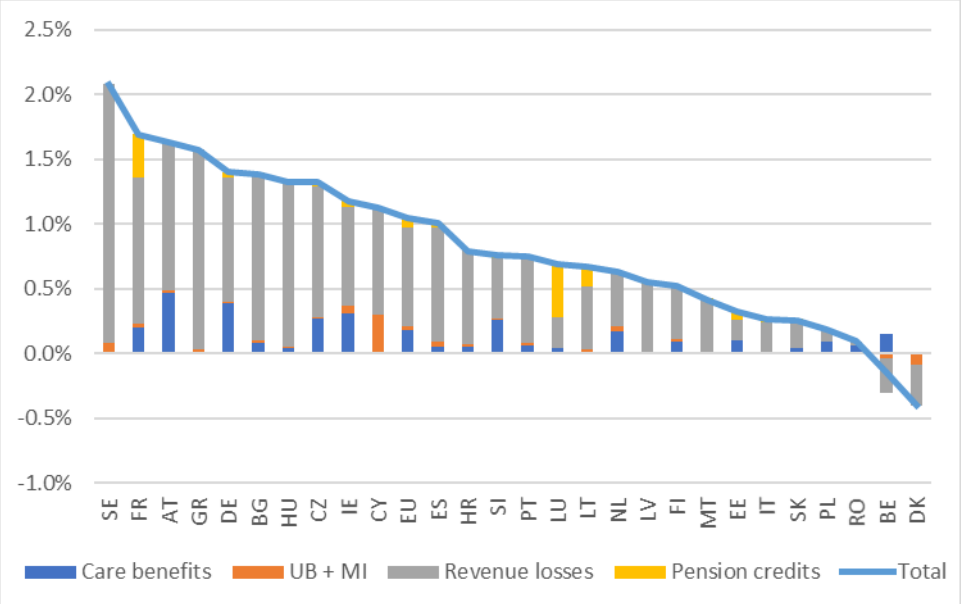
Adding up the costs of various components of informal care calculated in the previous sections gives an estimate of the total cost of informal care of 1.05% as a percentage of 2019 EU GDP:

- Lost revenues due to the employment gap: 0.29% during the care stint
- Lost revenues due to reduced work hours: 0.02%
- Lost revenues due to skills losses: 0.16% due to lower re-employment likelihoods
- Lost revenues due to skills losses: 0.29% due to the employment gap post-care stint
- Expenditures on care allowances: 0.19%
- Expenditures on unemployment benefits and minimum income benefits of informal carers in the employment gap: 0.02%
- Valuation of pension credits: 0.08%

At the EU level, the public costs of informal care are estimated at 1.05% of GDP (EUR 146 billion) and are mainly caused by lost tax and social security revenues (Figure 74). The public costs are highest in Sweden (2.1% due to the large employment gap), France (1.7%), Austria (1.6% including due to informal care allowances) and Greece (1.6%, due to a large employment gap). The costs are lowest in countries with a small employment gap of informal carers (notably Poland and Romania). In the two countries (Belgium and Denmark) where the employment rate of women aged 45-64 providing informal care is higher than for other women in that age category, the increased tax and social security revenues

compensate the expenditures on care allowances, which are even overestimated in Belgium.

Figure 74 - Total estimated public costs of informal care as a % of 2019 GDP



Notes: no data on informal care allowances Italy and Sweden.

The above public costs do not include items that could not be monetarised. In particular additional expenditures due to the faster deteriorating health of informal care providers (most notable for men above the age of 65) could not be monetarised. It should also be noted that the costs consist mainly of foregone tax and social security revenues rather than expenditures.

The fact that costs are associated with informal care does not imply that informal care should be avoided, but rather that it is not a “free lunch” to replace formal care with informal care, apart from the consideration that “light” care tends to dominate informal care as opposed to formal care.

8.8. Conclusions

Informal care affects the State budgets through lost revenues from income taxes and social security contributions and through expenditures on various benefits to informal care providers. The invisible lost revenues have the greatest impact on the State budget, namely an estimated 0.76% of the 2019 EU GDP. The largest part of this is associated with the reduced employment of women aged 45-64 (0.29% during the care stint and another 0.29% after the care stint because the re-employment likelihood is low). A limitation is that lost revenues during the care stint were only estimated for the informal carers for whom the employment gap was significant (i.e. women aged 45-64). The calculations about lost revenues due to a lower re-employment likelihood after the care stint assumes that the difference in re-employment likelihood persists until the age of 65 (after which people are assumed to stop working anyway).

Lower re-employment likelihoods of other informal carers than women aged 45-64 compared to their peer groups contribute to further lost revenues of an estimated 0.16% of EU GDP while lost revenues due to reduced working hours of women aged 18-44 providing intense informal care amount to only an estimated 0.02% of EU GDP.

Expenditures on care allowances account for a further estimated 0.19% of EU GDP. For some countries, no data is available or expenditures on care allowances were approximated. In the working age population, the employment rate of informal carers is similar as among non-carers, except for women aged 45-64 of whom some qualify for informal care allowances. Thus, the additional expenditures on unemployment benefits and minimum income support caused by a difference in employment rates of informal is limited to only an estimated 0.02% of EU GDP. Likewise, the value of pension credits is limited to an estimated 0.08% of EU GDP, because conditions apply to qualify as informal carer for pension credits. The calculation of pension credits assumes that pension credits for informal care fully repair pension entitlements, which need not always be the case.

All the above lost revenues and expenditures add up to an estimated 1.05% of EU GDP (EUR 146 billion in 2019). Between countries, the impact of informal care on the State budget is largest in Sweden (2.1%) due to the large employment gap, France (1.7%), Austria (1.6% including due to informal care allowances) and Greece (1.6%, due to a large employment gap). The impact on the State budget is smallest in countries where women aged 45-64 providing informal care are actually more often employed, notably in Poland and Romania. The estimated impact is even positive in Belgium and Denmark, where among women aged 45-64 the employment rate among informal carers is substantially higher than in the general population. These differences between countries may need to be explored in further detail in another study, for example with administrative data.

A Interview Guide

Information	To be filled in
Name	
Organisation/association	
Date	
Interviewer	

Background and explanation

Commissioned by the European Commission, Directorate-General for Employment, Social Affairs and Inclusion (DG EMPL), Ecorys, an international research and consultancy agency, and Erasmus University Rotterdam, is conducting a study on informal long-term care. The European Pillar of Social Rights ('the Pillar'), proclaimed on 17 November 2017, sets out key principles and rights for a renewed process of upward convergence towards better working and living conditions, including work-life balance and the right to adequate social protection. It will serve as a compass for a renewed process of convergence towards better working and living conditions among participating Member States.

Principle 18 of the Pillar states that everyone has the right to affordable long-term care services of good quality, in particular home-care and community-based services. In addition to formal care, informal care provided by e.g., family members, neighbours or friends, makes up a significant share of long-term care.

Member States have different policies and even different definitions for informal long-term care. In order to conduct a proper measurement and valuation of the impact of informal long-term caregiving across Europe, a standard definition of what informal LTC entails is required. In order to formulate a standard definition of informal LTC, we are currently conducting a literature review to search for relevant definitions of informal long-term care and conducting a qualitative interview study with key experts.

Hence, the aim of this interview is to place relevant definitions from the literature within the current policy context. We would like to thank you for your time for participating in this interview. Any information you will provide will be treated confidentially and we will not quote anything without your permission.

I. Introduction

1. Can you give a brief introduction of yourself and the organisation?
   a. What is your background and your position in the organisation, and how long have you been at the organisation?
   b. What is your direct involvement with informal long-term care or data on it?

II. Definition of informal long-term care

2. From a policy or data perspective, what does informal long-term care entail?
3. From a policy or data perspective, what is the distinction between formal and informal long-term care?
4. From a policy or data perspective, when should one speak of informal long-term in terms of:
   a. The care receiver (e.g., in terms of disability, focus on elderly etc.)?
   b. The care provider (e.g., in terms of age limit)?
   c. The relationship between care receiver and provider (e.g., parent-child relationship, other family members, friends, neighbours)?
   d. Type of care provided (e.g., help with (Instrumental) activities of daily living or other kind of tasks)?
      - *Activities of daily living include e.g. bathing, dressing, eating, getting in and out of bed or a chair, moving around, using the toilet, and controlling bladder and bowel functions*
      - *Instrumental activities include e.g. preparing meals, managing money, shopping for groceries or personal items, performing light or heavy housework, and using a telephone*
5. From a policy or data perspective, how should *informal* care be defined, e.g., should it be considered whether the care provider is being paid or not?
   a. In case of paid informal care, what type of payment may informal care entail, e.g., government assistance?
6. From a policy or data perspective, do you think duration of the care should be considered when defining informal long-term care?
   a. If yes, what threshold should be used, e.g., in months of care provided?
7. From a policy or data perspective, do you think intensity of the care should be considered when defining informal long-term care?
   a. If yes, what threshold should be used, e.g. how many hours per week?

III. Impacts of informal long-term care

8. What kind of direct costs (expenses) for the care provider or society should be considered when measuring the impact of informal long-term care? *E.g. travel costs, care allowance*
9. What kind of indirect costs (non-expenses) should be considered when measuring the impact of informal long-term care? *E.g. loss of job, health impact on care provider*.
10. Do you have any relevant databases and codebooks on informal care that you could share?

IV. Final notes

11. Is there any additional information you would like to share with us?
12. Do you have any additional questions or remarks that could be of use for our study?

Thank you very much for your cooperation.

B Literature overview table

The list below presents the 31 numbered studies used in the literature review of this study, followed by an overview table focusing on outcomes relating to the share of the population providing care, and impacts (in practice all indirect costs).

