

**Report for EUFAMI**

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# Understanding the value and impacts of informal care for people living with poor mental health



## **2 Value of caring report**

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# 1 Summary

Our survey of more than 700 caregivers across Europe and Canada highlights the tremendous and too often hidden value of caregiving. Potentially without the input of these (mainly close family) carers undoubtedly some of supports would need to be provided instead by health and social care systems. In short informal carers are fundamental to the functioning of any health and social care system; it is critical to therefore to invest in measures to support these caregivers and identify potential risk factors that might lead to a breakdown in caregiving support.

As part of our study we undertook a review of the literature finding relatively few studies looking at carers of serious and common mental disorders, compared to studies focused on dementia caregivers. So, despite the importance of caring for carers and understanding the value of caring, more can be done to highlight this issue for policy makers. In the case of dementia raising awareness of the value of caring has been very important; the increased focus on this topic over the last two decades has directly led to the development of supportive policies for carers in many European countries. Our survey and report aims to help change this; here we summarise some of our key findings, as well as provide some brief recommendations for different stakeholder groups.

## 1.1 Key findings

### The average length of the caring week exceeds the length of the working week

On average informal carers provide more than 43 hours of care every week, well in excess of the average working week. Average caring times did not differ significantly for different mental health problems. 41% of all carers have to balance caring with employment.

### Carers who live with the person they support have much longer 'caring weeks'

Carers who live with the person they support provide significantly higher levels of care than carers who live apart from the person they support; on average more than 65 hours a week compared to less than 26 hours per week.



### Each hour of caring time is valued by carers to be between €23.62 and €28.75

One approach used by economists to valuing caring time is to elicit values directly from carers. In our survey carers were asked on average how much they would need to receive to provide one extra hour of care themselves (€28.75), as well as how much they would be willing to pay for someone else to provide an extra hour of care (€23.62).

### The estimated economic value of informal care time is substantial

Across all countries, the average weekly value of caring time, as well as travel time and travel expenses, would be €1,441 using the willingness to accept approach or €1,164 using the willingness to pay approach. Overall, if the weekly value of caring is extrapolated over an entire year then the average value of caring hours would range between €74,907 or €61,026 depending on whether the willingness to accept or pay methods are used.

### The estimated economic value of informal care time is significantly greater for carers who live with the person they support

Because carers who live with the person they care for provide more hours of care, their mean weekly value of informal care is much higher. Overall using the willingness to accept approach the mean weekly value of caring would be €2,223 compared with €774 for carers who live separately. These figures using the willingness to pay methodology are €1,758 and €652 respectively. Annual costs for carers who live with the person they care for using the willingness to accept approach would be €115,596 compared with €40,248 for carers who live separately.

### The value of caring time is just one part of the true value of caring

The monetary value of hours of caring represents just a part of the true value of care. There are other impacts, some of which are difficult to measure monetarily. They include impacts of loneliness, long term impacts on career progression and the possible stigma associated with caring for someone with poor mental health. To partly address this, we have placed a monetary value on the adverse quality of life impacts of caring, assuming conservatively that each year of perfect quality of life can be valued at €30,000. If we include these impacts then the total average

economic impact of caring increases from €74,907 (using the willingness to accept value of carer hours) to €86,819.

### Carers are much more lonely than the general population.

As part of our survey we included the 3 item short form UCLA-3 loneliness instrument. Scores range from 3 (the lowest level of loneliness) to 9 (the highest levels of loneliness). Scores of 6 and above are often thought to indicate substantive loneliness. In our survey the overall mean loneliness score is 5.88; this is significantly greater than typical scores of between 3 and 4 for European populations. Loneliness scores were lowest when care recipients only had one mental morbidity at 5.62 rising to 5.99 for 2 morbidities and being over 6 for all additional levels of morbidity.

### Longer 'caring weeks' and living with the person carers support are among potential factors associated with higher levels of loneliness

In regression modelling potential factors that influence loneliness levels in carers include living with the person they support (and spending more



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time on caring activities. When caregivers had higher levels of happiness measured using the CQOL happiness instrument, they were less lonely.

### Quality of life for carers is 40% lower than if they were not caring.

Carers have 40% lower levels of quality of life than if they were not caring. Using the CarerQOL-7D the mean quality of life score is 60.29, (100 is highest value where caring has no impact on quality of life and 0 lowest value).

### Quality of life for carers who live with the person they care for is significantly lower

Quality of life scores for carers who live with the person they care for are significantly lower than for carers who live separately from the person they care for: 56.17 versus 63.78.

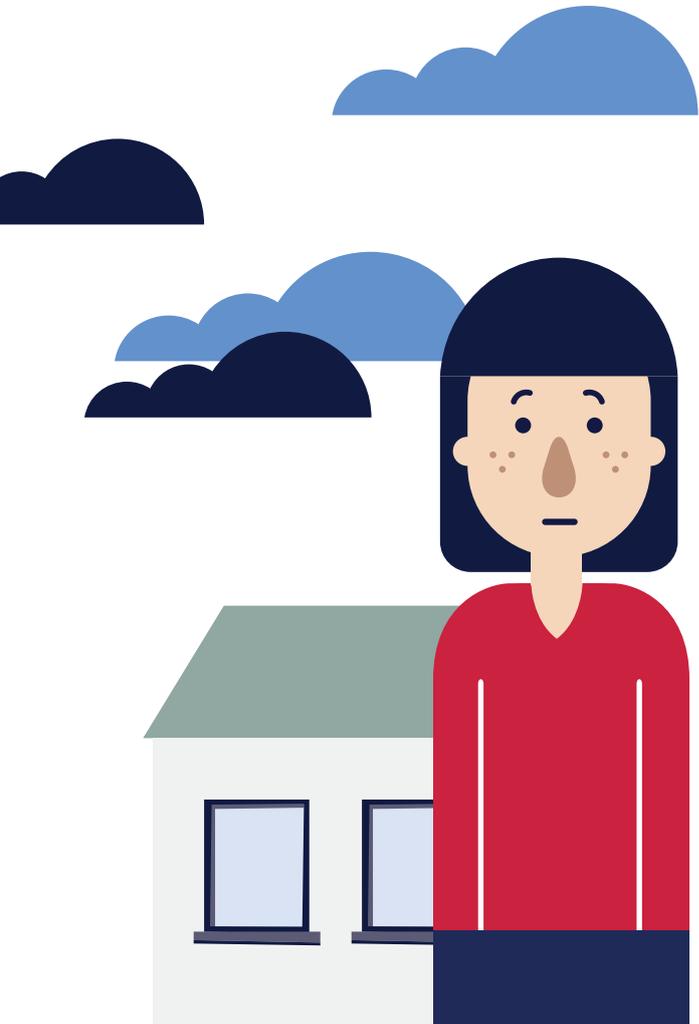
### Quality of life for carers is lower when the care recipient has multiple mental disorders

Quality of life scores decline as the number of mental disorders increases. Carer quality of life scores are lowest where care recipients have a personality disorder or an eating disorder, partly because most of these care recipients also have other diagnosed mental health problems.



### Carers reduce their time in work, education, volunteering and leisure

43% of carers have reduced their hours in work because of their caring responsibilities, on average by 19.49 hours a week. 82% of respondents gave up an average of 12 hours of leisure a week because of caring. A third of carers had reduced their participation in educational activities; a mean reduction of 9.62 hours per week. More than half of all respondents also reported reduced volunteering time, with a mean reduction of 6.15 hours per week.



### A quarter of carers in the survey self-report having a diagnosis of depression or anxiety disorder

71% of carers had been in contact with primary care doctors at least once in the previous 3 months. 27% of all carers reporting their health in the survey reported having a diagnosis depression and/or anxiety disorders. This is likely to underestimate the full extent of undiagnosed depression and anxiety in the carer population. Musculoskeletal health problems were also frequent with 86 (23%) of carers reporting having arthritis and 95 (26%) back pain.

### The majority of carers do not receive formal support to help with caring

We asked survey respondents about different types of support that they might receive. In all settings very few carers in our survey were receiving help from paid carers. Overall, only 15% of carers are complemented by paid carers, on average receiving 4 hours of paid care per week. 43% of care recipients attended some regular external activity, on average 2.6 days every week, with each of these activities on average lasting 75 minutes, thus also potentially providing some brief respite for carers. One third of carers also

indicated receiving some other form of additional support. Peer support for carers can be vital in protecting mental health and wellbeing; 45% of carers were involved in peer support groups for an average of 2 hours per week. Similar rates of peer group support participation were seen across all country groups.

