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What informal carers say about long-term care services' accessibility, affordability, and quality

& how Care plans should respond

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Table of contents

Summary

In a majority of European countries, care is mainly provided by informal carers. The prevalence and context for the provision of informal care depends on the structure of long-term care (LTC) services. LTC systems are challenged to offer users the opportunity to combine formal and informal care in a way that adequately addresses the needs and preferences of the care recipients without over relying on informal carers.

LTC has been included in the European Pillar of Social Rights and the European Care Strategy, which seeks to ensure the accessibility, affordability, and quality of LTC services across the European Union and improve the situation of care recipients, informal carers, and professional care workers. By use of the data collected through the InCARE survey, this report offers insights into informal carers' general assessment and experienced barriers regarding the accessibility, affordability, and quality of LTC services and general practitioners (GPs) in Europe.

Our results demonstrate that many informal carers negatively assess the accessibility, affordability, and quality of LTC services and GPs. Inequalities in accessibility, affordability, and quality are related to informal carers' living area, working conditions, income, and sense of obligation to care. More specifically, informal carers who live in urban areas, made changes in their work schedule to take care of someone close, face difficulties to make ends meet or feel obliged to care tend to more frequently report LTC services and GPs as inaccessible, too costly, or of poor quality than their counterparts from rural areas, with no changes in their work schedule, no difficulties to make ends meet, or no perceived obligation to care. A trend can also be observed whereby women more frequently assess LTC services and GPs as inaccessible or unaffordable than men. Notably, many informal carers also report being uncertain about the affordability and quality of LTC services.

European countries should recognise the pivotal role of informal carers in the LTC system, combat inequalities to enhance the accessibility, affordability, and quality of LTC services and ensure that informal carers have access to timely, reliable, and relevant information regarding formal LTC provision.

Background

The European Union is facing important demographic changes. Due to the increasing life expectancy and decreasing birth rates, the number of very old adults (i.e., 85 years and more) in Europe is projected to more than double between 2019 and 2050, from 12.5 million to 26.8 million (Eurostat, 2020). Consequently, the prevalence of chronic / age-related diseases and the demand for long-term care (LTC) are expected to rise (European Union, 2021).

Informal care is a major part of LTC in Europe, as informal carers account for close to 80% of care providers at European level (European Commission, 2022). Most Western European countries are gradually shifting from a focus on institutional care towards home- and community-based care provided by professional care workers and/or informal carers (Krabbe-Alkemade et al., 2020; Lehnert et al., 2019). This change of focus stems from austerity measures intended to reduce the high costs of institutional LTC services and thereby ensure financial sustainability of national healthcare systems, as well as individuals' preference for receiving care at home, also known as ageing-in-place (Lehnert et al., 2019). Moreover, LTC services in Europe are confronted with structural challenges, such as access and adequacy of LTC provision, quality of professional home-based care and residential care services, and employment (i.e., impact of informal care duties on women's participation in the labour market and undeclared care work) (Spasova et al., 2018).

To respond to these challenges, the European Union included LTC as one of the 20 social principles defined in its European Pillar of Social Rights. The pillar is divided in three chapters, covering the main areas of social and employment policy (i.e., equal opportunities and access to the labour market, fair working conditions, social protection, and inclusion) (European Commission, 2021). Principle 18 states that everyone has the right to affordable LTC of good quality, in particular home care and community-based services. In light of this, the European Union published a first-ever European Care Strategy in September 2022, which deploys an agenda to ensure the accessibility, affordability, and quality of LTC services across the European Union and improve the situation for care recipients, informal carers, and professional care workers. Considering the shortcomings of LTC systems as brought to light during the COVID-19 pandemic, the Strategy calls for an integrated approach to care in which care recipients, informal carers and professional care workers are all involved in the provision of care. Moreover, the main consequences of caregiving for informal carers themselves, including the negative effects on their work-life balance and health are also acknowledged. Therefore, the European Commission calls on Member States to design support measures for informal carers (e.g., counselling, psychological support, respite care, adequate financial support), while developing formal care services and facilitating cooperation between care recipient, informal carers, and professional care workers.

The availability and use of formal LTC services has an important impact on how informal carers take care of the care recipient (Kemp et al., 2013; Willemse et al., 2016). The study by Zigante et al. (2021) demonstrates a substitutive relationship between informal care and professional care. The researchers found a negative correlation between the availability of publicly-funded formal care and the intensity of informal care (i.e., 20+ hours a week). This substitute relationship is also highlighted by Verbakel (2018) as her study demonstrates that generous LTC provision in a country is related to a lower likelihood of providing intensive informal care (i.e., 11+ hours a week). In order to ease the pressure on informal carers, professional care workers need to acknowledge their role and expertise, and adopt an open and honest, proactive, and compassionate attitude towards them (Wittenbergh et al., 2018). To date, cooperation between informal carers and professional care workers has often been described as difficult. Informal carers experience a constant struggle with formal care services (e.g., in engaging with those services and understanding processes) (De Koker, 2018; McPherson et al., 2014). Informal carers, when searching for support, encounter difficulties in collecting information and navigating through the healthcare system (McPherson et al., 2014; Plöthner et al., 2019; Willemse et al., 2016). Furthermore, professional care workers feel uncertain about their responsibility in the cooperation and communication with informal carers (Hengelaar et al., 2018).

This scientific report sheds light on informal carers' general assessment of the accessibility, affordability, and quality of LTC services as well as general practitioners (GPs) in Europe (for themselves and/or the person they care for). In addition, sub analyses are presented regarding the perceived barriers concerning the accessibility, affordability, and quality of LTC services of informal carers in need of LTC services (for themselves and/or the person they care for) over the last year prior to the data collection period (September 2021 - March 2022). The results and recommendations can help organisations and policymakers at the local, national, and European level to determine strategic and informed care plans and develop interventions aiming to improve the interrelationship between care recipient, informal carers and professional care workers.

Data collection and sample

The findings reported in this paper are based on the data collected as part of the InCARE survey on attitudes, experiences, and expectations on LTC. The InCARE project[1] aimed to promote participatory, innovative, and integrated approaches to LTC policy and services development. Data was collected through an online survey from September 2021 to March 2022.

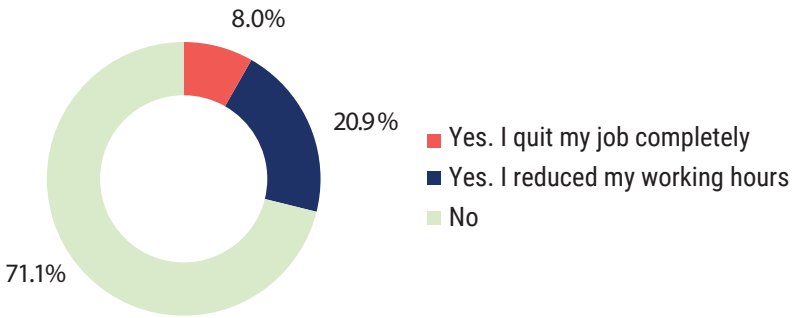
A series of InCARE publications based on the survey's outcomes already highlighted the most pronounced changes in preferences and attitudes towards the organisation, delivery, and financing of LTC in Europe, and the declining ability of healthcare systems to respond to population needs and expectations in a satisfactory manner. The findings presented in this paper focus more in detail on participants who indicated to have a loved one in need of regular help and LTC over the past ten years. The sample consists of 1,397 current and former informal carers.