1. Baji, Golicki, Prevolnik-Rupel, Brouwer, Zrubka, Gulácsi, Péntek. The burden of informal caregiving in Hungary, Poland and Slovenia: results from national representative surveys. The European Journal of Health Economics. 20 (2019) (Suppl 1):S5–S16. https://doi.org/10.1007/s10198-019-01058-x.
2. Barczyk & Kredler. Long-Term Care Across Europe and the United States: The Role of Informal and Formal Care. FISCAL STUDIES, vol. 40, no. 3, pp. 329–373 (2019) 0143-5671.
3. Berglund, Lytsy & Westerling. Health and wellbeing in informal caregivers and non-caregivers: a comparative cross-sectional study of the Swedish general population. Health and Quality of Life Outcomes (2015) 13:109. DOI 10.1186/s12955-015-0309-2.
4. Bom, Bakx, Schut & van Doorslaer. Health effects of caring for and about parents and spouses. The Journal of Economics of Ageing. (2019) 14. https://doi.org/10.1016/j.jeoa.2019.100196.
5. Ciccarelli & Van Soest. Informal Caregiving, Employment Status and Work Hours of the 50+ Population in Europe. De Economist. (2018) 166:363–396. https://doi.org/10.1007/s10645-018-9323-1.
6. De Zwart, Bakx, van Doorslaer. Will you still need me, will you still feed me when I'm 64? The health impact of caregiving to one's spouse. Health Economics. (2017) 26(S2):127–138. DOI: 10.1002/hec.3542.
7. Estrada Fernandez, Lacruz, Lacruz & Lopez. Informal care. European situation and approximation of a reality. Health Policy 123 (2019) 1163–1172. https://doi.org/10.1016/j.healthpol.2019.09.007.
8. Hajek & König. Informal caregiving and personality: Results of a population-based longitudinal study in Germany. PLoS ONE (2018) 13(9): e0203586 https://doi.org/10.1371/journal.pone.0203586.
9. Hajek & König. Impact of informal caregiving on loneliness and satisfaction with leisure-time activities. Findings of a population-based longitudinal study in Germany. Aging & Mental Health. (2018) 23:11, 1539-1545, DOI: 10.1080/13607863.2018.1506739.
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11. Hajek & König. Informal Caregiving and Subjective Well-Being: Evidence of a Population-Based Longitudinal Study of Older Adults in Germany. JAMDA 17 (2016) 300e305. http://dx.doi.org/10.1016/j.jamda.2015.10.015.
12. Heger. The mental health of children providing care to their Elderly parent. Health Econ. 26: 1617–1629 (2017). DOI: 10.1002/hec.3457.
13. Heger. Work and Well-Being of Informal Caregivers in Europe. 2014. Ruhr Economic Paper http://dx.doi.org/10.4419/86788587.
14. Hiel, Beenackers, Renders, Robroek, Burdorf & Croezen. Providing personal informal care to older European adults: Should we care about the caregivers' health? Preventive Medicine. 70 (2015) 64-68. https://doi.org/10.1016/j.ypmed.2014.10.028.
15. Joling, ten Have, de Graaf, O'Dwyer. Risk factors for suicidal thoughts in informal caregivers: results from the population-based Netherlands mental health survey and

incidence Study-2 (NEMESIS-2). BMC Psychiatry (2019) 19:320. https://doi.org/10.1186/s12888-019-2317-y.
16. Kaschowitz and Brandt. Health effects of informal caregiving across Europe: A longitudinal Approach. Social Science & Medicine 173 (2017) 72e80. http://dx.doi.org/10.1016/j.socscimed.2016.11.036.
17. Kaschowitz and Lazarevic (2020) Bedeutung des Gesundheitsindikators bei der Analyse der Gesundheitsfolgen informeller Pflege Anderer Indikator, anderes Ergebnis? Z Gerontol Geriat 2020 · 53:10–16. https://doi.org/10.1007/s00391-019-01663-8.
18. Kolodziej, Reichert, Schmitz. New Evidence on Employment Effects of Informal Care Provision in Europe. Health Services Research. 53:4, Part I (August 2018) DOI: 10.1111/1475-6773.12840.
19. Maquire, Hanly, Maquire. Beyond care burden: associations between positive psychological appraisals and well-being among informal caregivers in Europe. Quality of Life Research (2019) 28:2135–2146. https://doi.org/10.1007/s11136-019-02122-y.
20. Mortensen, Dich, Lange, Alexanderson, Goldberg, Head, Kivimäki, Madsen, Rugulies, Vahtera, Zins, Rod. Job strain and informal caregiving as predictors of long-term sickness absence: A longitudinal multi-cohort study. Scand J Work Environ Health. 2017;43(1):5-14. doi:10.5271/sjweh.3587 Schmitz & Westphal. Short- and medium-term effects of informal care provision on female caregivers' health. Journal of Health Economics 42 (2015) 174–185. http://dx.doi.org/10.1016/j.jhealeco.2015.03.002.
21. Schmitz & Westphal. Informal care and long-term labor market outcomes. Journal of Health Economics 56 (2017) 1–18. http://dx.doi.org/10.1016/j.jhealeco.2017.09.002.
22. Stanfors, Jacobs, Neilson. Caregiving time costs and trade-offs: Gender differences in Sweden, the UK, and Canada. SSM - Population Health 9 (2019) 100501. https://doi.org/10.1016/j.ssmph.2019.100501.
23. Uccheddu, Gauthier, Steverink, Emery. The pains and reliefs of the transitions into and out of spousal caregiving. A cross-national comparison of the health consequences of caregiving by Gender. Social Science & Medicine 240 (2019) 112517. https://doi.org/10.1016/j.socscimed.2019.112517.
24. Van den Broek & Grundy. Parental health limitations, caregiving and loneliness among women with widowed parents: longitudinal evidence from France. European Journal of Ageing. 2018. https://doi.org/10.1007/s10433-018-0459-2.
25. Van den Broek & Grundy. Does long-term care coverage shape the impact of informal care-giving on quality A difference-in-difference approach. Ageing & Society (2018), 1–18. doi:10.1017/S0144686X18001708.
26. Verbakel. How to understand informal caregiving patterns in Europe? The role of formal long-term care provisions and family care norms. Scandinavian Journal of Public Health, 2018; 46: 436–447. DOI: 10.1177/1403494817726197.
27. Verbakel, Tamlagsrønnin, Winstone, Fjæ, Eikemo. Informal care in Europe: findings from the European Social Survey (2014) special module on the social determinants of health. European Journal of Public Health, Vol. 27, Supplement 1, 2017, 90–95. doi:10.1093/eurpub/ckw229.
28. Wagner and Brandt. Long-term Care Provision and the Well-Being of Spousal Caregivers: An Analysis of 138 European Regions. J Gerontol B Psychol Sci Soc Sci. Vol. 73 (2018) No. 4, e24–e34. doi:10.1093/geronb/gbx133.
29. Zwar, König, Hajek. The impact of different types of informal caregiving on cognitive functioning of older caregivers: Evidence from a longitudinal, population-based study in Germany. Social Science & Medicine (2018) 214. 12–19. https://doi.org/10.1016/j.socscimed.2018.07.048.
30. Zwar, König, Hajek. Consequences of different types of informal caregiving for mental, self-rated, and physical health: longitudinal findings from the German Ageing Survey. Quality of Life Research. 2018. 27:2667–2679 https://doi.org/10.1007/s11136-018-1926-0.

Author(s) (year of publication)	EU data source	Category	Specific outcome considered	Share of care providers	Impact (costs/benefits)
1. Baji, Golicki, Prevolnik-Rupel, Brouwer, Zrubka, Gulácsi, Péntek; (2019)	HU, PL, SI CarerQol-7D survey, Nov 2018-Jan 2019	Health	Health status	% of informal caregivers: • Hungary: 14.9. • Poland: 15.0. • Slovenia 9.6.	• In Poland and Slovenia, the health status of caregivers was significantly lower than that of non-caregivers in the study sample. • No significant difference between caregivers and non-caregivers was observed in Hungary.
2. Barczyk & Kredler (2019)	SHARE 2004/2005, 2006/2007, 2013, 2015	-	-	Care receivers aged 65 and older, informal care hours as % of total care hours: • 22% in Northern countries. • 43% in Middle countries. • 81% in Southern countries.	
3. Berglund, Lytsy & Westerling (2015)	SE “Health on equal terms” survey 2004-2013	Health	Self-rated health Psycho-logical wellbeing Days in poor physical/mental health Days without work capacity due to health issues	Sweden: 10,5% of sample	• Caregivers report higher probability of poor self-rated health. • Psychological wellbeing was negatively associated with caregiving. • Caregivers reported more recent days with poor physical and mental health. • Caregiving was associated with more

Author(s) (year of publication)	EU data source	Category	Specific outcome considered	Share of care providers	Impact (costs/benefits)
					recent days of lost work capacity.
4. Bom, Bakx, Schut & van Doorslaer (2019)	STREAM 2010-2013	Health	Mental health Physical health	Netherlands: 22,8% of the sample in first wave (among which 31% provides care for more than 8 hours a week)	• Negative impact on mental health. • No physical health effect of informal care giving. • The mental health effect is stronger when individuals provide more informal care, and stronger for females and when caring for a spouse.
5. Ciccarelli & Van Soest (2018)	SHARE 2004-2013	Labour market	Employment Work hours	% of people aged 50-70 with a living parent caring informally for parent(s) (including personal care and practical care inside or outside household) [Table 3]: • Men: 11.7% (2.2% daily caregiver). • Women: 13.5% (3.7% daily caregiver).	• Informal caregiving at low intensity does not significantly affect the probability of being employed or hours of paid work. • There are negative effects of daily or almost daily caregiving on the employment probability and weekly hours of paid work. • These negative effects of daily caregiving are much stronger for females than for males.
6. De Zwart, Bakx, van Doorslaer (2017)	SHARE 2004/2005, 2006/2007, 2013, 2015	Health	Depressive symptoms Self-reported health	% of people aged 50-70 providing help with personal care for spouse or	• Caregiving leads to an immediate increase in depressive symptoms, prescription drug use