### The majority of carers have not had a formal assessment of their caring needs

Carer assessments are an important way to identify needs and also to help prevent crisis events occurring which could lead to the breakdown of caring relationships. Perhaps most critically carer assessment provides an opportunity to determine whether a carer may benefit from access to respite services. We asked survey respondents in all countries (except Denmark) about whether they had requested a formal assessment of their care needs. Overall, only 23% of respondent carers had requested or had such as assessment.



### 1.2 Recommendations

#### Recommendations for policy makers

Consider investing in support measures to help give carers supporting someone with mental health problems a break from the 'caring week' including a right to an assessment of carer needs, including the need for respite care.

Consider investing and evaluating measures aimed at reducing levels of loneliness experienced by caregivers and increasing access to emotional support, for instance through providing support for helplines as well as peer support groups.

More research is needed on the economic value and impact of caring for people with less common mental health problems. For instance, our survey suggests very adverse outcomes for carers of people with eating disorders, but numbers are too small to draw any firm conclusions.

Longitudinal studies that follow carers over time and compare experiences to non-carers would strengthen the evidence base further on the value and impacts of caring.

#### Recommendations for mental health and social care services

Caregivers at particular risk of poor quality of life and loneliness are more likely to be living with the person they support. They may benefit most from additional support from mental health and social care services.

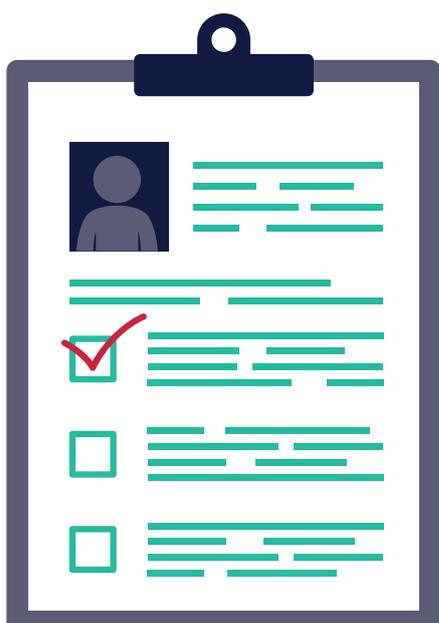
Mental health and social care services should consider working with family associations and other relevant stakeholders to provide more access to information, including formal psychological interventions, as well as peer-support.

#### Recommendations for caregivers and wider society

Awareness raising initiatives on the value for society provided by informal carers are needed. All caregivers play a very important role, but carers of people with mental health problems are much less prominent in research on the value of care than other carers, including carers supporting older people with dementia and related disorders, or young children with disabilities. The economic value provided by carers is very similar, regardless of the mental health problems of the people that they support.

While there are positive aspects of providing care, caregivers supporting people with any mental health problem are at risk of poor health. The challenges of caregiving can be just as demanding when supporting someone with severe depression as they are for someone with psychosis.

Family associations and other groups should consider regularly collecting information on time spent caring, levels of loneliness and quality of life, in order to help inform the policy debate. Measures are available that are free and relatively brief to use. They are contained in our survey.



# 2 Background and aims

Family and other informal caregiving is a fundamental contribution made to the welfare of all societies. We all rely throughout life on different levels of care and support from family and friends. Some of this caring is seen as a fundamental duty, this being most evident for parents providing care for their children until they reach adulthood. In this case many high-income countries provide financial help and other supports to help parents manage their caring responsibilities with some of their other activities such as going to work.

Yet too often for other groups that require care and support the same level of recognition of the value of care is not there. This includes family members and other informal carers supporting people with mental health problems that EUFAMI represents across Europe. These carers are an essential part of mental health support systems, but usually their contributions are not fully recognised, with insufficient support in many different countries for their own health and welfare needs.

EUFAMI's previous Caring for Carers Survey revealed many challenges faced by carers (1). While there are positive experiences from caring, their survey of over 1,000 carers in 22 countries revealed that more than one in three carers had reached breaking point where they found caring difficult to continue, with high levels of anxiety. It also revealed that caring often had a detrimental effect on the carer's own health, while around 15% of family caregivers felt they were treated differently because of the stigma associated with the mental health of the person they were caring for.

One critical step in changing this situation is to better identify and value the rewards and challenges associated with informal care in different country contexts. While reasonably well documented in respect of dementia, this is not well understood when looking at other mental health problems including anxiety and depression, bipolar disorder and psychoses. Take for example one parliamentary report in Canada, albeit written more than a decade ago, which stated that "caregivers feel excluded, ignored by the mental health, mental illness and addiction system in Canada. Ironically, it is these same family members who often provide most of the care and support to people living with mental illness." (2)

With this in mind EUFAMI in partnership with the London School of Economics and Political Science conducted a new carer survey. It should be stressed that this survey is not an update of the Caring for Carers survey. Instead the aim is twofold, firstly to better understand components of the economic impact of informal care in specific country contexts. Secondly, to make an estimate the economic value of informal caring, and separately provide a simple tool that can be used to help refine estimates of the value of informal caring. In preparing this report a rapid review of the literature on the value of informal care was also undertaken.

# 3 Survey methods

A survey was developed in consultation with EUFAMI. Our challenge was to design a questionnaire that would be delivered online, although a paper version of the survey was available on request. We also needed to balance the need to obtain specific information to allow us to estimate the value of care, with the risk of low levels of survey completion seen in longer surveys. Our survey is therefore shorter than the previous Caring for Carers Survey (C4C) and based on our review of the literature and past experience in estimating the value of informal care, we focused on seven key themes set out in Box 3.1.

As our survey was distributed online we did not expect all questionnaires to be fully completed, and prioritised the order of survey questions so that the most critical elements of the survey for our analysis: basic carer and care recipient characteristics, time spent caring and its value, levels of loneliness and quality of life, and impacts on normal daily activities such as participation in employment and leisure were prioritised.

The survey included key metrics needed to accurately value informal care including self-reported estimates of time spent caring, as well as using a validated carer specific quality of life instrument developed in the Netherlands – the

CarerQoL-7D – to measure the impact of caring on carer quality of life (3, 4). Carers are known to be at higher risk of loneliness compared to the general population (5, 6), but there has been limited research looking at the experience of informal carers of people with mental health problems. We looked at the potential association between experiences of caring and levels of loneliness, measured using the brief 3 item version of the University of California, Los Angeles, (UCLA-3) loneliness scale (7). A modified version of the Client Service Receipt Inventory was used to record carers self-reported use of selected health and social care services, including some specific carer supports, as well as caring-related travel time and expenses, over the previous three months. Some brief questions on contact with health services by people being supported were also included. Adapted versions of some questions related to the financial burden of caring from the previous C4C survey.

The survey was administered via QUALTRICS, a secure online survey collection system that is compliant with the GDPR. Ethical approval was provided by the London School of Economics and all responses were anonymous. Informed consent was required to participate in the survey, and critically respondents were free not to answer any questions they did not wish to answer.

To be eligible to participate respondents had to be, 18 years or old and caring for someone aged 18 years or older with at least one severe mental health condition (other than dementia and learning difficulties). They did not have to be the main informal carer, nor live in the same household as the person they cared for. Carers were not eligible to participate if they were formally employed to be a carer, but they were still eligible if they received a social welfare benefit for caring.

## Box 3.1 Key themes covered in carer survey

- Value of time spent caring
- Loneliness
- Carer Quality of Life
- Participation in employment, leisure, education and volunteering
- Carer contacts with health services
- Impacts on finances and family life
- Use of health services by person receiving informal care

The survey was launched online in September 2019, first in English and then adapted and translated into French, Spanish, Italian and Danish. Different country specific versions of the survey were available in English to cover the different contexts in the UK, Ireland, Canada and Malta. There were two French versions for Canada and France. Unlike the previous C4C survey that covered 22 countries our survey was tailored for and specifically targeted at eight countries that EUFAMI wanted to focus on: Canada, Denmark, France, Ireland, Italy, Malta, Spain & the UK. Respondents from beyond these eight countries were also free to take part in the survey but no active efforts were made to recruit these additional carers.

Recruitment to the survey was mainly dependent on awareness raising actions by EUFAMI and EUFAMI member associations through social media. This is a significant limitation of the analysis as in a survey of this type we are unable to apply probability-based sampling methods, which means that respondents to this survey may not be representative of the target population. Indeed, many carers who are members of family associations may be more informed and have access to more support than carers who are not members of family associations. Our reliance on an online survey also means that carers without these technologies, as well as those who are reluctant to use these technologies will also be missing. This means that the results of this survey must be treated cautiously and should not be interpreted as being representative of all carers.