Most informal carers were women (79.5%). Almost half of the sample was aged between 45 and 64 years (49.9%). 9.9% were between 18 and 29 years old, 24.5% between 30 and 44 years old, and 15.6% were aged 65 years and over. Higher education was also overrepresented, with nearly 75% of informal carers having completed a university or postgraduate degree. Most of the informal carers lived in an urban area (74.8%). The European countries most highly represented were Romania (19.5%), Spain (18.6%), Austria (18.0%), and Malta (13.4%).

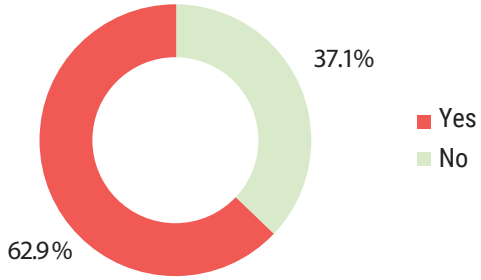
Most informal carers were employed (64.6%), 19.2% were retired. Notably, 28.9% of informal carers made changes in their work schedule as a result of their care responsibilities: 20.9% reduced their working hours and 8.0% had quit their job completely.

[1] More information regarding the InCARE project can be found on https://incare.euro.centre.org.

Did you ever give up paid work in order to provide regular help and LTC to someone close to you?



Did you ever feel you had to provide care to someone close to you despite a negative effect on your wellbeing?



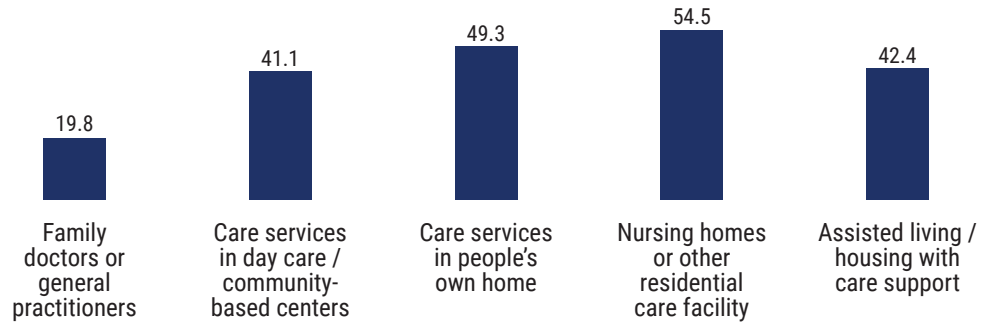
Although most of the participants with informal caregiving responsibilities considered their physical and mental health status as fair at least, 62.9% reported having to provide care to a loved one, despite a negative effect on their wellbeing. Also, 35.2% of the sample indicated to have been limited in activities of daily living (e.g., cooking, shopping, light housework, dressing) for at least the past six months because of their physical or mental health status.

Accessibility of LTC services

What types of LTC services are rated as difficult to access?

1 in 2 informal carers rated the accessibility of residential care (54.5%) and home-based care (49.3%) as very or fairly difficult. 2 in 5 informal carers rated the accessibility of assisted living (42.4%) and day care services (41.1%) as very or fairly difficult. Accessibility of GPs was better perceived by informal carers as less than 1 in 5 (19.8%) rated this type of LTC service as very or fairly difficult.

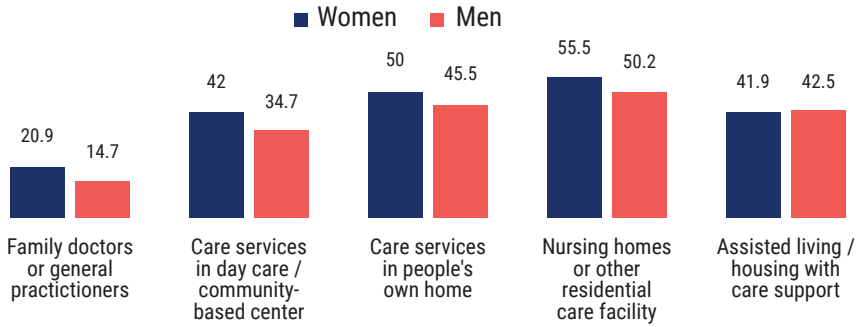
Share of respondents considering LTC services as very or fairly difficult to access, by type of service (in %)



For whom are LTC services most difficult to access?

Gender differences were visible in informal carers' assessment of the accessibility of LTC services. Women more often rated the accessibility of LTC services as very or fairly difficult than men, especially regarding the accessibility of GPs (20.9% for women versus 14.7% for men) and day care services (42.0% for women versus 34.7% for men).

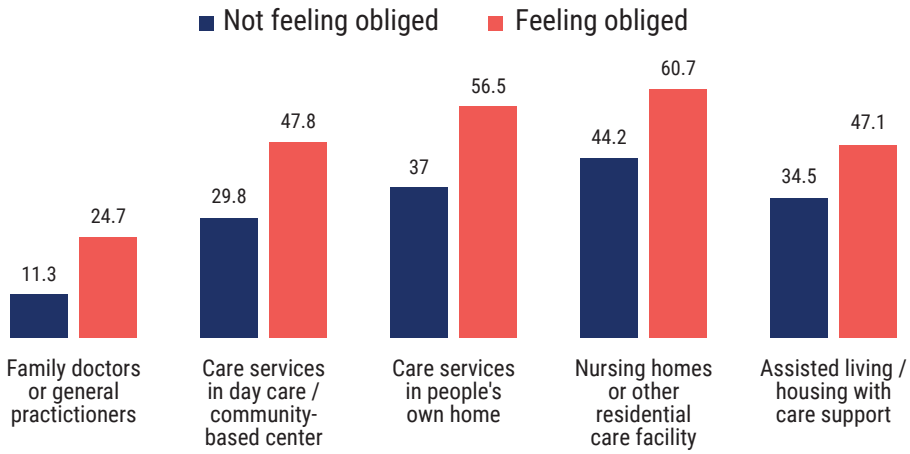
Share of respondents assessing negatively the accessibility of LTC services, by gender (in %)



Informal carers from urban areas more often rated the accessibility of day care services and home-based care, as very or fairly difficult compared to informal carers from rural areas. For instance, the results for home-based care amounted to 52.2% versus 39.9% respectively.

Informal carers who made changes in their work schedule more frequently rated the accessibility of GPs, day care services, home-based care, and residential care as very or fairly difficult compared to informal carers with no changes in their work schedule. Regarding residential care, approximately 3 in 5 informal carers who quit their job completely (62.0%) or who reduced their working hours (58.3%) rated the accessibility as very or fairly difficult compared to 52.7% of informal carers with no changes in their work schedule. The share of informal carers with difficulties to make ends meet and who assessed accessibility as very or fairly difficult was greater than the share of informal carers with no difficulties to make ends meet for all LTC services. For example, approximately 3 in 5 informal carers with difficulties to make ends meet (58.1%) rated the accessibility of home-based care as very or fairly difficult compared to 46.0% of informal carers with no difficulties to make ends meet. Also, the share of informal carers feeling obliged to care and who assessed accessibility as very or fairly difficult was greater than the share of informal carers not feeling obliged to care for all LTC services. For example, the results for home-based care were respectively 56.5% versus 37.0% and for residential care 60.7% versus 44.2%.