Author(s) (year of publication)	EU data source	Category	Specific outcome considered	Share of care providers	Impact (costs/benefits)
			Medical care use: Prescription drug use& doctor visits	partner within same household [Table 1]: 4%	(only females) and doctor visits (only females) and to a reduction in self-perceived health. • These effects are larger for women than for men. • There are no longer-term effects of informal caregiving found.
7. Estrada Fernandez, Lacruz, Lacruz & Lopez (2019)	ESS 2014/ 2015	Health	Dissatisfaction in life Limitations in daily living from health problems Depression Unhappiness Healthy habits: eating fruits and vegetables daily, having a healthy weight	Informal carers: 31.92% Among which 70.98% provides care for at least 1h/week and 3.79% for at least 20h/week	• Caregiving is not associated with a change in dissatisfaction with life. • Caregiving is however associated with more limitations in daily living, more depressed feelings. • For high-intensity female caregivers care provision is associated with a small increase in unhappiness. • The risk of depression increases as the daily hours of care increase. • Carers take better care of themselves, consume more fruits and vegetables and maintain a more appropriate weight. • When hours of care increase the healthy

Author(s) (year of publication)	EU data source	Category	Specific outcome considered	Share of care providers	Impact (costs/benefits)
					intake however decreases and less carers are able to maintain appropriate weight.
8. Hajek & König (2018)	DE GSOEP 2005, 2009, 2013	Other/ Health (Personal factors)	Personality	Germany: Mean hours of informal care conditional on providing care: Weekday: 2,8 Saturday: 3.0 Sunday:3.1	• Informal care is associated with changes in neuroticism. A reason for this might be that an increase in neuroticism is associated with an increase in negative emotions and depressive symptoms. • Increased conscientiousness (only when caring >5h on a Sunday). • Informal caregiving was not associated with openness to experience, extraversion and agreeableness.
9. Hajek & König (2018)	DE GSOEP 2002, 2008, 2011	Health Time use	Loneliness Number of important people in regular contact Satisfaction with leisure time activities	Germany: 14,5% of sample	• Informal caregiving was not associated with loneliness. • The onset of informal caregiving was associated with an increase in the number of individuals in regular contact.

Author(s) (year of publication)	EU data source	Category	Specific outcome considered	Share of care providers	Impact (costs/benefits)
					• The onset of informal caregiving was associated with a decrease in the satisfaction with leisure-time activities.
10. Hajek & König (2017)	DE DEAS 2002, 2008, 2011	Health	Depressive symptoms	Germany: 11.3% (2002), 13.1% (2008), 15.1% (2011)	• Informal caregiving was associated with depressive symptoms.
11. Hajek & König (2016)	DE DEAS 2002, 2008, 2011	Health	Physical health Mental health Life satisfaction + Positive and negative affect schedule (affective wellbeing)	Germany: 13.5% (2002), 14.8% (2008), 14.7% (2011)	• Informal care was associated with mental health in the total sample and in both sexes. Informal care was associated with worse life satisfaction in women. • The association of informal care on mental health was moderated by self-efficacy in the total sample. • There is no association found with physical health, positive or negative effect schedule.
12. Heger (2017)	SHARE 2004/2005, 2006/2007, 2011/2012, 2013	Health	Mental health	% of people aged 50-70 with a living parent caring informally for parent(s) (including personal care and practical care inside or outside household):	• There are small negative effects of caregiving on mental health for caregiving in general.

Author(s) (year of publication)	EU data source	Category	Specific outcome considered	Share of care providers	Impact (costs/benefits)
				• Women: 51%. • Men: 41%.	• The effect size increases for daughters if caregiving is triggered by the parent's need for care as indicated by only having a single parent.
13. Heger (2014)	SHARE 2004/2005, 2006/2007, 2008/2009	Health Labour	Labour force participation: employed, hours worked Cognitive ability: verbal fluency, word recall, numeracy Mental health Physical health	% of women aged 50-70 with a living parent, caring informally for parent(s) (including personal care and practical care inside or outside household), any (daily) [Table 2.2]: • PL: 20% (11%). • IT: 26% (14%). • AT: 27% (12%). • EL: 27% (13%). • ES 29% (18%). • FR: 29% (7%). • DE: 40% (8%). • DK: 40% (2%). • CZ: 43% (5%). • SE: 44% (3%). • NL: 45% (5%). • BE: 46% (14%).	• Dependent on the context parental caregiving by mature daughters can have negative impact on labour force participation (only in countries that rely strongly on family care). • No effect on hours worked. • Positive effect on verbal fluency (only in countries that rely strongly on family care). • No effect on word recall or numeracy. • Positive effect on depression (meaning more depressed feelings). • No effect on self-perceived health Positive / No effect on grip strength.

Author(s) (year of publication)	EU data source	Category	Specific outcome considered	Share of care providers	Impact (costs/benefits)
14. Hiel, Beenackers, Renders, Robroek, Burdorf & Croezen (2015)	SHARE, 2004/2005, 2006/2007, 2011/2012	Health	Self-rated health Mental health Physical health	% of people aged 50-70 providing personal care [Table 1]: 12.7%	• There was no association with self-rated health. • Providing informal personal care was significantly associated with poor mental health and poor physical health over a follow-up period of eight years. • There are significant interactions for age and employment status with providing personal care for the outcome mental health, indicating that respondents who were older or retired experienced more detrimental consequences of providing informal care.
15. Joling, ten Have, de Graaf, O'Dwyer (2019)	NL NEMESIS-2, 2010/2012, 2013/2015	Health	Suicidal thoughts	Netherlands: 34% provided care in the past 12 months	• Caregivers are not less likely to consider suicide than non-caregivers.
16. Kaschowitz and Brandt (2017)	SHARE 2004/2005, 2006/2007, 2011/2012, 2013	Health	Self-perceived health Depression scales	% of people aged 50-70 caregiving inside (personal care), % caregiving outside household (practical help) [Table 1]: • AT: 8.7; 16.3. • BE: 11.0; 25.2. • FR: 10.3; 16.8. • DE: 7.3; 14.7.	• Health consequences of caregiving vary not only between different welfare regimes but also between countries of similar welfare state types. • Caregivers inside household: negative

Author(s) (year of publication)	EU data source	Category	Specific outcome considered	Share of care providers	Impact (costs/benefits)
				• IT: 14.0; 16.33. • ES: 13.5; 8.5. • DK: 7.1; 19.0. • SE: 5.4; 17.0. • NL: 8.2; 21.1.	correlation between caregiving (vs. non-caregiving inside the household) and self-perceived health for most countries. • For informal caregiving outside household: positive significant correlation between caregiving and self-perceived health for all countries. • Only in Austria a significant effect was observed between providing care for someone outside the household and more depressive symptoms.
17. Kaschowitz and Lazarevic (2020)	SHARE 2004/2005, 2006/2007, 2011/2012, 2013, 2015	Health	Physical and mental health indicators		• Caregiving in domestic setting was associated with worse mental and physical health. • For caregivers outside the household associations were in most cases not present and in general caregivers outside the household reported better health than non-caregivers.

Author(s) (year of publication)	EU data source	Category	Specific outcome considered	Share of care providers	Impact (costs/benefits)
18. Kolodziej, Reichert, Schmitz (2018)	SHARE 2004/2005, 2006/2007, 2011/2012, 2013	Labour market	Working (full time, part time, self-employed) vs. not working (unemployed or homemaker)	% of people aged 20-64 providing care (including personal care and practical household help) to parent between 50-70: 7%.	• Children's willingness to provide informal care to their parents is altered by available alternatives of family caregivers. • Providing care to a parent is associated with a 14 percentage points lower probability to work. • No significant gender difference. • The effects in the pooled estimations are fully driven by the Southern and Eastern European countries.
19. Maguire, Hanly, Maguire (2019)	EQLS 2016/2017	Time use Health	Comparison of informal carers with full sample on: Self-rated health Time constraints, psychological appraisals, well-being Outcome of regression model: Well-being	• Frequent caregivers: 11.3%. • Caregivers were more likely to be female (64%), not employed (58%), and have a partner in the household (64%). • Caregivers were more likely to have obtained secondary education (65%), but less likely to have received third level education (24%) than non-caregivers.	• Caregivers report greater time burden and financial burden, and less likely to have time for the things they enjoyed. • 12% of the caregiving sample expressed a desire to spend less time caring. • Frequent caregivers reported lower self-rated health, more negative psychological appraisals, with the exception of sense of purpose, on which they

Author(s) (year of publication)	EU data source	Category	Specific outcome considered	Share of care providers	Impact (costs/benefits)
					did not differ to the wider sample. • Caregivers reported being less optimistic, having less autonomy, and having lower perceived resilience. They were more likely to feel excluded from society. • Informal caregiving is significantly negatively associated with well-being.
20. Mortensen, Dich, Lange, lexanderson, Goldberg, Head, Kivimäki, Madsen, Rugulies, Vahtera, Zins, Rod (2017)	FR GAZEL 2000, FI FPS 2012	Lost wage or lower income	Long-term sickness absence	Finland, public sector employees providing informal care: • 10% men. • 15% women. France, electricity and gas employees providing informal care: • 27% men. • 30% women.	• Women jointly exposed to high job strain and informal caregiving had a 34% increased risk of sickness compared to women with no high strain and no informal caregiving. • For men, informal caregiving was not associated with a higher risk of long-term sickness absence. • For women, high job strain and informal caregiving were associated with long-term sickness absence.
21. Schmitz & Westphal (2015)	DE GSOEP 2002-2010	Health	Mental health Physical health	Germany: 7% of sample starts care provision in first wave	• On the short term informal care provision has a negative impact