# 4 Survey results

## 4.1 Response overview

712 individuals gave their consent to take part in the study, with most responses received between 20 June 2019 and 31 March 2020. 12 responses were received in April and May 2020. All were from Canada. We decided to include these even though territories and provinces in Canada began going into COVID-19 lockdown from mid-March. Responses from all other countries except one from France, were received before the end of February, so should not have been affected by the COVID-19 pandemic. 50.1% of questionnaires were fully completed, while 34 questionnaires provided no information other than consent. Survey respondents took a median 14.23 minutes to complete questionnaires.

Figure 4.1 provides an overview of countries of respondents. 272 (38%) came from Denmark, followed by France 144 (21%), Spain 105 (15%), Ireland 53 (7%), Canada 46(7%) and the UK 38 (5%). Only 1% of responses were from Italy (5) and Malta (3). Potentially one reason for the low response rate in Italy may have been because the survey was not translated into German, as EUFAMI associates in Italy are in the German speaking regions of the country. 12 (2%) responses were received from other countries.

Table 4.1 provides detailed information on key characteristics of survey participants, both for the survey as a whole and for illustrative purposes only for specific groups of countries where numbers are high enough for some additional analysis: Spain, France, Denmark and Canada. Although there are substantive differences in welfare system, we considered the UK and Ireland similar enough to group into one cluster. There were insufficient numbers to do individual analysis for Italy, Malta and other countries.

## 4.2 Characteristics of carers

Table 4.1 provides a summary of carer characteristics for the overall survey and in different country settings. Overall, just 17% of carers were men; this rises to 20% when missing responses are excluded. This is very similar to the previous C4C survey where 80% of carers were also female. Only 10% of carers in Denmark are male; in all other countries at least 21% and up to 24% of carers are male.

Overall, the mean age of carers was 53.4 (s.d. 13.8); slightly lower than in the C4C survey where mean age had been 58.1. The mean age of respondents was lowest in Spain at 48.22 and highest in France at 60.9 years of age. Although the survey will have missed carers under the age of 18, only 22 carers (3%) of the study sample were under the age of 25. 460 carers (64%) were aged 25 – 64, with 130 carers (18%) aged 65 and older. 38% of carers in France were over the age of 65 and there were small numbers of carers over the age of 80 in all country groups.

322 (45%) of carers were married or in other co-habiting partnerships, with 105 (15%) being separated/divorced and 101 (14%) stated they were single. The number of married carers ranged from 33% in France to 61% in Canada. Spain had a much higher share of carers who stated that they were single (29%) than in the other countries.

Overall carers were more likely to be living separately from the person that they were supporting – 46% versus 36%, very similar to the C4C survey – but living arrangement patterns varied markedly between countries. 55% of all carers in Spain lived with the person they were supporting compared to just 27% in Denmark. Although our country specific samples are small, this may reflect cultural differences between countries with multi-generations more likely to live together in Spain compared to Denmark, but

Figure 4.1 Country breakdown for survey respondents (n=712)

Countries of informal carers

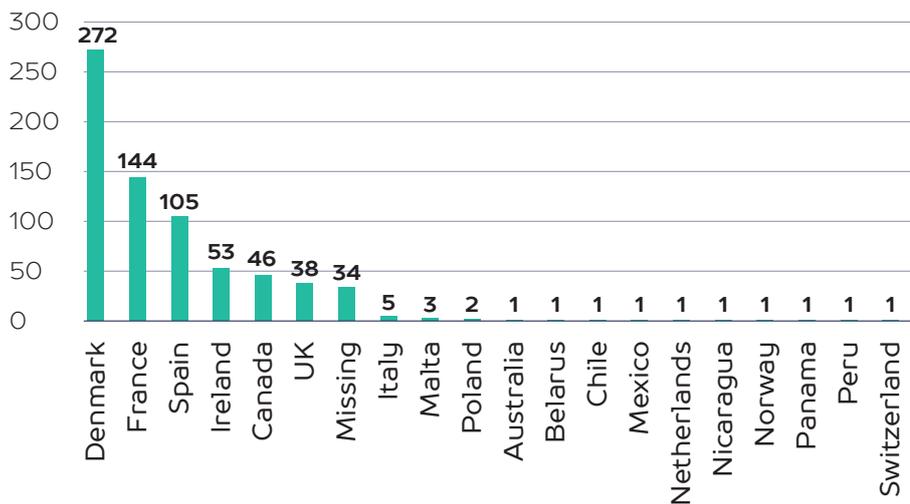
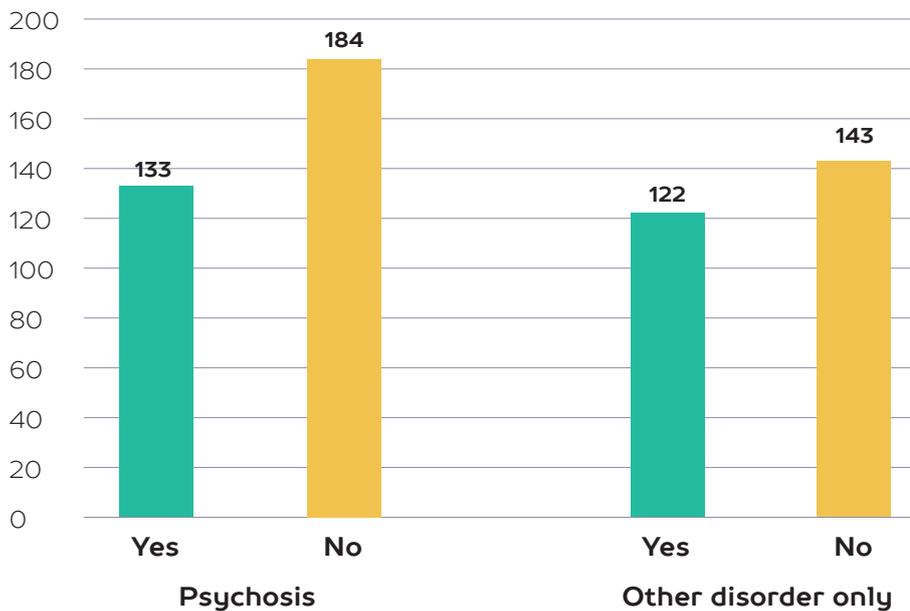


Figure 4.2 Living arrangements of carers of people with or without psychosis

Carer living with person being supported



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it may also be due to the younger overall age of carers in Spain.

We also examined whether there were differences in patterns of living arrangements between people caring for someone with a psychosis versus other caring for someone without psychosis. There were no significant differences and as Figure 4.2 shows, overall the majority of people with mental health difficulties lived independently of the person providing informal care.

Table 4.1B reports on labour force status and length of time spent caring. Overall, 290 (41%) of carers were employed, followed by 177 (25%) who were retired. If we exclude carers who did not respond to the question on labour force status, the number of employed carers rises to 51%, with retired carers accounting for 31% of survey respondents. This is a higher level of employment than seen in the C4C survey and is consistent with the lower mean age of respondents.

Looking at illustrative country data, carers were more likely to be employed, except in France where the majority of carers (57%) said that they were retired. Only 10% of carers were retired in Spain. 14% of carers in Spain said that they were on permanent disability pensions, which was much higher than in all other countries, except Canada (11%).

In our survey we also asked survey respondents to put themselves into one of 11 income groups, ranging from 0 to €100 per week to more than €1,000 per week. Median carer income was between €500 and €600 per week. 31% of respondents had incomes of €200 or less per week, while 16% had incomes of more than €900 per week.

Most respondents in the survey have had caring responsibilities for a very long time, with 449 (63%) saying that they had been caring for more

than three years. This rose to 85% of carers in France. Experienced carers may have different perspectives on caregiving having had time to adapt to their situation. This is something that we explore later in this report.

### 4.3 Relationship between carer and person receiving care

Table 4.2 indicates that over 393 carers (55%) were supporting their child; this is lower than seen in the C4C survey where 76% of carers were supporting a child. 71 respondents (10%) were supporting a parent, with the remainder mainly caring for siblings or other relatives. This difference in profile may be influenced by the reliance on an online survey. Data on caring relationships were also missing from 101 respondents. If these missing cases were excluded, as Figure 4.3 shows, more than 64% of all carers would then be supporting their child.

There are differences in caring relationships between countries. More than 90% of all carers in France were supporting a child compared with just 40% in Spain and 50% in the UK and Ireland. Nearly 20% of carers who reported their relationship to the person they cared for in Spain were supporting a sibling, while this was more than 10% in the UK and Ireland. In both of these countries 10% of carers were supporting a parent.