Share of respondents assessing negatively the accessibility of LTC services, depending on the sense of obligation to care (in %)



Focus on informal carers in need of LTC services during the last twelve months prior to the data collection period

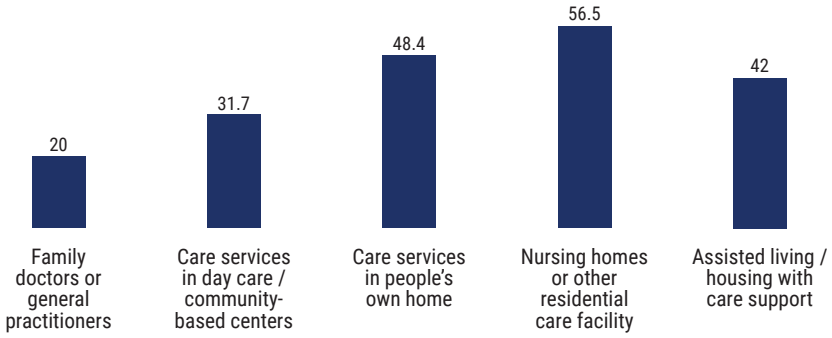
Many informal carers in need of LTC services during the last twelve months prior to the data collection period (whether for themselves or their loved one) reported being unable to access GPs (43.5%), home-based care (32.8%), and day care services (32.1%) due to accessibility issues. Approximately 1 in 4 informal carers during the last twelve months prior to the data collection period were unable to access residential care (25.6%) and assisted living (24.1%) due to limited availability. 18.0% of informal carers during the last twelve months prior to the data collection period also reported availability barriers for other services. For this group of informal carers in particular, changes in work schedule, household making ends meet and sense of obligation to care provided significant differences in availability barriers experienced in accessing LTC services. Informal carers who reduced their working hours or quit entirely, with difficulties to make ends meet or feeling obliged to care more often reported availability barriers in accessing LTC services than their counterparts with no changes in their work schedule, no difficulties to make ends meet, or no perceived obligation to care.

Affordability of LTC services

What types of LTC services are rated as unaffordable?

Residential care was considered as least affordable with 56.5% of informal carers rating this type of LTC service as not at all or not very affordable. Home-based care was assessed as not at all or not very affordable by 48.4% of informal carers, assisted living by 42.0% and day care services by 31.7%. Considering all LTC services, the GP was seen as most affordable: only 20% of informal carers rated this type of LTC service as not at all or not very affordable. An important group of informal carers reported being uncertain about the affordability of day care services (25.0%) and assisted living (40.8%). Also, 17.1% of informal carers were uncertain about the affordability of residential care and 14.1% about the affordability of home-based care.

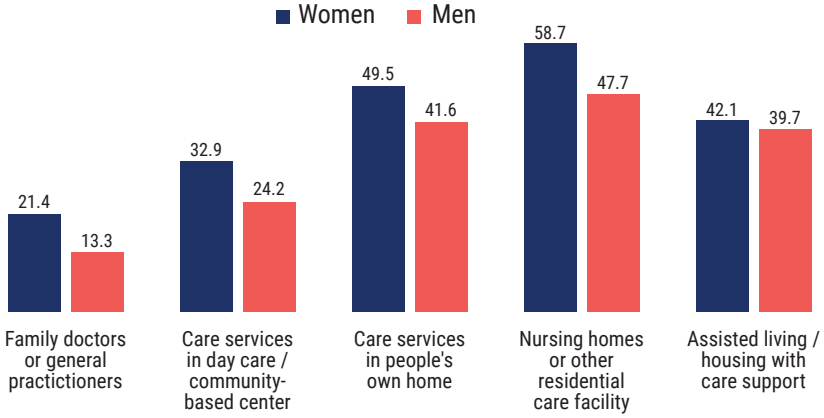
Share of respondents assessing negatively the affordability of LTC services, by types of services (in %)



For whom are LTC services most unaffordable?

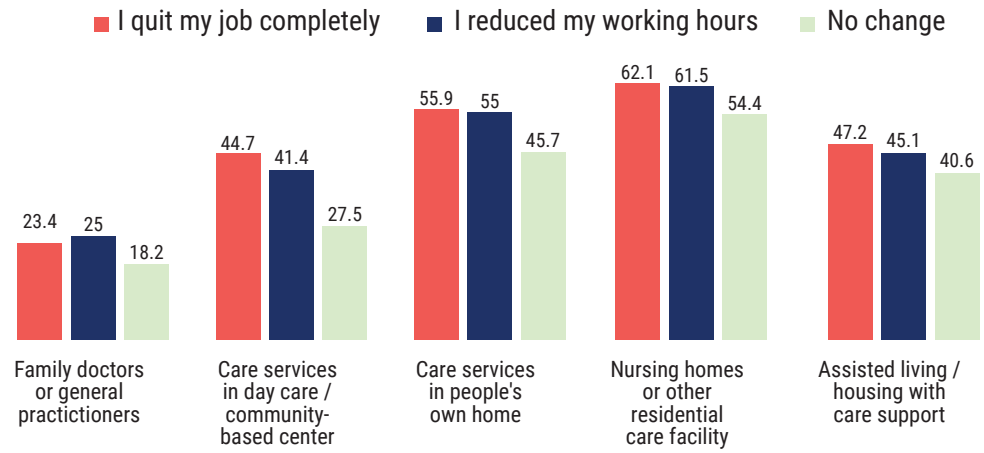
There is a trend of women rating LTC services more often as not at all or not very affordable than men: respectively 21.4% versus 13.3% for GPs, 32.9% versus 24.2% for day care services, 58.7% versus 47.7% for residential care, and 42.1% versus 39.7% for assisted living.

Share of respondents assessing negatively the affordability of LTC services, by gender (in %)



LTC services were more frequently rated as not at all or not very affordable by informal carers from urban areas compared to those from rural areas. This was especially the case for home-based care (50.1% of informal carers from urban areas versus 42.8% of informal carers from rural areas), and residential care (57.6% of informal carers from urban areas versus 52.8% of informal carers from rural areas). Informal carers who made changes in their work schedule rated GPs, day care services, home-based care, and residential care more frequently as not at all or not very affordable than informal carers with no changes in their work schedule. For instance, 44.7% of informal carers who quit their job completely and 41.4% of informal carers who reduced their working hours rated the affordability of day-care services as not at all or not very affordable compared to 27.5% of informal carers with no changes in their work schedule.

Share of respondents assessing negatively the affordability of LTC services, according to changes in work schedule (in %)



GPs, day care services, home-based care and residential care were more frequently rated as not at all or not very affordable by informal carers with difficulties to make ends meet compared to those with no difficulties. The percentages amounted respectively to 31.7% versus 15.2% for GPs, 42.6% versus 27.8% for day care services, 55.0% versus 45.6% for home-based care and 62.7% versus 54.9% for residential care. Informal carers feeling obliged to care assessed all LTC services more often as not at all or not very affordable compared to those who do not feel obliged to care. For instance, 62.3% of informal carers feeling obliged to care assessed residential care as not at all or not very affordable compared to 46.9% of those who do not feel obliged to care.