Author(s) (year of publication)	EU data source	Category	Specific outcome considered	Share of care providers	Impact (costs/benefits)
				Among caregivers: • 41% report to care for one hour per day. • 24% care for two hours. • 35% for three or more hours.	on mental health, five years after care provision the mental health effect is still negative but smaller and insignificant. • The study does not find physical health effects of informal caregiving in the short- and in the medium-run.
22. Schmitz & Westphal (2017)	DE GSOEP 2001-2013	Labour market	Labour market participation: Full-time work Being employed Weekly hours worked Gross hourly wage	Germany, among caregivers: • 40% report to care for one hour per day. • 25% care for two hours. • 35% for three or more hours.	• There are significant initial negative effects of informal care provision on the probability to work full-time. The 4 percentage points reduction in the probability to work full-time after caring for at least one year is persistent over time. • Providing care for a higher intensity (at least three hours per day) has a stronger long-term effect on the probability to work full-time. • There are no short-run effects on the likelihood of being in the labour force but quite considerable negative effects for both longer

Author(s) (year of publication)	EU data source	Category	Specific outcome considered	Share of care providers	Impact (costs/benefits)
					care episodes and higher care intensities. • Hourly wages are not affected in the short-run but a long-run wage penalty of around 1–1.5 Euro for women who provide care was found (irrespective of duration and intensity).
23. Stanfors, Jacobs, Neilson (2019)	SWETUS 2000/2001, 2010/2011	Labour market Time use	Paid work Routine housework Individual leisure time	Sweden: (intensive) caregivers in sample 5% (0.75%)	• There are no significant interaction effects of gender and caregiving intensity, confirming that men and women are similarly affected by not only caregiving responsibilities, but also by caregiving intensity. • Part-time work is positively associated with caregiver status. • Men or women with caregiving responsibilities in Sweden do not work less than non-caregivers. • Caregiving responsibilities are associated with men's and women's housework (positively) and leisure (negatively).

Author(s) (year of publication)	EU data source	Category	Specific outcome considered	Share of care providers	Impact (costs/benefits)
24. Uccheddu, Gauthier, Steverink, Emery (2019)	SHARE 2004/2005, 2006/2007, 2011/2012, 2013, 2015	Health	40-item Frailty index: physical and mental health problems	% of people aged 50-70 providing help with personal care for spouse or partner within same household: 5.2%	• The transition into caregiving leads to an increase of frailty scores, in both men and women. • For women, there is a small effect of the transition out of caregiving on lower frailty scores (only for those living in Southern and Eastern European countries). • No gender difference with respect to transitioning into caregiving in any of the four institutional contexts examined. Health effects of spousal caregiving appear to be strongest for men and women living in Southern and Eastern European countries, less strong in Western European countries, and smallest in Northern European countries.
25. Van den Broek & Grundy (2018)	FR: ERFI 2005, 2008, 2011	Health	Loneliness	France: 4.5% of sample provides personal care to parents	• Parental health limitations are associated with raised feelings of loneliness among daughters of widowed parents,

Author(s) (year of publication)	EU data source	Category	Specific outcome considered	Share of care providers	Impact (costs/benefits)
					regardless of whether or not the daughters provided informal care.
26. Van den Broek & Grundy (2018)	SHARE 2004/2005, 2006/2007, 2011/2012, 2013, 2015	Health	Quality of life	% of people aged 50-70 with a living parent caring informally for parents including personal care and practical household help (% frequent caregivers in brackets): Sweden: 21.3% (8.3) Denmark: 21.4% (9.1)	• Caregiving was associated with a decrease in quality of life, this impact was more detrimental in Sweden than in Denmark. • The country difference between Sweden and Denmark in the effect of caregiving on quality of life weakened significantly when LTC coverage was reduced in Denmark.
27. Verbakel (2018)	ESS 2014/2015	-	-	% Informal care (% intensive care in brackets) • AT: 22.0 (5.2). • BE: 38.7 (6.2). • CZ: 35.0 (8.8). • DK: 43.3 (4.7). • EE: 31.5 (9.2). • FI: 44.0 (4.9). • FR: 38.8 (5.9). • DE: 35.2 (6.2). • IE: 25.6 (8.9). • LT: 20.4 (6.8). • NL: 36.5 (6.1). • PL: 35.7 (8.8). • PT: 34.4 (11.0). • SI: 33.1 (5.6). • ES: 29.2 (9.9).	• Generous formal long-term care provisions crowded-out intensive caregiving, but also encouraged more people to provide (some) informal care. • The correlation between informal care and intensive care was negative, suggesting the existence of countries in which a small group takes up a large caring share and countries where many split the care

Author(s) (year of publication)	EU data source	Category	Specific outcome considered	Share of care providers	Impact (costs/benefits)
				• SE: 38.8 (4.2).	responsibilities in small shares. • Generous formal long-term care provisions coincided with higher prevalence of informal caregiving, but with lower prevalence of intensive caregiving. • Need of care did not relate to the prevalence of caregiving in a country.
28. Verbakel, Tamlagsrønnin, Winstone, Fjæ, Eikemo (2017)	ESS 2014/2015	Health	Mental well-being	% informal care (% intensive care in brackets) • FI: 43.6 (4.69). • DK: 42.8 (4.68). • SE: 39.7 (4.50). • FR: 39.2 (5.77). • BE: 37.9(6.96). • NL: 37.3 (6,11). • DE: 36.6 (6.54). • CZ: 36.4 (10.58). • PL: 36.3 (8.95). • SI: 32.9 (7.08). • PT: 32.9 (11.58). • EE: 31.8(9.85). • ES: 29.2 (10.86). • IE: 25.6 (9.97). • LT: 23.0 (8.21). • AT: 21.1 (5.96). • HU: 8.2. (3.45). Countries in Central, Eastern and Southern Europe had higher	• Informal caregivers reported significantly lower levels of mental well-being (i.e. more depressive symptoms). • Informal caregiving was significantly more detrimental for the mental health of females than for males. • The negative relationship between caregiving and mental health was much stronger when caregiving was intensive.

Author(s) (year of publication)	EU data source	Category	Specific outcome considered	Share of care providers	Impact (costs/benefits)
				proportions of intensive caregivers than the Nordic countries	
29. Wagner and Brandt (2018)	SHARE 2013	Health	Life satisfaction, loneliness, depression (in relation to availability of formal care)	% of people aged 50-70 providing help with personal care for spouse or partner within same household: 6%	• Life satisfaction was significantly lower for spousal caregivers. • Spousal caregivers were more satisfied with life when LTC services were available. • Spousal caregivers reported higher scores for loneliness and depression. • Sense of control over once life has a beneficial impact on the experienced levels of loneliness and depression, for informal carers this sense of control is linked to the availability of formal LTC services.
30. Zwar, König, Hajek (2018)	DE DEAS 2008, 2011, 2014	Health	Cognitive functioning	Germany: • Help around the house: 8.65%. • Looking after someone: 11.80%. • Performing nursing care services: 4.82%. • Performing nursing care services: 4.82%	• Starting to look after someone was significantly associated with an increase of cognitive functioning, only found in females. • Help around the house and performing nursing care services were not

Author(s) (year of publication)	EU data source	Category	Specific outcome considered	Share of care providers	Impact (costs/benefits)
					associated with cognitive functioning.
31. Zwar, König, Hajek (2018)	DE DEAS 2008, 2011, 2014	Health	Depressive symptoms Self-rated health Pulmonary function Morbidity	Germany: Help around the house: 10.5% Looking after someone: 13.0% Performing nursing care services: 5.0%	• When caregivers started helping around the house, depressive symptoms increased significantly. Beginning to look after someone led to a significant increase in depressive symptoms. For nursing care services no significant association with depressive symptoms was found. • Engaging in helping around the house, to start looking after a person, and performing nursing care services led to a significant decrease in self-rated health. • None of the three caregiving types (start helping around the house, beginning to look after someone, nursing care) had a significant influence on pulmonary function. No significant effects of any of the caregiving types on morbidity were found.

C Results of data appraisal

Provision of informal care

Most of the investigated databases define informal care by excluding childcare and domestic tasks, either by specifying the types of tasks (SHARE) or by specifying the health status of the care receiver (SILC ad hoc module 2016, EHIS, EQLS, ESS 2014, USS and IZG). They all include both help to household members and relatives and friends outside the household.

SILC and SOEP define care responsibility less specifically because they combine this category with domestic tasks. However, these datasets allow to identify whether another adult household member has limitations in activities because of health problems. This approach separates informal care from mere domestic tasks, but limits informal care to care of adult household members. In addition, SILC and SOEP only register the main activity, so employed informal care providers are not included either. The EU-SILC 2016 ad hoc module overcomes these limitations but cannot be matched with the longitudinal EU-SILC data.

The LFS 2018 ad hoc module distinguishes care for children (below age 15) and care for disabled or elderly relatives, but does not differentiate childcare between children with or without long-term health problems. The general LFS survey does not even distinguish between childcare and care for incapacitated adults (Table C1).