Figure 4.3 Relationship between carer and person receiving care (n=611)

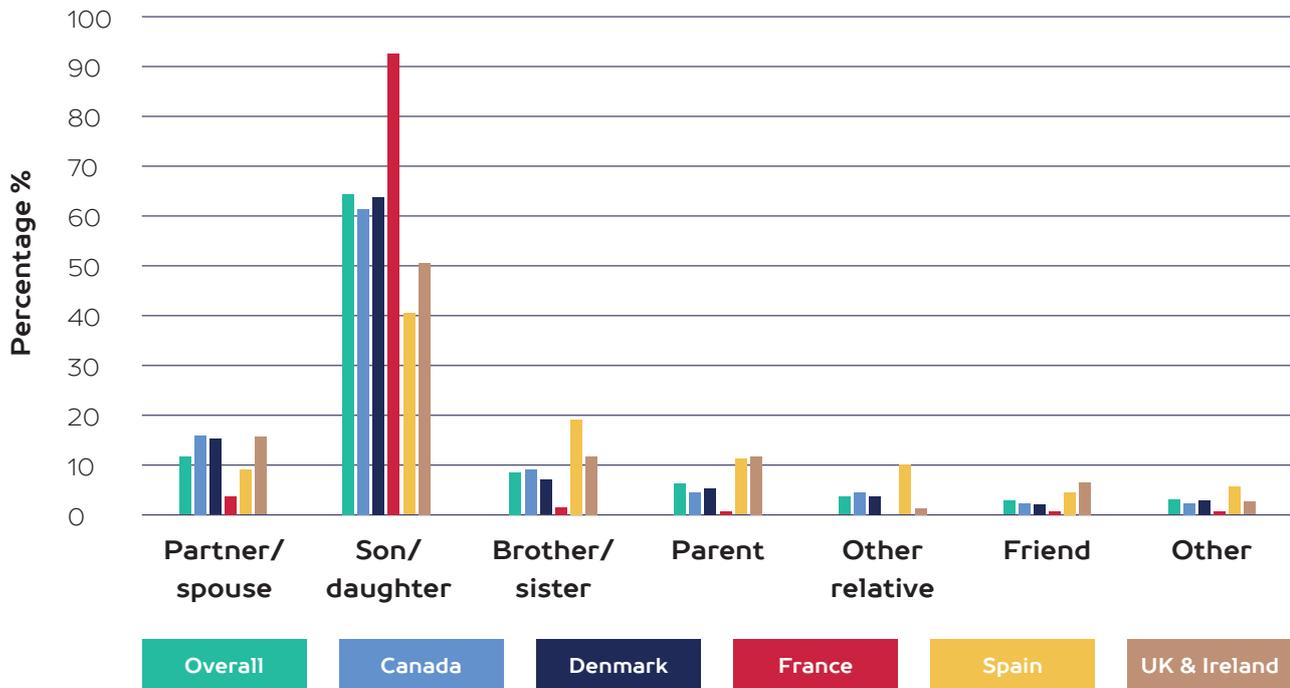


Table 4.2 Relationship between carer and person being cared for (n=712)

Person being cared for	Overall		Canada		Denmark		France		Spain		UK & Ireland	
		%		%		%		%		%		%
Partner / Spouse	71	10%	7	15%	37	14%	5	3%	8	8%	12	13%
Son / Daughter	393	55%	27	59%	155	57%	126	88%	36	34%	39	43%
Brother / Sister	52	7%	4	9%	17	6%	2	1%	17	16%	9	10%
Parent	38	5%	2	4%	13	5%	1	1%	10	10%	9	10%
Other Relative	22	3%	2	4%	9	3%	0	0%	9	9%	1	1%
Friend	17	2%	1	2%	5	2%	1	1%	4	4%	5	5%
Other	18	3%	1	2%	7	3%	1	1%	5	5%	2	2%
Missing	101	14%	2	4%	29	11%	8	6%	16	15%	14	15%

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Table 4.1A Carer characteristics (n=712)

	Overall	%	Canada	%	Denmark	%	France	%	Spain	%	UK & Ireland	%
<b>Gender</b>												
Male	123	17%	11	24%	28	10%	34	24%	22	21%	21	23%
Female	482	68%	32	70%	213	78%	100	69%	69	66%	54	59%
Other	10	1%	1	2%	2	1%	2	1%	2	2%	2	2%
Missing	97	14%	2	4%	29	11%	8	6%	12	11%	14	15%
<b>Age in Years</b>												
Mean (Range)	53.42		55.11		51.35		60.9		48.22		54.96	
Age Range	18 – 86		25 – 83		23 – 86		18 – 85		19 – 86		18 – 85	
18-24	22	3%	0	0%	7	3%	2	1%	8	8%	2	2%
25-64	460	66%	31	68%	204	75%	80	56%	73	70%	55	60%
65+	130	18%	13	28%	30	11%	54	38%	12	11%	19	21%
Missing	100	14%	2	4%	31	11%	8	6%	12	11%	15	17%
<b>Civil status</b>												
Single	101	14%	3	7%	36	13%	8	6%	30	29%	15	16%
Married/Same sex civil partnership/Co-habiting	322	45%	28	61%	158	58%	47	33%	38	36%	43	47%
Separated/Divorced	105	15%	9	20%	37	14%	28	19%	18	17%	12	13%
Other	48	7%	1	2%	7	3%	35	24%	2	2%	1	1%
Widowed/surviving partner from a civil partnership	26	4%	3	7%	2	1%	14	10%	2	2%	3	3%
Prefer not to say	6	1%	0	0%	1	0%	2	1%	2	2%	1	1%
Missing	104	15%	2	4%	31	11%	10	7%	13	12%	16	18%
<b>Living Situation</b>												
Same accommodation	255	36%	20	43%	74	27%	54	38%	58	55%	39	43%
Living separately	327	46%	21	46%	154	57%	79	55%	27	26%	34	37%
Missing	130	18%	5	11%	44	16%	11	8%	20	19%	18	20%

Table 4.1B Carer characteristics (n=712)

	Overall	%	Canada	%	Denmark	%	France	%	Spain	%	UK & Ireland	%
<b>Labour force status</b>												
Retired	177	25%	14	30%	42	15%	82	57%	10	10%	22	24%
Student	21	3%	0	0%	15	6%	0	0%	2	2%	1	1%
Permanent disability	28	4%	5	11%	3	1%	3	2%	15	14%	1	1%
Looking after home	35	5%	4	9%	4	1%	5	3%	8	8%	12	13%
Employed	290	41%	18	39%	158	58%	35	24%	40	38%	34	37%
Looking for work	20	3%	2	4%	6	2%	3	2%	4	4%	2	2%
Missing	141	20%	3	7%	44	16%	16	11%	26	25%	19	21%
<b>Length of time caring</b>												
0-3 months	21	3%	1	2%	12	4%	2	1%	4	4%	0	0%
4-6 months	15	2%	0	0%	7	3%	1	1%	7	7%	3	3%
7-12 months	16	2%	2	4%	8	3%	1	1%	1	1%	1	1%
13-18 months	11	2%	2	4%	3	1%	1	1%	3	3%	2	2%
19-24 months	15	2%	2	4%	5	2%	1	1%	3	3%	4	4%
25-36 months	33	5%	1	2%	15	6%	4	3%	5	5%	0	0%
More than 3 years	449	63%	32	70%	157	58%	123	85%	62	59%	63	69%
Missing	152	21%	6	13%	65	24%	11	8%	20	19%	18	20%