Focus on informal carers in need of LTC services during the last twelve months prior to the data collection period

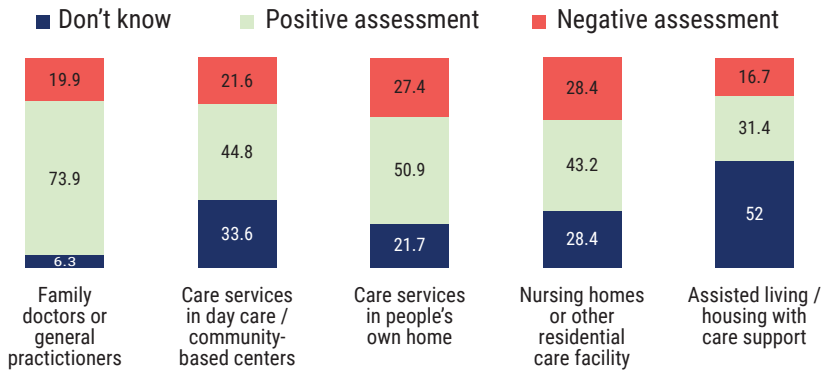
Informal carers in need of LTC during the last twelve months prior to the data collection period (whether for themselves or for a loved one) most often reported being unable to access residential care due to affordability barriers (30.8%), followed by home-based care (26.7%), assisted living (20.3%), other services (14.5%), day care services (13.5%) and GPs (10.0%). Changes in work schedule, household making ends meet and sense of obligation to care provided significant differences in the affordability barriers in accessing LTC services for this particular group of informal carers. Informal carers who reduced their working hours or quit entirely, with difficulties to make ends meet or feeling obliged to care more often reported being unable to access LTC services due to cost than their counterparts with no changes in their work schedule, no difficulties to make ends meet, or no perceived obligation to care. In addition, gender showed significant differences, where women informal carers were unable to access GPs, day care services and other services due to cost barriers more often than men.

Quality of LTC services

What types of LTC services are rated as very of fairly bad in terms of quality?

The quality of residential care was rated as very or fairly bad by 28.4% of informal carers, home-based care by 27.4%, day care services by 21.6%, GPs by 19.9% and assisted living by 16.7%. Notably, many informal carers were uncertain about the quality of LTC services. For instance, 1 in 3 was uncertain about the quality of day care services (33.6%), 1 in 4 about the quality of residential care (28.4%), and 1 in 5 about the quality of home-based care (21.7%). More than half of informal carers was uncertain about the quality of assisted living (52.0%).

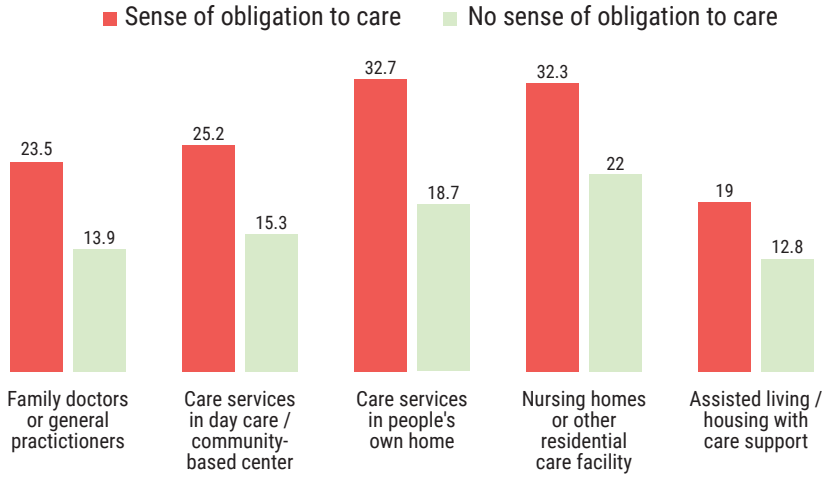
Share of respondents assessing negatively the quality of LTC services, by type of LTC service (in %)



For whom are LTC services most poor in terms of quality?

The quality of LTC services was more frequently rated as very of fairly bad by informal carers from urban areas compared to informal carers from rural areas. This was especially the case for home-based care (29.7% versus 20.1%), and residential care (29.4% versus 24.6%), where greater differences were found between informal carers from urban areas and informal carers from rural areas respectively. Informal carers who quit their job completely or reduced their working hours more often assessed the quality of day care services, home-based care, residential care and assisted living as very or fairly bad compared to informal carers with no changes in their work schedule. For instance, 40.6% of informal carers who quit their job completely and 31.1% of informal carers who reduced working hours rated the quality of residential care as very or fairly bad compared to 26.3% of informal carers with no changes in their work schedule. The quality of LTC services was more frequently assessed as very or fairly bad by informal carers with difficulties to make ends meet compared to those with no difficulties. This was especially the case for GPs (26.2% versus 18.6% respectively), day care services (31.6% versus 18.5% respectively), and home-based care (30.9% versus 26.5% respectively). Informal carers feeling obliged to care rated more often the quality for all LTC services as very or fairly bad compared to those who do not feel obliged to care:

Share of respondents assessing negatively the quality of LTC services, according to sense of obligation to care (in %)



respectively 23.5% versus 14.0% for GPs, 25.2% versus 15.4% for day care services, 32.7% versus 18.8% for home-based care, 32.3% versus 22.0% for residential care and 18.9% versus 12.8% for assisted living.

Focus on informal carers in need of LTC services during the last twelve months prior to the data collection period

Quality was most reported as a barrier to access care by informal carers in need of LTC services during the last twelve months prior to the data collection period (whether for themselves or for a loved one) for residential care (13.5%), followed by GPs (10.6%), home-based care (10.0%), day care services (8.1%), assisted living (6.5%) and other services (5.3%). Especially changes in work schedule, household making ends meet and sense of obligation to care provided significant differences in the quality of LTC services for this particular group of informal carers. Informal carers who reduced their working hours or quit entirely, with difficulties to make ends meet or feeling obligated to care more frequently reported quality as a barrier to accessing LTC services compared to their counterparts with no changes in their work schedule, no difficulties to make ends meet, or no perceived obligation to care.

Discussion and policy recommendations

This report explores informal carers' general assessment and perceived barriers regarding the accessibility, affordability, and quality of LTC services as well as GPs. Insight into these experiences is essential to offer LTC services that are suited to the needs and preferences of both care recipients and their informal carers. The differences in informal carers' assessment and experienced barriers, as outlined in this report, raise important concerns with respect to the alignment of current policy initiatives and the vision and expectations of Europeans. The limitations in terms of scale and representativity of the sample prevent this paper from giving a comprehensive description of informal carers' attitudes towards LTC services. Nonetheless, it provides a list of issues and policy pointers for the improvement of the cooperation between informal carers and professional care workers. We provide several recommendations that should be considered and reflected in LTC initiatives, policy plans and reforms both at local, national, and European level.

Informal carers play a vital role in enabling (older) persons in need of care to age in place and stay at home for as long as possible. As care needs are expected to rise (European Union, 2021), informal carers will continue to be important care actors, especially considering the increasing shortages of professional care workers and constraints on public budget for LTC. However, social and structural changes (e.g., increased women's employment rate, decreased birth rate, more geographically dispersed families, etc.) may limit the availability of informal carers in the future. The old-age dependency ratio is often used to study the level of potential informal support by the working-age population (20-64 years) for older adults. The old-age dependency ratio for the EU-27 was 34.1 % in 2019, meaning that there were approximately 3 persons of working age for every older person (Eurostat, 2020). Population projections suggest that the EU-27 old-age dependency ratio will reach 56.7 % by 2050, meaning that there will be fewer than two persons of working age for every older person. Furthermore, several factors like the informal carers' age and gender, the care receivers' physical health, caregiving tasks, hours of care, etc. lead to an increase in informal carers' burden (Metzelthin et al., 2017). This is especially the case in the current period as many studies highlighted the increased burden resulting from the COVID-19 pandemic (Budnick et al., 2021; Gräler et al., 2022; Lambotte et al., 2021). **European countries should recognise the essential role and contributions of informal carers in the LTC provision, offer a wide range of support measures to alleviate the burden of informal carers, further develop professional care services to ensure choice and an adequate balance between informal and professional care, and enhance efforts to facilitate cooperation within the care triad (i.e., care recipient, informal carers, and professional care workers)**.