Table C1 - Review template, Provision of informal care

Source	Variable name and description
Provision of informal care	
SILC AH16	**PC260.** Care or assistance provided Y/N. Guideline: Childcare is not included, unless it is care provided to children due to their long-term health problems including chronic illness and disability.
SILC+SOEP	**PH030**. Limitation in activities because of health problems (if reported by an adult household member) Y/N and **PL031** main activity = domestic tasks or care responsibility. *Note 1: includes only care to household members and if it is a main activity* *Note 2: SILC 2016 cross-sectional data can be matched with 2016 ad hoc module but longitudinal data cannot be matched with ad hoc modules (or cross-sectional data)*
EHIS	**IC1.** Providing care or assistance to one or more persons suffering from some age problem, chronic health condition or infirmity, at least once a week (professional activities excluded) Y/N;
LFS AH18	**Q3_careres**: Do you take care of relatives or children of yours from the age of 15 who are ill or disabled or elderly relatives? They may live in- or outside your household. *Note: Q3_careres is skipped if the respondent or his/her partner has children in the household (Q1_careres) and does not regularly take care of children outside the household (Q2_carerer is not "Yes, regularly") which limits the completeness of this variable.*
LFS	**LEAVREAS, FTPTREAS, SEEKREAS.** Looking after children or incapacitated adults, as reasons for leaving job, for part-time work and for not searching employment. *Overestimates informal LTC because it includes parental tasks.*
SHARE	**SP008_GiveHelp**. In the last twelve months, have you **personally** given any kind of help listed on this card to a family member from outside the household, a friend or neighbour? **SP018_GiveHelpInHH**. Let us now talk about help within your household. Is there someone living in this household whom you have helped regularly during the last twelve months with personal care, such as washing, getting out of bed, or dressing? Y/N;

Source	Variable name and description
Provision of informal care	
	Note: there is also a module about help given to a deceased relative, with actually more detail than the general modules on giving and receiving informal care. However, this seems too specific for this study.
EQLS	**Q42 (Q36)**. In general, how often are you involved in any of the following activities outside of paid work? - Caring for disabled or infirm family members, neighbours or friends under 75 years old; - Caring for disabled or infirm family members, neighbours or friends aged 75 or over
ESS 2014	**E17, CARD 50.** Do you spend any time looking after or giving help to family members, friends, neighbours or others because of any of the reasons on this card: long-term physical ill health or disability, long-term mental ill health of disability or problems related to old age.
UK: USS	**aidhh** (sick person in household) Is there anyone living with you who is sick, handicapped or elderly whom you look after or give special help to (for example, a sick or handicapped (or elderly) relative/ husband/ wife/ friend, etc)? Y/N **aidxhh** AM31 (sick person not in household): Do you provide some regular service or help for any sick, disabled or elderly person not living with you?
NL: IZG	**MantHlp.** Did you provide help in the past 12 months? Clarification: Help to partner, family, friends or neighbour due to physical, psychic, mental disabilities or old age. Examples are household tasks, helping with washing and dressing, comforting, transport or tasks in and around the house. Do not include professional or volunteering work. **Vrywrk**. Did you volunteer in the past 12 months in healthcare or welfare? Clarification: Help to people who need help due to physical, psychic or mental disabilities or old age and whom you did not know beforehand. Think of providing company, transport, household tasks, chores or day activities. Please include incidental help. Do not include professional care or non-care related volunteering **MantHlpAct, Vrywrkact**. Do you still provide this help?
Eurofamcare	**C11NUMEL**. How many people do you give support / care to for more than four hours a week who are 65 years old or more?

Most databases do not distinguish between paid and unpaid care, and the implicit assumption seems that care for relatives or friends is unpaid. Absence of employment contract is also implicit. The implicit assumption is clear because all databases also include a question about employment, or about work for pay or profit. Thus, it seems unlikely that respondents mix up care provided informally or as a paid and employed professional (Table C2).

Table C2 - Review template, Paid or unpaid care

Source	Variable name and description
Paid or unpaid care	
SILC AH16	**PC2060, guideline**: Only voluntary (unpaid) assistance should be taken into account. Financial support or benefits from the government to provide this care and assistance (e.g. carer's allowance, carer's credit and tax relief) are not considered to be a pay. The questionnaire includes use of formal care (besides informal care).
SILC+SOEP	**PL031**. Implicitly assumed unpaid, because the first four items cover paid work
EHIS	**IC1**. professional activities excluded
LFS AH18	**Q3_careres.** Implicitly assumed unpaid, because other variables cover paid work
LFS	**LEAVREAS, FTPTREAS, SEEKREAS.** Implicitly assumed unpaid, because WSTATOR covers work for pay or profit.
SHARE	**SP008_GiveHelp, SP018_GiveHelpInHH.** Implicitly assumed unpaid, because EP002_PaidWork (combined with EP005_CurrentJobSit) covers paid work
EQLS	**Q42 (Q36)**. Outside of paid work
ESS 2014	**E17.** Do not count anything you do as part of your paid employment.
UK: USS	**Aidhh:** no clarification, but a variable F121 indicates receipt of invalid care allowance **Aidxhh**, clarification: Exclude help provided in course of employment
NL: IZG	**MantHlp**, **MantHlpAc**, clarification: Do not include professional work **Vrywrk, Vrywrkact**, no clarification on paid or unpaid care
Eurofamcare	Only persons who provide informal care are recruited. However, there are questions about the use of formal care (in addition to informal care): **E27E– E34E**.

With SILC and EHIS, only breaks at 10 or 20 hours per week are possible. These breaks are also possible with the USS. With Eurofamcare (if at least 4 hours per week), EQLS, IZG and data almost any breakdown by hours per week is possible (Table C3). Thus, with most databases non-low-intensity care could be defined as care of at least 10 hours per week. This is also in line with examples that experts provided in interviews, such 2 hours per day, or 8 hours on one day in a week.

Table C3 - Review template, Time spent on care giving and frequency

Source	Variable name and description
Time spent on care giving and frequency	
SILC AH16	**PC270**. Number of hours per week of care or assistance provided. <10, 10-20 or 20+. Guideline: The care or assistance provided does not need to be frequent but it needs to be something what is repeated.
SILC+SOEP	--- (no questions about time spent on giving care or frequency)
EHIS	**IC3.** Number of hours per week the respondent provides care or assistance to the person(s) suffering from any chronic condition or infirmity or due to old age. <10, 10-20 or 20+
LFS AH18	--- (no questions about time spent on giving care or frequency)
LFS	--- (no questions about time spent on giving care or frequency)
SHARE	--- (no question on time spent on giving care) **SP011_HowOftGiveHelp**. (care receiver not in household) About daily / About every week / About every month / Less often **SP018_GiveHelpInHH**. Clarification: By regularly we mean daily or almost daily during at least three months. We do not want to capture help during short-term sickness of family members
EQLS	**Q43 (Q37).** On average, how many hours per week are you involved in any of the following activities outside of paid work?

Source	Variable name and description
Time spent on care giving and frequency	
	d. Caring for disabled or infirm family members, neighbours or friends < 75 years old … hours e. Caring for disabled or infirm family members, neighbours or friends aged 75 or over … hours **Q42 (Q36).** In general, how often are you involved in any of the following activities outside of paid work? (separately for care receivers under 75 years old and 75 or over) Every day / Several days a week / Once or twice a week / Less often / Never / DK / Refuse
ESS 2014	**E18**, hours per week: 1-10 / 11-20 / 21-30 / 31-40 / 41-50 / More than 50
UK: USS	**Aidhrs.** In total, how many hours do you spend each week looking after or helping (him/her/them)? 0-4 / 5-9 / 10-19 / 20-34 / 35-49 / 50-99 / 100 +. If it varies: <20 or 20+ *Note: this includes hours of care given to both persons in the household and those not in the household* No frequency question
NL: IZG	**MantUur, VryWrkUur.** How many hours a week? **MantFreq.** How often? Daily / Weekly / Monthly / Less often **VryWrkFreq**. How often? Regularly / Incidentally
Eurofamcare	Only informal care of more than 4 hours per week is regarded. **C12HOUR**. On average, how many hours a week do you give care and support to ELDER?

SHARE only includes care that lasted at least three months. A breakdown by 3 months is also possible with EU-SILC (for care as main activity), USS, IZG and Eurofamcare. With EHIS, LFS, EQLS, it is not possible to limit long-term care to care lasting at least 3 months (Table C4). However, from the IZG survey and a German report[133], it turns out that most informal care lasts for years rather than months. For EU-SILC and IZG, this creates the problem that start and end are unlikely to fall in the past twelve months, and thus that for most informal care providers in EU-SILC we neither know when they started or stopped. Therefore, a separate section is devoted to the analysis of durations.

[133] Jacobs et al., Die Versorgung der Pflegebedürftigen, in WIDO (2017), Pflege-report 2017, https://www.wido.de/fileadmin/Dateien/Dokumente/Publikationen_Produkte/Buchreihen/Pflegereport/2017/Kapitel%20mit%20Deckblatt/wido_pr2017_kap21.pdf, Section 21.2.3, Figure 21.6.

Table C4 - Review template, Duration of care

Source	Variable name and description
Duration of care	
SILC AH16	See SILC.
SILC+SOEP	**PL221A-PL221L**. Months (January-December) in which domestic tasks or care responsibilities were the main, in combination with a household member who has difficulty with daily tasks due to old age or health problems (PH040) **PL089**. Proxy variable for number of months in the past 12 months in which domestic tasks or care responsibility was the main activity. Available for cross-sectional version only. *Note: PL221A-PL221L enable to distinguish between for example 3 consecutive months and 3 months in the past 12 months.* In addition, these data can be used to estimate which proportion of informal care providers still provide care one year later.
EHIS	IC1. Guideline: Only care or assistance related to **long-term (chronic) health condition**, infirmity (congenital or acquired physical defect) or old age should be included *Note: the duration is not explicit, but implicitly the form of care must be long-term*
LFS AH18	See LFS
LFS	**LEAVTIME**. Time in months since the person last worked. At least the categories: Less than 1 month 1-2 months 3-5 months 6-11 months (4 categories of 12 months or longer) *Note: this could be combined with LEAVREAS: left job to look after children or incapacitated adults but even if the current unemployment was for example less than 3 months, the eventual duration could exceed 3 months (this is called right-censoring in statistics).*
SHARE	**SP008_GiveHelp**. (care receiver not in household): no breakdown or limitation of duration. **SP018_GiveHelpInHH**. (care receiver in household). Clarification: at least three months. We do not want to capture help during short-term sickness. *Note: the three month could be consecutive, or just 3 months in the past 12 months.*
EQLS	--- (no questions or clarifications about duration)
ESS 2014	--- (no questions or clarifications about duration)
UK: USS	The USS can be used to estimate which proportion of informal carers still provide informal care one year later because it is a longitudinal dataset.
NL: IZG	**MantJr, MantMnd, VrywrkJaar, VrywrkMaand** (both care to relations and volunteer work) For how long do/did you provide help? Years and Months.
Eurofamcare	**C67DURAT.** How long have you been caring for ELDER? (exact number of months)

Some datasets do not specify the kind of care provided (SILC, LFS, EQLS, USS). EHIS and SHARE limit care to activities of daily living and instrumental activities of daily living. IZG and Eurofamcare in addition include emotional support as care. In line with the literature review, care that is only given in the form of emotional support will be excluded (Table C5).