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### 4.4 Role of carers

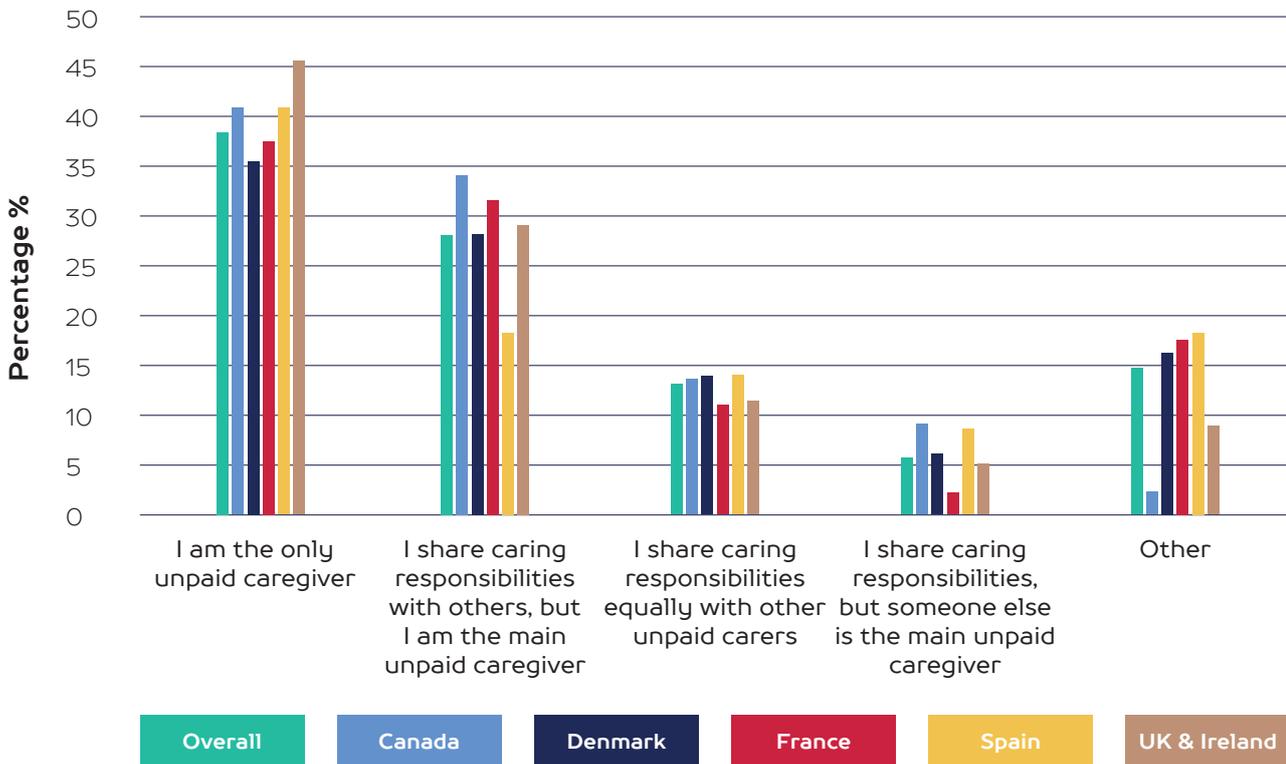
Table 4.3 indicates overall that 238 respondents (33%) were the only informal carer, with 24% sharing care but being the primary carer. Similar results were seen in all countries, Figure 4.4 provides an overview of the caring role for the 619 respondents who provided information on their caring relationship with the person they care for. Of these 38% indicated that they were the only informal carer, with a further 28% being

primary carers, but having support from other carers. This is broadly similar to respondents in the C4C survey where 36% of respondents were sole carers and 35% were the main carer but sharing care with others. The UK and Ireland had the highest number of sole carers (45%). In Denmark, France and Spain 15% of carers did not fall into any of the main caring groups.

Table 4.3 Caring role

Relationship	Overall	%	Canada	%	Denmark	%	France	%	Spain	%	UK & Ireland	%
I am the only unpaid caregiver	238	33%	18	39%	87	32%	51	35%	38	36%	36	40%
I share caring responsibilities with others, but I am the main unpaid caregiver	174	24%	15	33%	69	25%	43	30%	17	16%	23	25%
I share caring responsibilities equally with other unpaid carers	81	11%	6	13%	34	13%	15	10%	13	12%	9	10%
I share caring responsibilities, but someone else is the main unpaid caregiver	35	5%	4	9%	15	6%	3	2%	8	8%	4	4%
Other	91	13%	1	2%	40	15%	24	17%	17	16%	7	8%
No response	93	13%	2	4%	27	10%	8	6%	12	11%	12	13%
Total Responses	712		46		272		144		105		91	

Figure 4.4 Role of carers



### 4.5 Profile of care recipients

Overall, 50% of respondents indicated that the person they were caring for was male compared to 33% caring for women. As Table 4.4 indicates there were differences between countries, a slight majority of care recipients in Denmark were women, while in France 69% of care recipients were men. The mean age of care recipients was 38.48 (s.d. 16.01), with an age range between 18 and 96. Only 51 (7%) of care recipients were aged 65 and older, but all countries had some participants aged 75 or higher.

45% of care recipients had one or more psychotic conditions, but again there is substantial variation in sample characteristics in some countries: 69% and 65% of care recipients in France and Canada

had a diagnosed psychotic disorder compared with 36%, 42% and 41% in Denmark, Spain and the UK and Ireland. As Figure 4.5 indicates, overall 233 (32.7%) of all study participants were supporting someone with at least a diagnosis of schizophrenia, followed by 139 (20%) participants supporting someone with at least a diagnosis of major depression.

We also looked in more detail at the specific mental health issues of care recipients. Respondents could indicate one or more of 15 different potential mental disorders, as well as indicate that there had been no formal diagnosis. Responses were received from 563 respondents (79%). When adjusting our analysis solely to

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include the 563 participants for whom caring data were available, 42% of all care recipients had a diagnosis of schizophrenia, followed by 25% with major depression, 20% with general anxiety disorder, 17% with bipolar disorder and 15% with schizoaffective disorders. 65% of respondents had either schizophrenia, schizoaffective disorders or other psychoses, very similar to the 64% reported in the C4C survey as having with schizophrenia or psychosis.

In all country groups schizophrenia was the most frequent diagnosis recorded with the exception of Denmark where 40% of all care recipients had major depression, compared with 29% with schizophrenia.

We also looked at the number of care recipients who had multiple mental health problems. Overall, almost half of all care recipients were living with at least two conditions, and more than a quarter had more than three conditions. Again, Figure 4.5 indicates some variation across countries, with

60% of care recipients in Denmark having two or more conditions. This is perhaps unsurprising given the high levels of depression and general anxiety disorders among care recipients. Where care recipients did have two or more conditions, we asked survey respondents to indicate what they considered to be the care recipients main mental health problem. As Figure 4.6 shows 27% of respondents felt schizophrenia to be their main mental health issue, followed by 13% who considered major depression to be their main mental health issue.

We also asked survey participants to indicate whether their care recipient had a physical comorbidity; 132 (19%) of the sample indicated that they did, but responses were missing from 436 (61%) participants so it is difficult to draw any conclusions about the prevalence of comorbidity from the survey.



Figure 4.5 Reported mental health problems (%) (multiple responses possible)