According to our study many informal carers in Europe do not have access to LTC services. Approximately half of the sample assessed the accessibility of residential care and home-based care as very or fairly difficult, 40% for assisted living and day care services, and 20% for GPs. Approximately 2 in 5 informal carers in need of LTC services during the last twelve months prior to the data collection period (whether for themselves of their loved one) reported availability barriers for GPs, 1 in 3 reported availability barriers for home-based care and day care services, and 1 in 4 for residential care and assisted living. **Significant investment is needed in the provision of LTC services to facilitate the access to those services for informal carers and their care recipient**. Although accessibility of GPs was assessed as higher in comparison to the other LTC services by informal carers in general, many informal carers in need of LTC services during the last twelve months prior to the data collection period reported being unable to access GPs due to accessibility issues. As the data were collected between September 2021 and March 2022, this could possibly be related to the COVID-19 pandemic which increased the experienced distance to formal care services. Also, many informal carers rated LTC services as not at all or not very affordable, especially regarding residential care and home-based care. Looking more closely to informal carers in need of LTC during the last twelve months prior to the data collection period, more than 1 in 4 informal carers reported being unable to access residential care and home-based care due to cost barriers. Quality was reported as a barrier to access residential care by 13.5% of informal carers in need of LTC services during the last twelve months prior to the data collection period. Our data reaffirms the negative correlation between the accessibility, affordability and quality of care and the prevalence and intensity of informal care.

The results highlight the prevalent inequalities when it comes to LTC services' accessibility, affordability, and quality from the perspective of informal carers. Gender inequalities are visible, especially in LTC services' accessibility and affordability. Spatial disparities are observed in which informal carers living in an urban area more often perceive LTC

services as inaccessible, unaffordable, and of poor quality. Also, having a lower socio-economic status negatively affects LTC services' accessibility, affordability, and quality consistently. The fact that experiences with LTC are related to the socio-economic status of carers strengthens the argument for social protection to cover LTC during times of inflation and energy crisis, which aggravates the risk of impoverishment. In order to translate the principle 18 of the European Pillar of Social Rights on access to good quality and affordable care for every European into reality, **policy measures should be put in place to combat gender, geographical and socio-economic inequalities so as to create an equal LTC system**. The results call upon **the use of an intersectional perspective**, which recognises informal carers in their diversity and not only ensures that different categories or social identities of informal carers are targeted (Hengelaar et al., 2021; O'Connor et al., 2019). Taking diversity into account should enable a better understanding between informal carers and professional care workers, and thus improve their cooperation. Also, it should support policy makers to create more effective and relevant policy solutions that advance social justice (Hunting, 2014).

Informal carers too often bridge the gaps in LTC services. Our results confirm the lack of adequate alternative professional care options of good quality, forcing informal carers to reduce their working hours or leave the labour market altogether. Informal carers who quit their job completely or reduced their working hours more systematically assessed LTC services as unavailable, unaffordable and of poor quality compared to informal carers with no changes in their work schedule. The results call for **systems to better accommodate employment and care responsibilities and create sufficient work-life balance measures**. The lack of adequate professional LTC options is also reflected upon the results with regard to the perceived obligation to care. Our results demonstrate that informal carers who feel obliged to care more systematically assess LTC services as inaccessible, unaffordable and of poor quality. Our findings stress the importance of the availability of affordable care of good quality to ensure that informal care emanates from self-determination, rather than an obligation. Having a sense of free choice is particularly important as it is strongly and positively associated with informal carer's wellbeing (Al-Janabi et al., 2018).

Finally, the number of informal carers (i.e., persons who have been confronted with care needs and the healthcare system) not being certain of the accessibility, affordability, and quality of LTC services is remarkable. The percentages of informal carers who are uncertain of LTC services was particularly high regarding the quality dimension. These results seem to indicate that informal carers may be lacking information on available services and experience difficulties to navigate complex information (Plöthner et al., 2019; Willemse et al., 2016). **LTC systems should ensure that informal carers have access to timely, reliable, and relevant information**. Access to LTC services is a prerequisite to informal carers' ability to assess the affordability and quality of LTC services. The capacity to make informed decisions as regards the care arrangement that best suits the personal needs of the care recipient and/or informal carer depends on a comprehensive definition of access. The latter should not only focus on the physical accessibility of services for all, but include the availability of comprehensive information, formal care services' ability to reach out to informal carers and the proactive identification of informal carers who often do not define themselves as such.

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Tables

Tables related to informal carers' profile

Table 1: Have either you or someone you are close to ever been in need of any regular help and long-term care over the past ten years? (n=2,373)

	%
No	38,3
Yes	61,4
Missing	0,3

Table 2: Who was this person in need of care? (n=1,459)

	%
Me personally	4.2
My partner	4.6
One of my parents/parents-in-law	48.0
One of my grandparents	24.2
One of my children	1.9
One of my siblings (brother/sister)	3.4
Another relative or acquaintance	13.8

Table 3: Gender of the participants (n=1,368)

	%
Woman	79.5
Man	20.5

Table 4: Age of the participants (n=1,268)

Minimum	18 y
Maximum	90 y
Mean	49.9 y
St. dev.	14.41

Table 5: Age of the participants in categories (n=1,268)

	%
18-29 years	9.9
30-44 years	24.5
45-64 years	49.9
65-79 years	14.4
80+ years	1.2

Table 6: Marital status (n=1,302)

	%
Married/civil partnership	55.7
Not married but living with partner	13.7
Single never married	16.0
Divorced	8.2
Widowed	3.5
Other	2.9

Table 7: Highest education level (n=1,302)

	%
Primary	2.5
Secondary	20.5
University	39.0
Postgraduate	34.3
Other	3.7

Table 8: Occupational status (n=1,301)

	%
Employed	64.6
Unemployed	2.1
In education/training	6.7
Looking after home/family	1.7
Retired	19.2
Unable to work due to illness	0.8
Other	5,0

Table 9: Country of residence (n=1,397)

	%
Austria	18.0
Belgium	6.7
Bulgaria	0.2
Cyprus	0.1
Czech Republic	0.2
Denmark	0.5
Estonia	0.2
Finland	0.4
France	2.9
Germany	3.9
Greece	0.5
Hungary	0.1
Ireland	3.5
Italy	8.0
Lithuania	0.3
Luxembourg	0.4
Malta	13.4
Netherlands	0.9
Poland	0.4
Portugal	0.4
Romania	19.5
Slovakia	0.1
Slovenia	0.5
Spain	18.6
Sweden	0.2

Table 10: Born in country of residence (n=1,396)

	%
No	8.8
Yes	91.2

Table 11: Type of living area (n=1,392)

	%
Rural area/village	24.8
Small/middle-sized town	36.8
Large town	38.4

Table 12: Is your household able to make ends meet...? (n=1,298)