Table C5 - Review template, Type of care provided

Source	Variable name and description
Type of care provided	
SILC AH16	**PC260**. Guideline: All types of care or assistance should be taken into consideration. There is no further distinction between types of care provided.
SILC+SOEP	--- (no questions or clarifications about type of care provided)
EHIS	**IC1**. Guideline: "Care or assistance" means help to other person with personal care or activities of household care. This includes also activities like accompanying a person – except your partner or your child – to a doctor, to a bank or offices, for shopping or for a walk or other types of leisure time activities. There is no further distinction between types of care provided. *Note1: for respondents aged 55+, **PC2** and PC3 about care received and care needed relate to PC1, difficulty in:* - *Feeding yourself* - *Getting in and out of a bed or chair* - *Dressing and undressing* - *Using toilets* - *Bathing or showering* *Note2: contrary to SILC, EHIS is not a household survey, and no link between respondents giving and receiving care in the same household is possible.* *Note3: the guideline states: Any kinds of help should be considered: help from another person, the use of technical aids and housing adaptation. Hence, no link possible with informal LTC.*
LFS AH18	--- (no questions or clarifications about type of care provided)
LFS	--- (no questions or clarifications about type of care provided)
SHARE	**SP010_TypesOfHelpGiven**. (care receiver not in household) 1. personal care, e.g. dressing, bathing or showering, eating, getting in or out of bed, using the toilet 2. practical household help, e.g. with home repairs, gardening, transportation, shopping, household chores 3. help with paperwork, such as filling out forms, settling financial or legal matters **SP018_GiveHelpInHH.** (care receiver in household) Limited to **"**personal care, such as washing, getting out of bed, or dressing"
EQLS	--- (no questions or clarifications about type of care provided)
ESS 2014	--- (no questions or clarifications about type of care provided)
UK: USS	--- (no questions or clarifications about type of care provided)
NL: IZG	**SrtHlp**. Care to relations only, not volunteer work. Emotional support / Transport / Supporting with doctor visits / Administrative help / Household tasks / Personal instrumental care (such as showering) / Nursing care / Coordinating provision of care / Other
Eurofamcare	**E27B-E34B:** Who, if anyone, helps ELDER to meet their needs? • Health needs e.g. assistance with medication, medical treatment, rehabilitation, therapy etc • Physical / personal e.g. washing, dressing, eating or going to the toilet • Mobility e.g. inside or outside the house, transport • Emotional / Psychological / Social e.g. companionship, reassurance • Domestic e.g. housework • Financial management e.g. paying bills for the cared for from ELDER's own money • Financial support e.g. Supporting ELDER by providing them with money • Organising and managing care & support e.g. contacting services

Care recipients will be broadly defined to include household members, other relatives and friends, neighbours, (ex-colleagues) and/or acquaintances. Volunteer work, even in communities such as church communities are considered out of scope. SHARE is the only database that explicitly includes care to (ex-) colleagues as a category, in Eurofamcare respondents might indicate this. The LFS 2018 ad hoc module limits informal care to relatives, and EU-SILC longitudinal data analysis is only possible for care given to household members with limitations in activities due to health problems. All other databases enable the application of the broad definition of the relation between care giver and care receiver.

For SHARE, the following categories are not included: 25 (Minister, priest, or other clergy), 26 (Therapist or other professional helper) and 27 (Housekeeper/Home health care provider) because these categories include professionals or semi-professionals providing care for pay, and category 96 “None of these” because it might include volunteers in hospitals or via organisations that use a mix of volunteers and professionals (Table C6).

Table C6 - Review template, Relation to care receiver

Source	Variable name and description
Relation to care receiver	
SILC AH16	**PC260**. Only household members / Only non-household members / Both
SILC+SOEP	**PL031** main activity = domestic tasks or care responsibility. If an adult household member reports a limitation in activities because of health problems, care provision is reasonable to assume. Otherwise, it could be either care to children, non-household members or “housekeeping” status. So in practice, only adult household members.
EHIS	**IC2**. Prevailing relationship of the person(s) suffering from any chronic condition or infirmity or due to old age being provided with care or assistance at least once a week from the respondent (Family/Non-family). Guideline: person to whom most care is provided (only one answer possible) Family: relatives living either in or outside your household **PC2**. Question about care needed, only asked for persons of age 55 and older.
LFS AH18	**Q3_careres.** 1. No care responsibilities. 2. Only for own children in household. 3. Only for own children outside the household. 4. For own children in- and outside the household. 5. Only for incapacitated relatives. 6. For own children in the household and incapacitated relatives. 7. For own children outside the household and incapacitated relatives. 8. For own children in- and outside the household and incapacitated relatives. 9. Not applicable (not included in the filter). Blank. No answer / Don’t know. *Note: Q3_careres is skipped if the respondent or his/her partner has children in the household (Q1_careres) and does not regularly take care of children outside the household (Q2_carerer is not “Yes, regularly”) which limits the completeness of this variable.*
LFS	**LEAVREAS, FTPTREAS, SEEKREAS**. “Children or incapacitated adults” (no further distinction). *Definition is broad, actually too broad because it includes parental tasks.*
SHARE	**SP009_ToWhomGiveHelp**. (care receiver not in household) **SP019_ToWhomGiveHelpInHH**. (care receiver in household) Relatives (20 categories) 21. Friend 22. (Ex-)colleague/co-worker 23. Neighbour

Source	Variable name and description
Relation to care receiver	
	24. Ex-spouse/partner 25. Minister, priest, or other clergy 26. Therapist or other professional helper 27. Housekeeper/Home health care provider 96. None of these *Note 1: meaning of categories 25-27 is not yet clear, they seem a double-check on the care giver rather than categories of care receivers* *Note 2: the family relation in combination with the age of the caregiver is also an indirect indicator of the age of the care receiver. For example a parent is likely at least 20 years older and a sibling is likely to have a similar age.*
EQLS	**Q42-Q43 (Q36-Q37).** One item: disabled or infirm family members, neighbours or friends (only further distinction is age < 75 or 75+)
ESS 2014	**E17**. Family members, friends, neighbours or others without further distinction. However, **F45a-F45c** ask whether the spouse is permanently sick or disabled, or retired in which case care is presumably more likely provided to family members
UK: USS	**Aidhua. AM32P1** (person in household) **Aidhu1, Aidh2** (persons not in household) Who is the (sick, handicapped or elderly) person/ people you look after? - Relatives (4 categories) - Friend or neighbour - Client(s) of voluntary organisation - Other **Naidxhh**: number of persons not in household to whom respondent provides care
NL: IZG	**RelPers**. (not volunteer work) Choose the person to whom you provide at this moment / in the past 12 months the most care and answer the questions only for this person. What is/was his/her relationship with you: - Family (7 categories) - Friend or acquaintance - Neighbour - Other, namely … **LftPers**. (not volunteer work) What is his/her age? (exact or estimated age) For volunteer work (as defined in IZG) there is no relation by default
Eurofamcare	Only care receivers aged 65 or more are considered. **E15RELAT, E15SPEC**. 8 categories: - Relatives (7 categories) - Other, please specify

EHIS excludes volunteer workers. With USS and Eurofamcare it is possible to exclude volunteer workers and with IZG it is even possible to limit volunteer workers to community volunteers. For the other databases, we have to assume that volunteers are implicitly excluded (Table C7).

Table C7 - Review template, LTC provision as a volunteer

Source	Variable name and description
LTC provision as a volunteer	
SILC AH16	--- (no questions or clarifications about LTC provision as a volunteer)
SILC+SOEP	--- (no questions or clarifications about LTC provision as a volunteer)
EHIS	**IC1.** Guideline: The care or assistance of un-paid volunteers working for NGOs should be excluded as well as any care provided as part of the respondent's profession
LFS AH18	--- (no questions or clarifications about LTC provision as a volunteer)
LFS	--- (no questions or clarifications about LTC provision as a volunteer)
SHARE	**XT023_WhoHelpedADL.** *Only asked for help to a deceased relative, up to 3 persons of:* - *Relatives (12 categories)* - *Unpaid volunteer* - *Professional helper (e.g. nurse)* - *Friend or neighbour of the deceased* - *Other person* *Note: this relates to **XT020_IntroDiffADL**:* - *Dressing, including putting on shoes and socks* - *Walking across a room* - *3. Bathing or showering* - *4. Eating, such as cutting up your food* - *5. Getting in or out of bed* - *6. Using the toilet, including getting up or down*
EQLS	--- (no questions or clarifications about LTC provision as a volunteer)
ESS 2014	--- (no questions or clarifications about LTC provision as a volunteer)
UK: USS	**Aidhu1, Aidh2** (persons not in household) - Client(s) of voluntary organisation
NL: IZG	**MantHlp, MantHlpAct**, clarification: Do not include volunteering work **Organ.** How did you volunteer in healthcare or welfare? - Through a care establishment (care home, home for disabled or hospital) - Through a welfare establishment (community centre, youth work, meal service) - Through a volunteer organisation, e.g. Sunflower, Red Cross or Union of Volunteers - Through a religious establishment, church or mosque - Through a different establishment - Not through an establishment
Eurofamcare	**E15spec.** This specification of “other” might include volunteer work

We propose to include both care to older persons and care to younger persons with medical needs. With EQLS, only an age breakdown by age 75 is possible. EHIS includes specific questions to care receivers aged 55+ and Eurofamcare is limited to care receivers aged 65+. With EHIS and Eurofamcare, it is also possible to differentiate the analysis to care receivers aged 75+, as well as in EU-SILC (Table C8).