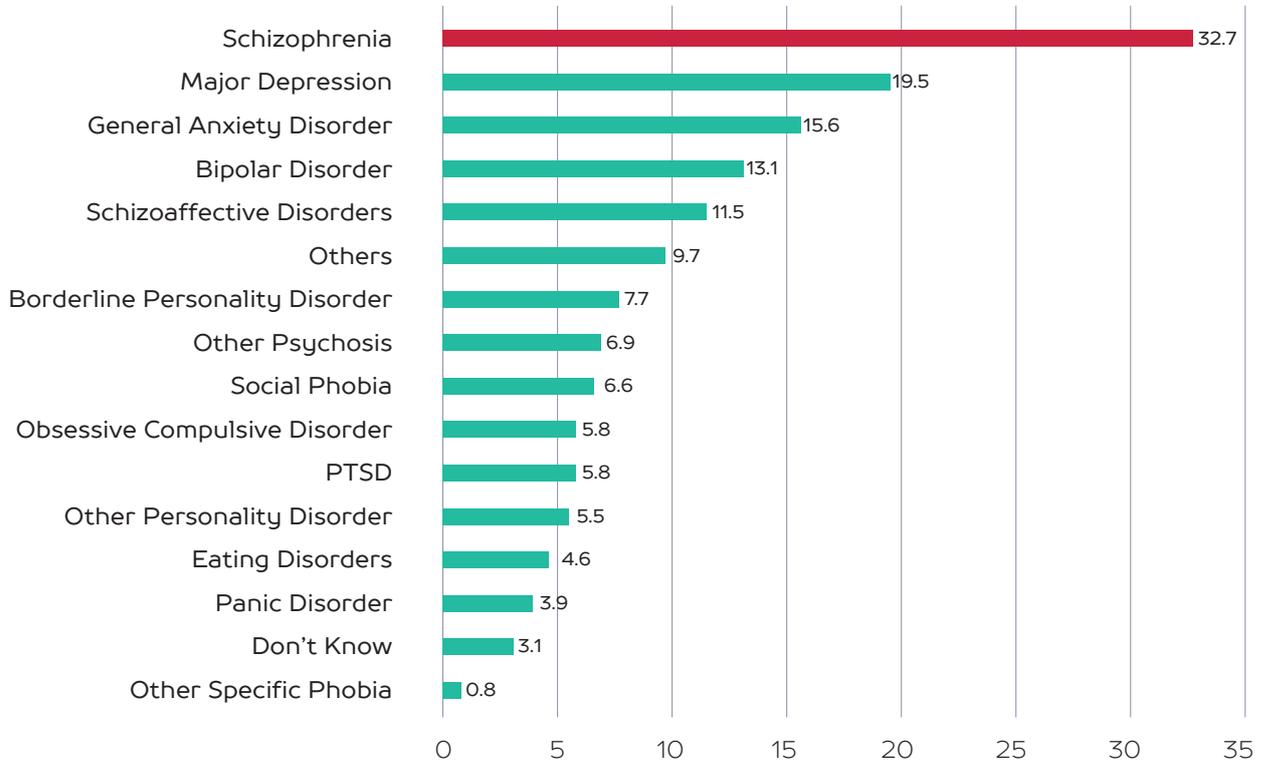
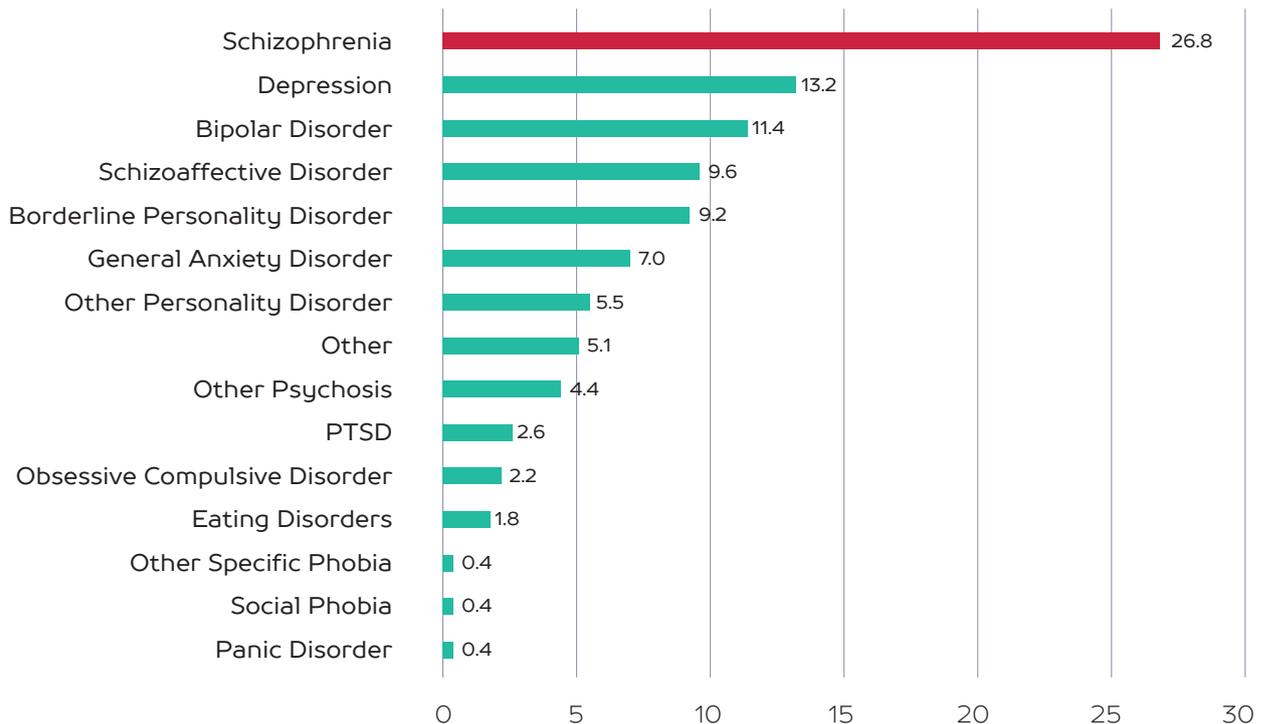


Figure 4.6 Primary mental health problems



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Table 4.4 Profile of care recipients (n=712)

	Overall	%	Canada	%	Denmark	%	France	%	Spain	%	UK & Ireland	%
<b>Gender</b>												
Male	353	50%	26	57%	114	42%	100	69%	58	55%	43	47%
Female	234	33%	16	35%	120	44%	31	22%	27	26%	31	34%
Other	16	2%	2	4%	6	2%	3	2%	3	3%	1	1%
Missing	109	15%	2	4%	32	12%	10	7%	17	16%	16	18%
<b>Age in Years</b>												
Mean	38.49		46.1		34.28		35.92		42.73		48.07	
Age Range	18 – 96		18 – 75		18 – 80		18 – 72		18 – 96		18 – 93	
18–24	120	17%	1	2%	71	26%	15	10%	18	17%	7	8%
25–64	415	58%	35	76%	155	57%	114	79%	52	50%	48	53%
65+	55	8%	5	11%	10	4%	4	3%	15	14%	18	20%
Missing	122	17%	5	11%	36	13%	11	8%	20	19%	18	20%
<b>Psychosis</b>												
Yes	317	45%	30	65%	98	36%	99	69%	44	42%	37	41%
No	395	55%	16	35%	174	64%	45	31%	61	58%	54	59%
<b>Co-morbidity</b>												
Yes	132	19%	0	0%	0	0%	76	53%	22	21%	25	27%
No	144	20%	14	30%	91	33%	4	3%	18	17%	14	15%
Missing	436	61%	46	70%	181	67%	64	44%	65	62%	52	57%

Table 4.5 Mental health profile of care recipients (excluding missing responses n=563)

	Overall	%	Canada	%	Denmark	%	France	%	Spain	%	UK & Ireland	%
Schizo-phrenia	233	41%	22	55%	60	29%	82	62%	36	44%	28	35%
Major Depression	139	25%	8	20%	81	40%	15	11%	14	17%	17	21%
General Anxiety Disorder	111	20%	10	25%	48	23%	19	14%	8	10%	22	28%
Bipolar Disorder	93	17%	3	8%	34	17%	25	19%	14	17%	13	16%
Schizo-affective Disorders	82	15%	10	25%	24	12%	26	20%	11	13%	7	9%
Other	69	12%	6	15%	34	17%	8	6%	10	12%	10	13%
Borderline Personality Disorder	55	10%	3	8%	29	14%	8	6%	11	13%	1	1%
Other Psychosis	49	9%	4	10%	25	12%	6	5%	6	7%	7	9%
Social Phobia	47	8%	3	8%	26	13%	10	8%	2	2%	3	4%
PTSD	41	7%	4	10%	24	12%	2	2%	6	7%	3	4%
Obsessive Compulsive Disorder	41	7%	6	15%	15	7%	7	5%	5	6%	7	9%
Other Personality Disorder	39	7%	0	0%	27	13%	5	4%	4	5%	3	4%
Eating Disorders	33	6%	3	8%	15	7%	5	4%	7	9%	1	1%
Panic Disorder	28	5%	2	5%	17	8%	3	2%	2	2%	3	4%
Don't know	31	6%	2	5%	4	2%	7	5%	2	2%	11	14%
Other Specific Phobia	6	1%	0	0%	2	1%	3	2%	0	0%	1	1%
<b>Total Care Recipients</b>	563		40		205		132		82		80	

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Figure 4.7 Prevalence of multi-mental morbidity