	%
Very easily	17.8
Easily	25.5
Fairly easily	31.4
With some difficulty	20.0
With difficult	3.5
With great difficulty	1.8

Tables related to informal carers' relationship with person in need of care

Table 13: Who was this person in need of care? (n=1,397)

	%
My partner	4.8
One of my parents/parents-in-law	50.1
One of my grandparents	25.3
One of my children	1.9
One of my siblings (brother/sister)	3.5
Another relative or acquaintance	14.4

Table 14: person in need of care living with informal carer (n=1,393)

	%
No	5.5
Yes	94.5

Table 15: In what ways do/did you personally get involved in helping this person? (n=1,397)

	%
Visiting regularly to keep company	60.3
Cooking and preparing meals	38.6
Doing shopping	50.6
Cleaning and household maintenance	37.9
Taking care of finances and everyday administrative tasks	38.4
Help with eating	27.4
Help with mobility	41.4
Help with dressing	34.6
Help with using the toilet	29.1
Help with bathing or showering	33.6
Organising professional care	43.2
Others	15.7
Don't know	0.6

Table 16: Was the appropriate help and long-term care given to this person? (n=1,391)

	%
Yes, totally	53.1
Yes, but only partly	39.5
No	6.0
I don't know	1.4

Tables related to informal carers' wellbeing

Table 17: Give up paid work in order to provide care (n=1,388)

	%
Yes, I quit my job completely	8.0
Yes, I reduced my working hours	20.9
No	71.1

Table 18: Did you ever had to provide care to someone close to you despite a negative effect on your wellbeing? (n=1,387)

	%
No	37.1
Yes	62.9

Table 19: Physical health (n=1,300)

	%
Very poor	0.3
Poor	4.2
Fair	41.7
Very good	43.5
Excellent	10.2

Table 20: Mental health (n=1,300)

	%
Very poor	0.3
Poor	4.9
Fair	31.9
Very good	46.1
Excellent	16.8

Table 21: To what extent have you been limited, for at least the past six months, in activities people normally do, because of a physical or mental health condition? (n=1,294)

	%
Severely limited	4.6
Somewhat limited	30.6
Not at all limited	64.8

Table 22: Difficulties in doing activities by yourself because of the physical or mental health condition (n=942)

Cooking\ preparing meals	7.9
Shopping	11.9
Light housework	7.7
Occasional heavy housework	40.2
Taking care of finances and everyday administrative tasks	6.6
Eating	3.1
Getting in and out of a bed or chair	7.7
Dressing and undressing	4.0
Using toilet	1.5
Bathing or showering	4.6
Using telephone	1.8
Managing medication	1.3
Moving around at home	4.0

Tables related to informal carers' experiences with long-term care

Accessibility of long-term care services

Table 23: Accessibility of long-term care services in the proper country

	Very or fairly difficult	Fairly or very easy	Don't know
Family doctors or general practitioners (n=1,375)	19.8	78.5	1.7
Care services in day care / community-based centers (n=1,319)	41.1	35.4	23.5
Care services in people's own home (n=1,336)	49.3	38.8	12.0
Nursing homes or other residential care facility (n=1,313)	54.5	26.7	18.7
Assisted living / housing with care support (n=1,293)	42.4	16.0	41.6

Table 24: Accessibility of long-term care services in the proper country

		Very or fairly difficult	Fairly or very easy	Don't know
Gender (n=1,349)*	Woman	20.9	77.3	1.8
	Man	14.7	84.2	1.1
Type of living area (n=1,373)	Rural area	18.5	80.3	1.2
	Urban area	20.1	78.1	1.7
Changes in work schedule (n=1,372)*	Yes, I quit my job completely	32.1	65.1	2.8
	Yes, I reduced my working hours	20.6	77.3	2.1
	No	18.0	80.6	1.4
Households making ends meet (n=1,287)**	Difficult	30.5	68.3	1.2
	Easy	15.8	82.6	1.6
Sense of obligation to care (n=1,372)**	No	11.3	86.6	2.2
	Yes	24.7	73.9	1.4

* p<=0.05; ** p<=0.001

Table 25: Accessibility of care services in day care / community-based centers according to informal carers' characteristics

		Very or fairly difficult	Fairly or very easy	Don't know
Gender (n=1,299)*	Woman	42.0	33.8	24.1
	Man	34.7	43.1	22.1
Type of living area (n=1,317)*	Rural area	39.2	41.5	19.3
	Urban area	41.7	33.6	24.8
Changes in work schedule (n=1,317)*	Yes, I quit my job completely	46.5	31.7	21.8
	Yes, I reduced my working hours	48.9	28.1	23.0
	No	38.2	38.0	23.8
Households making ends meet (n=1,235)*	Difficult	48.9	28.6	22.5
	Easy	38.4	36.9	24.7
Sense of obligation to care (n=1,316)**	No	29.8	43.2	27.1
	Yes	47.8	30.9	21.3

* p<=0.05; ** p<=0.001

Table 26: Accessibility of care services in own home according to informal carers' characteristics

		Very or fairly difficult	Fairly or very easy	Don't know
Gender (n=1,315)	Woman	50.0	37.9	12.1
	Man	45.5	43.2	11.3
Type of living area (n=1,334)**	Rural area	39.9	52.3	7.8
	Urban area	52.2	34.6	13.2
Changes in work schedule (n=1,334)*	Yes, I quit my job completely	55.7	36.1	8.2
	Yes, I reduced my working hours	58.2	31.2	10.6
	No	46.0	41.3	12.8
Households making ends meet (n=1,252)**	Difficult	58.1	31.0	11.0
	Easy	46.0	41.7	12.3
Sense of obligation to care (n=1,333)**	No	37.0	46.7	16.3
	Yes	56.5	34.0	9.5

* p<=0.05; ** p<=0.001

Table 27: Accessibility of nursing homes or other residential care facilities according to informal carers' characteristics

		Very or fairly difficult	Fairly or very easy	Don't know
Gender (n=1,294)	Woman	55.5	25.3	19.3
	Man	50.2	32.6	17.2
Type of living area (n=1,311)*	Rural area	54.2	32.6	13.2
	Urban area	54.6	25.0	20.4
Changes in work schedule (n=1,312)*	Yes, I quit my job completely	62.0	18.0	20.0
	Yes, I reduced my working hours	58.3	19.8	21.9
	No	52.7	29.8	17.6
Households making ends meet (n=1,233)*	Difficult	59.2	19.7	21.0
	Easy	52.1	29.7	18.3
Sense of obligation to care (n=1,310)**	No	44.2	35.0	20.8
	Yes	60.7	21.9	17.3

* p<=0.05; ** p<=0.001

Table 28: Accessibility of assisted living / housing with care support according to informal carers' characteristics

		Very or fairly difficult	Fairly or very easy	Don't know
Gender (n=1,275)	Woman	41.9	15.1	43.0
	Man	42.5	20.2	37.3
Type of living area (n=1,291)*	Rural area	43.9	19.9	36.2
	Urban area	42.0	14.8	43.1
Changes in work schedule (n=1,292)	Yes, I quit my job completely	46.3	13.7	40.0
	Yes, I reduced my working hours	46.9	12.0	41.1
	No	40.7	17.5	41.9
Households making ends meet (n=1,213)*	Difficult	47.5	11.6	40.9
	Easy	40.1	17.5	42.4
Sense of obligation to care (n=1,290)**	No	34.5	20.8	44.6
	Yes	47.1	13.1	39.8