Table C8 - Review template, Informal LTC receivers

Source	Variable name and description
Informal LTC receivers	
SILC AH16	See SILC
SILC+SOEP	**PH030**. Indirectly, if person has limitation in activities because of health problems and if a household member has domestic tasks or care responsibilities as main activity (PL031)
EHIS	**PC2**. Usually receiving help with one or more self-care activities: feeding yourself, getting in and out of a bed or chair, dressing and undressing, using toilets, bathing or showering *Note: only asked to persons aged 55 years and older*
LFS AH18	--- (no questions asked about receiving informal LTC)
LFS	--- (no questions asked about receiving informal LTC)
SHARE	**SP002_HelpFrom**. Thinking about the last twelve months, has any family member from outside the household, any friend or neighbour given you any kind of help (listed on this card)? **SP020_RecHelpPersCareInHH**. And is there someone living in this household who has helped you regularly during the last twelve months with personal care, such as washing, getting out of bed, or dressing? INSTRUCTION: By regularly we mean daily or almost daily during at least three months. We do not want to capture help during short-term sickness. *Note: the question is a bit ambiguous. It could mean help with giving care, or receiving care. The latter is assumed.* **SP005_HowOftenHelpRec**. About daily / About weekly / About monthly / Less often No questions or clarifications about duration
EQLS	**Q76**. In the last 12 months, have you, or someone close to you, received regular (at least several times a week) help or care from any of the following people? a. Family members, friends or neighbours in your/this person's home b. Someone outside the formal health and care services who was paid for their help Yes, I have / Yes, someone close to me has / Nobody has Frequency: at least several times a week. No questions or clarifications about duration.
ESS 2014	--- (no questions asked about receiving informal LTC)
UK: USS	--- (no questions asked about receiving informal LTC)
NL: IZG	--- (no questions asked about receiving informal LTC)
Eurofamcare	**E16SEX, E17AGE, E18NAT, E19ETHN, E20MARS.** Gender, age, nationality, ethnicity and marital status of care receiver

Some datasets provide indirect information on the reason for providing informal care. SILC and SOEP, EHIS, SHARE, EQLS and Eurofamcare contain variables on reasons for not receiving (or having difficulty in receiving) suitable care from a health professional. This can be seen as an indication for receiving informal care due to unmet needs for professional care. The Dutch IZG also explicitly asks for whether care is provided because no one else was available to provide this care. However, it is not required that this 'no one else' is a professional. IZG and Eurofamcare also provide information on another reason for receiving of providing informal care: that people do not want to receive formal care (Table C9).

Table C9 - Review template, Unmet (formal) medical need and reason

Source	Variable name and description
Unmet (formal) medical need and reason	
SILC AH16	See SILC.
SILC+SOEP	**PH040**. (cross-sectional only, not longitudinal version): reported unmet medical need of an adult household member and reason (affordability, waiting list, not knowing a good doctor or specialist may point to lack of access to formal care as reason for informal care)
EHIS	**UN1A, UN1B**. Have you experienced delay in getting healthcare in the past 12 months due to: - Long waiting lists - Distance or transportation problems **UN1C**. Could not afford: - Medical care - Dental care - Prescribed medicines - Mental health care (by a psychologist, psychotherapist or a psychiatrist, for example) *Note: no link possible with receiving informal LTC, but useful to cross-validate reasons for unmet medical need.*
LFS AH18	See LFS
LFS	**NEEDCARE**. Unemployed and part-time workers are asked if suitable care services for ill, disabled, elderly are not available or affordable (items 2 and 3) which could be combined with provision of Looking after children or incapacitated adults as reasons for not searching work or working part-time
SHARE	**HC114_UnmetNeedCost. HC115_UnmetNeedWait.** Was there a time in the past 12 months when you needed to see a doctor but could not because: - Of cost - You had to wait too long. *Note: this can be combined very usefully with questions about informal care received.*
EQLS	**Q61 (Q47).** Thinking about the last time you needed to see or be treated by a GP, family doctor or health centre, to what extent did any of the following make it difficult or not for you to do so? - Distance to GP/doctor's office / health centre - Delay in getting appointment - Waiting time to see doctor on day of appointment - Cost of seeing the doctor - Finding time because of work, care for children or for others *Note 1: only for the survey years 2003, 2007, 2011, 2016, and the last item only in 2011, 2016* *Note 2: can be combined with Q60 Have you or someone else in your household used any of the following [medical] services in the last 12 months?, to assess unmet medical need*
ESS 2014	--- (E14-15 ask about unmet medical demand and reasons, but there is no question about whether the respondent received informal care (only whether they provided it)
UK: USS	--- (servuse include items 2 "local hospital" and 3 "social care services" and srvynot includes 6 reasons for not using them, but there are no questions about receiving informal care)
NL: IZG	**Doormy**. The person preferred to receive care from me (Y/N) **Uitstel**. To avoid or postpone professional care (Y/N) **Beschikbaar**. Nobody else was available.
Eurofamcare	**C70FAC1 – C80FAC11, C80SPEC**. (multiple choice, plus which is the principal reason)

Source	Variable name and description
Unmet (formal) medical need and reason	
	• A sense of duty • There was no alternative • The cost of professionals would be too high • Emotional bonds (love, affection) • Caring for ELDER makes me feel good • ELDER would not wish for anyone else to care for them • Because of my religious beliefs • I found myself in these circumstances almost by chance without making a decision • There were economic benefits for me [Carer] and / or ELDER • A personal sense of obligation toward ELDER as a family member • Other, please specify **C68ILL.** If you were ill is there anybody who would step in to help with ELDER? **C69BREAK.** If you needed a break from your caring role is there someone who would look after ELDER for you?

SHARE and SILC are longitudinal databases, meaning that respondents are interviewed more than once, in different years. SHARE is in addition a specific dataset about informal care, and thus offers the best possibilities to analyse labour market transitions. With longitudinal EU-SILC data, this is only possible for care to a household member as main activity.

The LFS, USS, IZG and Eurofamcare are cross-sectional databases that include information about people who stopped or worked less hours because of the informal care they provided. The LFS in addition includes information about people seeking work who immediately before they started to seek work had the provision of informal care as main activity. We will need to explore the usefulness of this variable, but it could provide information that is missing from other data (Table C10).

Table C10 Review template, Health and Labour market transitions of care givers

Source	Variable name and description
Health and labour market transitions of care givers	
SILC AH16	See SILC
SILC+SOEP	For household members, we only know if they had limitations in their daily activities due to health problems ("needed care" for short) at the moment of the interview, so changes in employment status in the past 12 months cannot be linked to that. However, we observe: Whether the household member needed care at the time of one interview and no longer at the time of the subsequent interview one year later Whether the household member did not need care at the time of one interview but did at the time of the subsequent interview one year later This can be linked to the employment (and health) status of the care giver at both moments The variable **PL170** in cross-sectional data, item 5 "*Childcare and care for other dependents*" as a reason for a change of job in the past 12 months
EHIS	--- (no questions about transitions of health or employment, no longitudinal data)
LFS AH18	Career break for incapacitated relative: not worked or has reduced working time for at least one month in employment history to take care of incapacitated relative (of 15 years and older): Work interruption/Only reduced working time/No interruption or reduction. See further LFS
LFS	**EXISTPR, YEARPR, MONTHPR**. Existence of previous employment experience; and year and month in which person last worked **PRESEEK**: situation immediately before persons started to seek employment (or was waiting for new job to start) - code 4 "Person had domestic/care responsibilities".
SHARE	**EP127_PeriodFromMonth, EP128_PeriodFromYear, EP129_PeriodToMonth**, **EP130_PeriodToYear** From to what year / month have you been employed / unemployed? *Note: this is asked for all employment/unemployment spells since the last interview* In addition, SHARE is a longitudinal survey, so health and employment status of care givers can be followed through subsequent interviews.
EQLS	Which of these categories best describes your situation? - Includes unemployed for less than 12 months or 12+ months Unemployment for less than 12 months implies a transition from employment (or possibly school) to unemployment. Otherwise, no indicator of health or employment transitions.
UK: USS	**ajbhhe, ajbhhf, ajbhh** AE72E : In the past year have household or family responsibilities ever required you to leave paid employment?, AE72F : In the past year have household or family responsibilities ever required you to work fewer hours? AE73 : What responsibilities were these? (that necessitated AE72AF) *Note: would have to be combined with other care variables*
ESS 2014	--- (no questions about transitions of health or employment, no longitudinal data)
NL: IZG	**GezondAcht. Because of** providing care, my health situation decreased. **ComWrkHlp.** Are you able to combine work and providing care? Easy/Medium/Difficult **StopWrk.** Did you quit working in the past 12 months due to providing care? Yes, structurally/Yes, temporarily/No **MindrWrk.** Did you work less hours due to providing care? Yes, structurally/Yes, temporarily/No **VkntieDag.** Past 12 months: Take up holiday-leave to provide care? **BetVerlof.** Past 12 months: Take up paid leave to provide care? **OnbetVerlof.** Past 12 months: Take up unpaid leave to provide care? **Ziek.** Past 12 months: Take up sick-days to provide care?
Eurofamcare	**C175EMPL,** Are you currently employed?