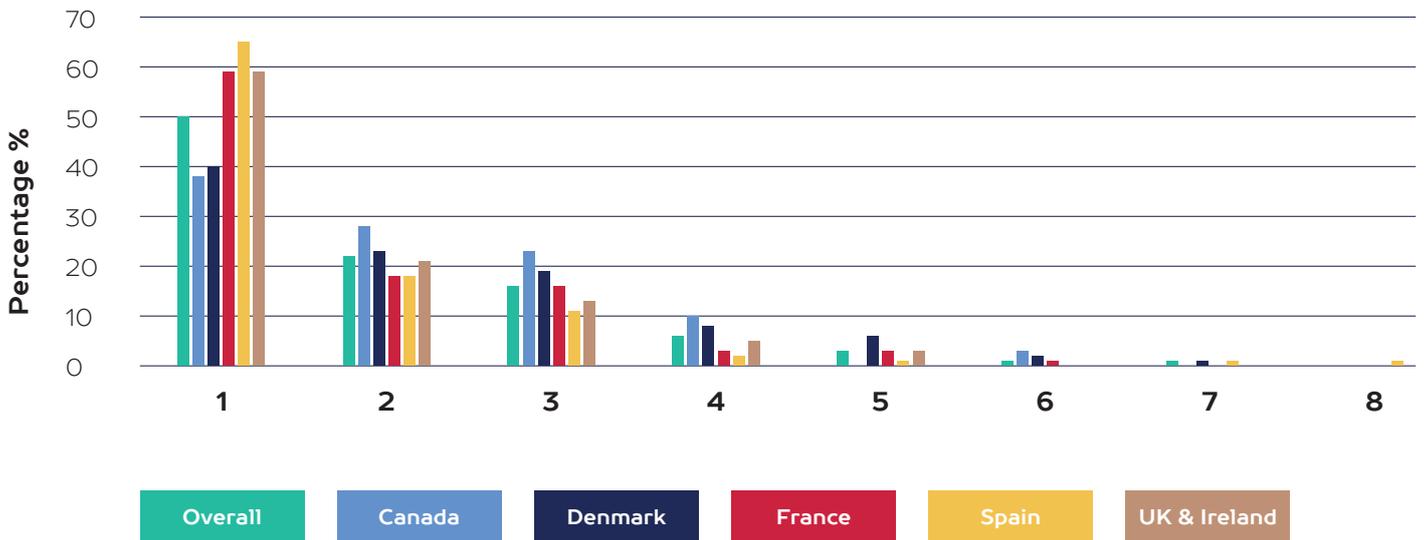


Table 4.6 Prevalence of multi-morbidity in care recipients

Number of conditions	Overall		Canada		Denmark		France		Spain		UK & Ireland	
		%		%		%		%		%		%
1	281	51%	15	38%	83	40%	78	59%	53	65%	47	59%
2	122	22%	11	28%	48	23%	24	18%	15	18%	17	21%
3	89	16%	9	23%	38	19%	21	16%	9	11%	10	13%
4	31	6%	4	10%	17	8%	4	3%	2	2%	4	5%
5	19	3%	0	0%	12	6%	4	3%	1	1%	2	3%
6	8	1%	1	3%	5	2%	1	1%	0	0%	0	0%
7	3	1%	0	0%	2	1%	0	0%	1	1%	0	0%
8	1	0%	0	0%	0	0%	0	0%	1	1%	0	0%

# 5 Time spent caring

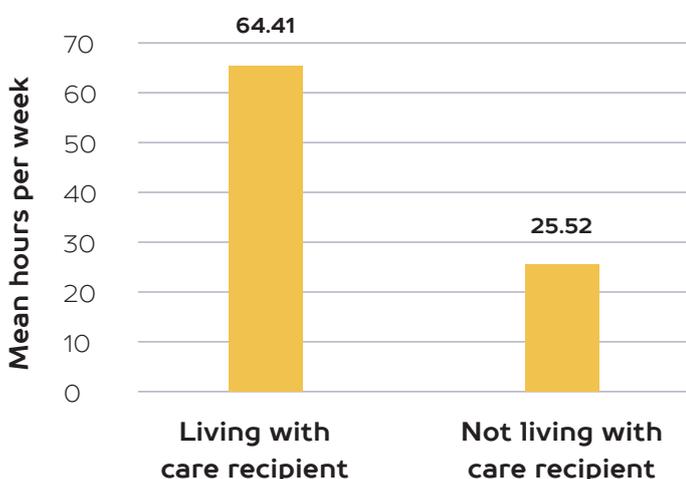
## 5.1 Total time caring

One key way in which the value of caring is measured is to estimate the amount of time spent providing care. In our survey carers were asked to indicate how many hours per week they spent providing care, using a visual analogue scale running from 0 to 168 hours per week. Responses from 563 carers were recorded, providing an average of 43.42 hours (s.d. 45.3) every week. This is a substantial amount of caring time and much higher than that recorded in the previous C4C survey (21.8 hours). The average caring week is longer than a regular working week, but the situation is even more taxing for carers who lived with the person they support. These carers reported a significantly much higher number of mean hours of care per week: 65.41 (s.d. 51.50) versus 25.52 (s.d. 29.83) hours per week ( $p=0.000$ ) (Figure 5.1).

There was no significant difference in hours of care provided by 112 male carers (46.25) versus 436 female carers (42.99) ( $p=0.50$ ), but one way

Figure 5.1 Average hours of care per week and caring living arrangements

Average hours of care per week



analysis of variance indicated that there are some significant differences in hours of care provided depending on the relationship between the carer and the care recipient (Table 5.1). Running post-hoc pairwise comparisons to identify which differences in mean hours were significant we found that carers supporting a partner/spouse provided significantly more mean weekly hours of care (62.33) than carers supporting a son or daughter (40.63) ( $p=0.007$ ). This level of weekly hours of care is similar to that for carers that live with the person they care for, as is the case for most spousal carers. There were no other significant differences between different carer relationships although the higher number of hours for spousal carers was almost significantly greater than for carers of parents or brothers or sisters.

Table 5.2 illustrates that reported mean and median hours of care per week are significantly greater in Spain ( $p=0.000$ ) than in all other countries. This drives up the mean and median hours of care for the overall sample. One possibility is that the 82 responses from Spain may not be representativeness of Spanish carers. However, one earlier study solely looking at caregivers of people with schizophrenia in Spain reported high levels of care in excess of 70 hours per week (8). There may be specific contextual factors that lead to higher caring time. Spain has a higher share of non-spousal carers than in the other countries in this study, and the traditional reliance on families to provide care in Spain may also mean that there is a greater reliance on informal care. Excluding Spain mean hours of care would be 37.40 and median hours of care would fall to 21.

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Table 5.1 Mean hours of care by carer relationship

In a typical week, how many hours in total do you spend providing care? This could range between 0 and 168 hours per week – Total hours of care provided per week

	N	Mean	Std. Deviation	Std. Error	95% Confidence Interval for Mean		Minimum	Maximum
					Lower Bound	Upper Bound		
Partner / Spouse	66	62.33*	46.54	5.73	50.89	73.77	0	168
Son / Daughter	365	40.63*	45.29	2.37	35.97	45.29	0	168
Brother / Sister	45	37.47	39.94	5.95	25.47	49.47	0	168
Parent	33	34.94	35.87	6.24	22.22	47.66	0	168
Other Relative	17	49.29	50.22	12.18	23.47	75.12	0	168
Friend	15	51.87	55.10	14.23	21.35	82.38	3	160
Other	13	51.85	51.49	14.28	20.73	82.96	0	168
Total	554	43.45	45.53	1.93	39.66	47.25	0	168

\* p=0.007 Partner/Spouse vs Son/Daughter Bonferroni post hoc test.

Table 5.2 Mean and median hours of informal care

Average hours by Country	Overall	Canada	Denmark	France	Spain	UK & Ireland
Mean	43.42	36.3	38.4	29.7	79.55*	45
Median	25	20.5	20	20	75	34
Range	0-168	0-168	0-168	0-168	0-168	0-168

\* p=0.000 Spain vs all other country clusters Bonferroni post hoc test.

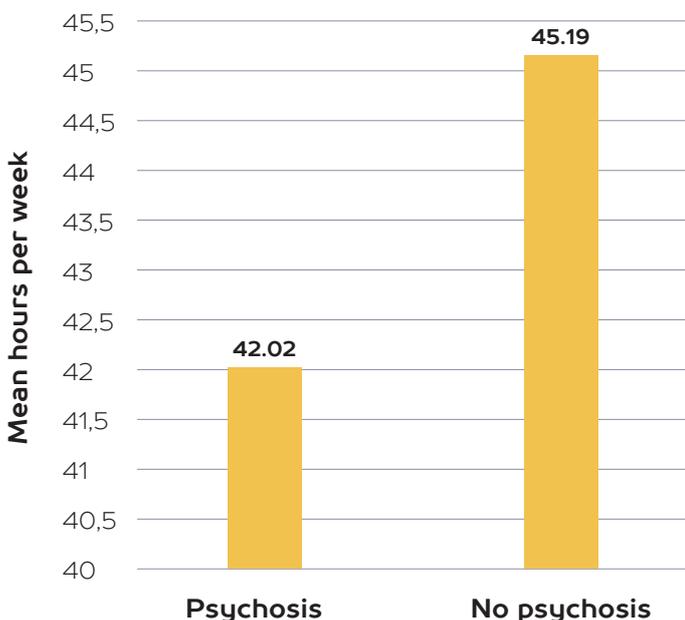
## 5.2 Differences in total time caring by mental health problem

As well as looking at differences in hours spent caring in different country contexts, we can also look at how time spent caring can vary by the type of mental health problems being supported. As we have seen almost half of all carers support people living with multiple mental health conditions, so a simple comparison of hours spent caring by condition is not very revealing. Looking solely at 290 individuals who had just one psychotic condition, the mean number of hours of care received per week was 41.67, compared with 38.57 for the 47 people caring for someone solely with one mood disorder. There are only 11, 13 and 4 people receiving care who only have one anxiety, personality or eating disorder.