* p<=0.05; ** p<=0.001

Table 29: In need for services during the last twelve months, but not available or not easily accessible (n=1,397)

	%
Family doctors or general practitioners	43.5
Care services in day care / community-based centers	32.1
Care services in people's own home	32.8
Nursing homes or other residential care facility	25.6
Assisted living / housing with care support	24.1
Other services	18.0

Table 30: In need for services during the last twelve months, but not available or not easily accessible according to informal carers' characteristics

		Family doctors or general practitionners	Care services in day care / community-based centers	Care services in people's own home	Nursing homes or other residential care facility	Assisted living / housing with care support	Other services
Gender (n=1,368)	Woman	45.1*	32.5	33.8	25.7	24.8	19.0
	Man	37.7*	31.3	29.9	25.3	21.7	14.9
Type of living area (n=1,392)	Rural area	46.1	31.6	34.8	28.1	26.4	20.0
	Urban area	42.5	32.3	32.3	24.9	23.5	17.2
Changes in work schedule (n=1,388)	Yes, I quit my job completely	56.8**	36.0	28.8*	27.0	21.6*	19.8*
	Yes, I reduced my working hours	54.5**	35.9	41.4*	29.7	31.4*	23.8*
	No	38.9**	30.8	30.9*	24.4	22.5*	16.1*
Households making ends meet (n=1,298)	Difficult	52.3**	32.2	37.7*	30.4*	28.3*	20.1
	Easy	41.1**	31.9	31.1*	24.5*	22.8*	17.4
Sense of obligation to care (n=1,387)	No	32.3**	26.5**	26.3**	22.4*	20.6*	17.3
	Yes	50.3**	35.7**	37.0**	27.8*	26.5*	18.6

* p<=0.05; ** p<=0.001

Affordability of long-term care services

Table 31: Affordability of long-term care services in the proper country

	Not at all or not very affordable	Fairly or very affordable	Don't know
Family doctors or general practitioners (n=1,380)	20.0	76.7	3.3
Care services in day care / community-based centers (n=1,298)	31.7	43.3	25.0
Care services in people's own home (n=1,323)	48.4	37.6	14.1
Nursing homes or other residential care facility (n=1,303)	56.5	26.4	17.1
Assisted living / housing with care support (n=1,275)	42.0	17.3	40.8

Table 32: Affordability of family doctors or GPs according to informal carers' characteristics

		Not at all or not very affordable	Fairly or very affordable	Don't know
Gender (n=1,354)*	Woman	21.4	75.6	3.1
	Man	13.3	83.1	3.6
Type of living area (n=1,378)	Rural area	19.4	77.4	3.2
	Urban area	20.1	76.7	3.2
Changes in work schedule (n=1,377)*	Yes, I quit my job completely	23.4	74.8	1.9
	Yes, I reduced my working hours	25.0	70.5	4.5
	No	18.2	78.7	3.1
Households making ends meet (n=1,288)**	Difficult	31.7	64.3	4.0
	Easy	15.2	82.0	2.8
Sense of obligation to care (n=1,376)**	No	14.7	81.4	3.9
	Yes	23.2	73.9	2.9

* p<=0.05; ** p<=0.001

Table 33: Affordability of care services in day care / community-based centers according to informal carers' characteristics

		Not at all or not very affordable	Fairly or very affordable	Don't know
Gender (n=1,276)*	Woman	32.9	41.4	25.6
	Man	24.2	52.1	23.8
Type of living area (n=1,296)	Rural area	28.6	49.3	22.0
	Urban area	32.8	41.4	25.8
Changes in work schedule (n=1,297)**	Yes, I quit my job completely	44.7	40.4	14.9
	Yes, I reduced my working hours	41.4	33.7	24.9
	No	27.5	46.5	26.0
Households making ends meet (n=1,215)**	Difficult	42.6	33.1	24.3
	Easy	27.8	46.0	26.2
Sense of obligation to care (n=1,295)**	No	21.0	49.9	29.1
	Yes	38.1	39.4	22.5

* p<=0.05; ** p<=0.001

Table 34: Affordability of care services in own home according to informal carers' characteristics

		Not at all or not very affordable	Fairly or very affordable	Don't know
Gender (n=1,301)	Woman	49.5	36.8	13.6
	Man	41.6	42.7	15.7
Type of living area (n=1,321)**	Rural area	42.8	46.2	11.0
	Urban area	50.1	34.9	15.0
Changes in work schedule (n=1,322)*	Yes, I quit my job completely	55.9	36.6	7.5
	Yes, I reduced my working hours	55.0	32.0	12.9
	No	45.7	39.3	14.9
Households making ends meet (n=1,241)*	Difficult	55.0	31.1	13.9
	Easy	45.6	40.0	14.4
Sense of obligation to care (n=1,320)**	No	37.0	44.9	18.0
	Yes	55.3	33.1	11.6

* p<=0.05; ** p<=0.001

Table 35: Affordability of nursing homes or other residential care facilities according to informal carers' characteristics

		Not at all or not very affordable	Fairly or very affordable	Don't know
Gender (n=1,284)*	Woman	58.7	25.3	15.9
	Man	47.7	30.8	21.4
Type of living area (n=1,301)**	Rural area	52.8	35.8	11.4
	Urban area	57.6	23.5	18.8
Changes in work schedule (n=1,302)**	Yes, I quit my job completely	62.1	18.9	18.9
	Yes, I reduced my working hours	61.5	17.8	20.7
	No	54.4	29.7	15.9
Households making ends meet (n=1,221)**	Difficult	62.7	17.2	20.1
	Easy	54.9	28.6	16.4
Sense of obligation to care (n=1,300)**	No	46.9	35.1	18.0
	Yes	62.2	21.4	16.4

* p<=0.05; ** p<=0.001

Table 36: Affordability of assisted living / housing with care support according to informal carers' characteristics

		Not at all or not very affordable	Fairly or very affordable	Don't know
Gender (n=1,256)	Woman	42.1	16.6	41.3
	Man	39.8	20.9	39.5
Type of living area (n=1,273)*	Rural area	41.9	22.3	35.9
	Urban area	42.1	15.7	42.2
Changes in work schedule (n=1,274)	Yes, I quit my job completely	47.2	16.9	36.0
	Yes, I reduced my working hours	45.1	13.9	41.0
	No	40.6	18.3	41.1
Households making ends meet (n=1,193)	Difficult	46.5	13.4	40.1
	Easy	40.5	18.8	40.7
Sense of obligation to care (n=1,272)*	No	36.5	21.0	42.5
	Yes	45.2	15.1	39.7

* p<=0.05; ** p<=0.001

Table 37: In need for long-term care services during the last twelve months, but too costly (n=1,397)

	%
Family doctors or general practitioners	10.0
Care services in day care / community-based centers	13.5
Care services in people's own home	26.7
Nursing homes or other residential care facility	30.8
Assisted living / housing with care support	20.3
Other services	14.5

Table 38: In need for long-term care services during the last twelve months, but too costly according to informal carers' characteristics