Source	Variable name and description
Health and labour market transitions of care givers	
	C175HOUR. If yes, how many hours do you work in an average week? **C178WOR1.** I have had to reduce my working hours (Y/N) **C178HOUR.** If yes, by how many per week? **C180WOR2.** I had to give up work **C180HOUR.** If yes, how many hour per week were you working before you gave up work? No data on changes in health status (only about current health status)

All databases include basic data about the care giver: not only gender and age, but also a range of other socio-economic data (Table C11).

Table C11 - Review template, Socio-economic status of care giver

Source	Variable name and description
Socio-economic status of care giver	
Employment	All
Education	All
Income	All except IZG and ESS
Ethnicity	All except LFS (nationality instead) and IZG
Health status	All except LFS
Household composition	All except LFS
Living in urban/rural area	All except SHARE and IZG

Information on whether informal care is combined with formal care is available from only one EU database (SILC 2016), as well as from the Dutch IZG survey and Eurofamcare. SHARE covers hospitalization and nursery homes, but not formal homecare (Table C12).

Table C12 - Review template, combination of informal and formal LTC

Source	Variable name and description
Combination with formal LTC	
SILC AH16	**HC160** (Y/N). Use of health care services (of the household member with difficulty in daily activities due to health problem in a household where someone provides is mainly active with care responsibilities / domestic tasks **HC200** (Y/N). Professional home care received, **HC210** number of hours of professional home care received.
SILC+SOEP	--- (no question about use of formal care)
EHIS	--- (EHIS is not a household survey so provision of informal LTC and use of formal care cannot be matched)
LFS AH18	--- (no question about use of formal care)
LFS	--- (no question about use of formal care)
SHARE	Receivers of informal LTC: HC012_PTinHos (visits to hospital), HC014_TotNightsinPT (number of nights), and HC064_InOthInstLast12Mon (visits to rehabilitation or convalescence center), HC066_TotNightStayOthInst (number of nights), HC029_NursHome (stays in nursing home), HC031_WksNursHome (number of weeks)
EQLS	**---** (Q60 asks if someone else in the household receives formal care, but Q42 is not specific about whether informal LTC is provided to a household member)
ESS 2014	**---** (no question whether recipient of informal LTC used formal LTC, only about the provider)
UK: USS	--- (servuse includes items 2 “local hospital” and 3 “social care services” but cannot be linked to questions about receiving informal care)
NL: IZG	**ZorgIns**: did care recipient live in a care or nursery home (Y/N)? **HlpAnder**, items 5 “volunteer”, 6 “home care or district nurse”, 7 “household help”, 8 “case manager or housing counsellor”
Eurofamcare	**Q27-Q34**. One item is: service / support organisations (voluntary, private or public)

D Present value calculations

For the summation of probabilities over workers and the calculations of Present Values, the tool uses the following formula for the sum of a geometric progression for $a \neq 1$:

$$\sum_{i=m}^{n} a^i = \frac{a^m - a^{n+1}}{1-a} \quad (1)$$

Assuming that an informal carer seeking work enters it with probability *p* each year, and in addition assuming that employment is permanent until the retirement age, and lastly assuming that the annual wage rate *w* remains constant over time, then his or her expected income from work in a certain year is:

- the annual wage rate if immediately finding employment.
- minus the wage rate multiplied with the probability of that the person never entered employment.

Thus, for the first year the expected income from work is $w - (1-p)\cdot w = p\cdot w$. For the second year, the expected income from work is $w - (1-p)2\cdot w = p\cdot(2-p)\cdot w$. Note that expected income in the second year remains *w* if *p*=1 and remains 0 if *p*=0. More in general, the expected income from work is $w\cdot(1-(1-p)^t)$.

Discounting future values at rate r, and starting with year 0, the expected discounted income from work in year 0 remains $p\cdot w$ (no discounting in year 0). The present value in year 1 is times:

$$w \cdot \left(1 - (1-p) + \frac{1-(1-p)^2}{1+r}\right)$$

More in general, the present value of expected income from work up to and including year n is:

$$w \cdot \sum_{t=0}^{n} (1-(1-p)^{t+1}) \cdot \frac{1}{(1+r)^t}$$

In order to apply the formula for geometric progressions, this is rewritten as

$$w \cdot \sum_{t=0}^{n} \left(\frac{1}{1+r}\right)^t - w \cdot (1-p) \cdot \sum_{t=0}^{n} \cdot \left(\frac{1-p}{1+r}\right)^t$$

The first term represents income from work if finding employment immediately, or not having given up employment in the first place. If there is a persistent difference in the probability of entering employment between informal carers (p_1) and a comparison group (p_2), then the first terms cancel out and the difference becomes:

$$\frac{w \cdot (1+r)}{(r+p_1) \cdot (r+p_2)} \cdot \left\{ (p_2 - p_1) - \left(\frac{1-p_1}{1+r}\right)^{n+1} + \left(\frac{1-p_2}{1+r}\right)^{n+1} \right\}$$

On the other hand, if the difference in re-employment probability is assumed to apply only to the first year of job search, and p_2 is assumed to drop to p_1 after the first year, then the first terms still cancel out and the present value of income loss becomes:

$$-w \cdot (1-p_1) \cdot \sum_{t=0}^{n} \left(\frac{1-p_1}{1+r}\right)^t + w \cdot (1-p_2) \cdot \sum_{t=0}^{n} \cdot \left(\frac{1-p_1}{1+r}\right)^t = w \cdot (p_1 - p_2) \cdot \sum_{t=0}^{n} \left(\frac{1-p_1}{1+r}\right)^t$$

Which simplifies further to:

$$w \cdot \frac{(p_1 - p_2) \cdot (1+r)}{r+p_1} \cdot \left\{ 1 - \left(\frac{1-p_1}{1+r}\right)^{n+1} \right\}$$

Based on Dutch IZG data, care stints in the age category 18-44 years are assumed to last 3 years across the EU, and care stints in the age category 45-64 are assumed to last 5 years for men and 6 years for women. Further assuming that informal care starts equally likely at any year in either age category, younger informal carers are assumed to start at age 31. Informal carers in the age category 45-64 may have started their care stint before turning 45, and the average care stint is assumed to have started on average at age 52.

This means that people who gave up employment to provide (typically intense) informal care, on average start looking for work again at age:

- category 18-44 years: 34.
- men 45-64 years: 57.
- women 45-64 years: 58.

The last year of work is assumed to be 64 across the EU. Thus:

- n=0 at age 64.
- n=6 at age 58.
- n=7 at age 57.
- n=30 at age 34.

For the employment gap of 6% for women aged 45-64, p_1 = 0.17 and p_2 = 1, and the difference in probability of employment applies throughout the remainder of the working life, so the formula reduces to:

$$\frac{w}{(0.17+r)} \cdot \left\{ (1 - 0.17 - \left(\frac{1-0.17}{1+r}\right)^{7} \right\}$$

For men aged 45-64, p_1 = 0.22 and p_2 = 0.30 and under the assumption that the difference in re-employment probability persists throughout the remainder of the working life, the formula reduces to:

$$\frac{w \cdot (1+r)}{(r+0.22) \cdot (r+0.30)} \cdot \left\{ (0.08) - \left(\frac{1-0.22}{1+r}\right)^{9} + \left(\frac{1-0.30}{1+r}\right)^{8} \right\}$$

For women aged 18-44, p_1 = 0.20 and p_2 = 0.24 and the formula with persistent re-employment probability reduces to:

$$\frac{w \cdot (1+r)}{(r+0.20) \cdot (r+0.24)} \cdot \left\{ (0.04) - \left(\frac{1-0.20}{1+r}\right)^{30} + \left(\frac{1-0.24}{1+r}\right)^{30} \right\}$$

Lastly, for men aged 18-44, p_1 = 0.31 and p_2 = 0.33 and the formula with persistent difference in re-employment probability reduces to:

$$\frac{w \cdot (1+r)}{(r+0.31) \cdot (r+0.33)} \cdot \left\{ (0.02) - \left(\frac{1-0.31}{1+r}\right)^{30} + \left(\frac{1-0.33}{1+r}\right)^{30} \right\}$$

However, if the difference is assumed to apply only to the first year of job search.

Lastly, the present value of expected income loss is discounted further to the start of the care stint and then calculated as an annuity. Using a discount rate of 2% or 4% per year, the multipliers of the annual wage rate then become with persistent differences of re-employment probabilities:

					PV-multipliers		Annuity multipliers	
Group	**n**	**p1**	**p2**	**Applicable %**	**r = 0.02**	**r = 0.04**	**r = 0.02**	**r = 0.04**
M 18-44	30	0.31	0.33	1	-18%	-16%	6%	6%
M 45-64	7	0.22	0.3	1	-196%	-162%	42%	36%
F 18-44	30	0.2	0.24	1	-72%	-62%	25%	22%
F 45-64	8	0.17	1	0.06	-31%	-27%	6%	5%

If the difference in probability applies only in the first year of searching for work, then the associated wage loss becomes smaller for younger informal carers and male informal carers:

					PV-multipliers		Annuity multipliers	
Group	n	p1	p2	Applicable %	r = 0.02	r = 0.04	r = 0.02	r = 0.04
M 18-44	30	0.31	0.33	1	-6%	-6%	2%	2%
M 45-64	7	0.22	0.3	1	-30%	-29%	6%	6%
F 18-44	30	0.2	0.24	1	-19%	-17%	6%	6%
F 45-64	8	0.17	1	0.06	-31%	-27%	6%	5%

The associated wage loss is relatively high for older men due to the large difference in re-employment probability while the wage loss is relatively high for younger women because the smaller difference applies to a longer remainder of the career. The impact of the discount rate is relatively small because the wage loss is not incurred with certainty.

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