		Family doctors or GPs	Care services in day care / community-based centers	Care services in people's own home	Nursing homes or other residential care facility	Assisted living / housing with care support	Other services
Gender (n=1,368)	Woman	10.9*	14.0*	27.0	30.6	19.9	15.6*
	Man	6.4*	10.0*	24.2	30.6	19.2	9.3*
Type of living area (n=1,392)	Rural area	11.9	13.9	28.7	29.9	22.9	14.2
	Urban area	9.5	13.3	26.1	31.0	19.4	14.7
Changes in work schedule (n=1,388)	Yes, I quit my job completely	16.2*	14.4**	28.8*	29.7*	17.1*	18.9**
	Yes, I reduced my working hours	12.8*	22.4**	32.8*	37.6*	26.9*	21.7**
	No	8.6*	10.8**	24.9*	29.2*	18.8*	12.1**
Households making ends meet (n=1,298)	Difficult	17.9**	21.6**	32.2*	38.9**	26.7**	22.2**
	Easy	7.0**	10.3**	24.9*	28.5**	18.2**	12.7**
Sense of obligation to care (n=1,387)	No	6.0**	8.4**	21.0**	23.9**	16.3*	9.1**
	Yes	12.5**	16.6**	30.4**	35.2**	22.8*	17.9**

* p<=0.05; ** p<=0.001

Quality of long-term care services

Table 39: Quality of long-term care services

	Very or fairly bad	Fairly or very good	Don't know
Family doctors or general practitioners (n=1,373)	19.9	73.9	6.3
Care services in day care / community-based centers (n=1,302)	21.6	44.8	33.6
Care services in people's own home (n=1,313)	27.4	50.9	21.7
Nursing homes or other residential care facility (n=1,288)	28.4	43.2	28.4
Assisted living / housing with care support (n=1,253)	16.7	31.4	52.0

Table 40: Quality of family doctors or GPs according to informal carers' characteristics

		Very or fairly bad	Fairly or very good	Don't know
Gender (n=1,347)	Woman	20.2	73.3	6.4
	Man	18.2	76.3	5.5
Type of living area (n=1,371)	Rural area	18.5	74.1	7.4
	Urban area	20.4	73.7	5.9
Changes in work schedule (n=1,371)	Yes, I quit my job completely	20.2	69.7	10.1
	Yes, I reduced my working hours	21.3	73.8	4.9
	No	19.5	74.3	6.3
Households making ends meet (n=1,281)**	Difficult	26.2	64.0	9.8
	Easy	18.6	76.9	4.5
Sense of obligation to care (n=1,368)**	No	13.9	80.2	5.9
	Yes	23.5	69.9	6.5

* p<=0.05; ** p<=0.001

Table 41: Quality of care services in day care / community-based centers according to informal carers' characteristics

		Very or fairly bad	Fairly or very good	Don't know
Gender (n=1,279)	Woman	21.4	43.8	34.8
	Man	20.9	49.4	29.7
Type of living area (n=1,299)	Rural area	19.4	49.0	31.6
	Urban area	22.2	43.4	34.4
Changes in work schedule (n=1,300)*	Yes, I quit my job completely	24.5	43.9	31.6
	Yes, I reduced my working hours	28.9	38.6	32.5
	No	19.0	46.8	34.2
Households making ends meet (n=1,218)**	Difficult	31.6	35.5	32.9
	Easy	18.5	47.0	34.5
Sense of obligation to care (n=1,298) **	No	15.3	49.8	34.9
	Yes	25.2	42.0	32.8

* p<=0.05; ** p<=0.001

Table 42: Quality of care services in own home centers according to informal carers' characteristics

		Very or fairly bad	Fairly or very good	Don't know
Gender (n=1,293)	Woman	27.4	51.1	21.5
	Man	26.8	50.9	22.3
Type of living area (n=1,311)**	Rural area	20.1	62.1	17.8
	Urban area	29.7	47.4	22.9
Changes in work schedule (n=1,312)*	Yes, I quit my job completely	35.6	48.5	15.8
	Yes, I reduced my working hours	31.7	49.3	19.1
	No	25.3	51.7	23.0
Households making ends meet (n=1,230)*	Difficult	31.0	44.4	24.6
	Easy	26.5	53.0	20.5
Sense of obligation to care (n=1,309)**	No	18.7	56.8	24.5
	Yes	32.7	47.3	20.0

* p<=0.05; ** p<=0.001

Table 43: Quality of nursing homes or other residential care facilities centers according to informal carers' characteristics

		Very or fairly bad	Fairly or very good	Don't know
Gender (n=1,268)	Woman	28.6	42.2	29.1
	Man	27.4	47.0	25.6
Type of living area (n=1,285)*	Rural area	24.6	51.2	24.3
	Urban area	29.4	40.9	29.8
Changes in work schedule (n=1,286)**	Yes, I quit my job completely	40.6	26.0	33.3
	Yes, I reduced my working hours	31.1	38.1	30.8
	No	26.3	46.6	27.2
Households making ends meet (n=1,210)	Difficult	31.5	37.4	31.1
	Easy	27.1	45.0	27.9
Sense of obligation to care (n=1,284)**	No	22.0	53.1	24.9
	Yes	32.3	37.5	30.3

* p<=0.05; ** p<=0.001

Table 44: Quality of assisted living / housing with care support according to informal carers' characteristics

		Very or fairly bad	Fairly or very good	Don't know
Gender (n=1,233)*	Woman	16.1	29.9	54.0
	Man	18.0	37.6	44.4
Type of living area (n=1,250) *	Rural area	16.6	37.6	45.8
	Urban area	16.6	29.5	53.8
Changes in work schedule (n=1,251)*	Yes, I quit my job completely	21.1	27.8	51.1
	Yes, I reduced my working hours	22.2	25.6	52.2
	No	14.5	33.6	52.0
Households making ends meet (n=1,175)	Difficult	19.9	27.5	52.6
	Easy	14.9	33.1	51.9
Sense of obligation to care (n=1,249)**	No	12.8	37.2	50.0
	Yes	19.0	27.9	53.1

* p<=0.05; ** p<=0.001

Table 45: In need for long-term care services during the last twelve months, but of poor quality (n=1,397)

	%
Family doctors or general practitioners	10.6
Care services in day care / community-based centers	8.1
Care services in people's own home	10.0
Nursing homes or other residential care facility	13.5
Assisted living / housing with care support	6.5
Other services	5.3

Table 46: in need for long-term care services during the last twelve months, but of poor quality according to informal carers' characteristics

		Family doctors or general practitionners	Care services in day care / community-based centers	Care services in people's own home	Nursing homes or other residential care facility	Assisted living / housing with care support	Other services
Gender (n=1,368)	Woman	10.4	7.7	10.1	13.4	6.3	5.3
	Man	10.3	9.3	10.0	13.2	6.8	5.7
Type of living area (n=1,392)	Rural area	7.8	6.1	7.0*	11.9	5.8	5.2
	Urban area	11.6	8.7	11.0*	13.9	6.7	5.3
Changes in work schedule (n=1,388)	Yes, I quit my job completely	11.7**	9.9	14.4*	19.8*	8.1	9.0*
	Yes, I reduced my working hours	17.9**	11.0	14.1*	16.9*	8.3	7.9*
	No	8.4**	7.0	8.4*	11.8	5.8	4.2*
Households making ends meet (n=1,298)	Difficult	17.3**	9.7	11.2	15.5	7.6	7.3
	Easy	8.0**	7.2	9.4	12.2	6.0	4.5
Sense of obligation to care (n=1,387)	No	6.6**	5.3*	7.6*	11.1	4.7*	2.5**
	Yes	13.1**	9.7*	11.6*	14.9	7.6*	7.0**

*** p<=0.05; ** p<=0.001**

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