We also looked at the differences in mean hours of care per week between people being supported who have at least one psychotic condition, with those that do not have a psychotic condition. As Figure 5.2 indicates while the mean number of hours of care provided to people without a psychotic condition was higher compared to people who had one or more psychotic conditions, 45.19 hours versus 42.05 hours, this difference was not significant ( $p=0.417$ ). The mean weekly number of caring hours was also higher for carers of someone who has experienced periods of agitation in the last 3 months versus those that have not: 43.84 versus 38.09 hours, but this difference was also not significant ( $p=0.265$ ).

Figure 5.2 Average number of hours of care per week for people with a psychotic condition compared to people without a psychotic condition

Average hours of care per week



## 5.3 Breakdown of caring time by caring activity

We also asked carers to indicate how they spent their caring time on different potential caring activities. As Table 5.3 shows, with the exception of help with basic activities of daily living, such as washing and dressing, which was not a common caring task, more than 50% of carers were spending at least 1–5 hours every week on each caring task. Emotional engagement and support to care recipients was the most common activity, provided every week by 96% of carers. More than 81% of carers were also helping to manage behaviour every week and 80% provided regular help in managing the finances of the care recipient.

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Table 5.3 Reported caring time for different caring activities (%)

Reported hours	Supervision	Emotional support/ engagement	Managing behaviour	Other emotional/ support Psychosocial care	Household tasks	Health care co-ordination	Managing finances	Travel	Other practical tasks	Activities of daily living
0	30.57	4.08	18.94	28.53	21.23	29.61	19.44	32.57	30.56	57.82
1-5	40.57	44.57	54.32	46.76	34.92	54.75	64.79	51.71	55.86	24.78
6 -10	7.43	14.95	10.86	12.35	15.36	8.10	8.17	9.14	8.02	9.44
11 - 15	3.71	8.15	3.62	1.76	6.98	1.68	2.54	3.14	0.93	3.24
16 - 20	3.43	7.07	2.51	3.24	7.54	1.40	1.13	0.57	1.54	1.77
21 - 25	1.14	4.08	1.95	2.06	3.91	1.68	0.85	0.29	0.31	0.29
26 - 30	2.00	4.08	0.84	0.29	3.63	0.28	0.28	0.00	0.00	0.29
31 - 40	1.14	1.90	1.11	0.29	1.40	0.00	0.00	0.57	0.00	0.00
41 - 50	1.43	1.90	0.28	0.00	1.12	0.28	0.28	0.00	0.62	0.29
51 - 60	1.43	2.45	0.84	0.29	0.56	0.00	0.00	0.29	0.62	0.29
60 - 80	1.71	0.82	0.84	0.88	0.84	0.56	0.28	0.29	0.00	0.29
80 - 100	0.57	2.17	1.39	0.88	0.56	0.00	0.56	0.29	0.31	0.00
More than 100 hours	4.86	3.80	2.51	2.65	1.96	1.68	1.69	1.14	1.23	1.47
<b>Total Responses</b>	350	368	359	340	358	358	355	350	324	339

# 6 Impacts of caring on the usual activities of carers

## 6.1 Work, education, volunteering and leisure

Our survey indicates that substantial numbers of carers report adverse impacts of caring on their ability to participate in work, education, volunteering and leisure. Table 6.1 indicates that 43% of 485 carers who responded to this question had reduced their hours in work because of their caring responsibilities. On average for carers who had reduced their working time, this was 19.49 hours a week, which is equivalent to more than half of a working week. There was general similarity across countries in hours per week or working time lost, ranging from 17.36 hours in Denmark to 19.21 in Canada, but Spain was distinctive where carers had given up 24.25 working hours per week.

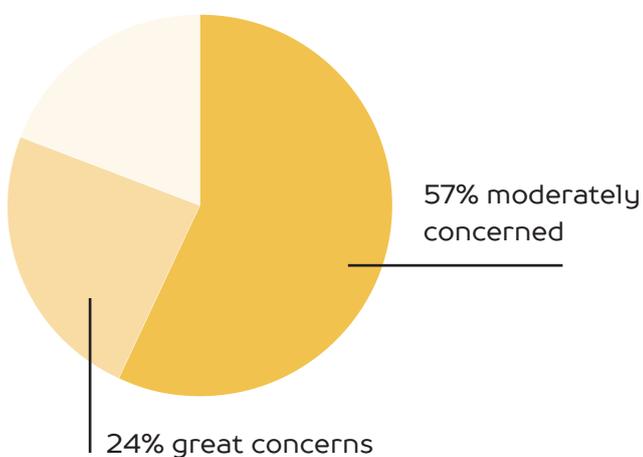
Unsurprisingly very high numbers of respondents had given up leisure time due to their caring responsibilities; overall 82% of respondents gave up an average of 12 hours of leisure a week. In Spain 91% of carers gave up an average of 16.38 hours of leisure per week. A third of carers had reduced their participation in educational activities; a mean reduction of 9.62 hours per week. However there were great differences in participation in education, this only affected 8% of carers in France compared with 51% of carers in Spain and 45% of carers in the UK and Ireland. More than half of all respondents also reported reduced volunteering time, with a mean reduction of 6.15 hours per week. Spanish carers reduced volunteering time the most, by an average of 10.36 hours per week.

## 6.2 Impacts on carer finances

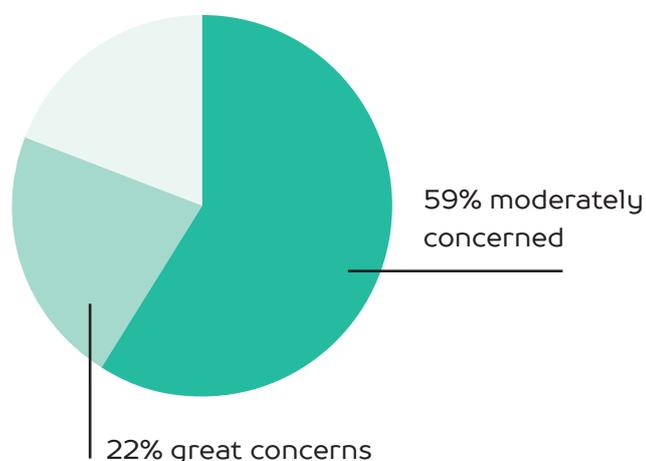
235 carers responded to our survey question on carer finances. 57% were at least moderately concerned with their finances due to caring while 24% had great concerns about their finances. These responses are more negative in our survey than in the previous C4C survey where similar questions were asked, with 48% being at least moderately concerned with their finances. Our figures did not differ significantly across countries, with Spanish carers being most worried, with 36% of carers being greatly concerned about their finances.

59% of all carers were at least moderately concerned with the extra costs of caring, while 22% had great concerns over extra costs. Again this is greater than in the C4C survey where 46% and 14% of carers were at least moderately or had great concerns about the extra costs of care respectively. Carers were also asked whether they had any concerns over unexpected crisis costs of care. More than 31% had great concerns over these crisis costs. Over 80% were at least moderately concerned about the finances of the person that they were caring for; this is much higher than the 66% of carers reported in the C4C survey.

**Concerns about carer finances:**



**Concerns about extra costs:**



**6.3 Carers, work opportunities and retirement security**

While nearly half of all 230 responding carers did not feel that there was any impact, 17% felt that caring had a lot of impact on their careers, including on their opportunities for promotion. One third of carers were concerned about their level of income in retirement due to reduced working opportunities. 36% of carers stated that they had or would have to postpone their retirement because of their caring responsibilities.

**6.4 Caring and family relationships**

29% of carers stated that caring had strengthened their family relationships, while 28% felt that these relationships had been weakened a lot as a result of caring. There were few differences across countries, although fewer carers (22%) in the UK and Ireland felt that there had been positive impacts on their family relationships compared to the study average.

Table 6.1 Impact of caring on participation in work, education, volunteering and leisure

	Overall	%	Canada	%	Denmark	%	France	%	Spain	%	UK & Ireland	%
<b>Reduced work</b>												
Yes	208	43%	20	53%	61	35%	40	34%	38	54%	41	64%
No	277	57%	18	47%	113	65%	78	66%	32	46%	23	36%
Mean hour reduction	19.49		19.21		17.36		17.92		24.25		18.87	
<b>Reduced education</b>												
Yes	157	32%	15	39%	58	33%	10	8%	36	51%	29	45%
No	327	68%	23	61%	116	67%	108	92%	34	49%	35	55%
Mean hour reduction	9.62		6.25		7.41		6.83		17.46		6.34	
<b>Reduced volunteering</b>												
Yes	255	53%	28	74%	99	57%	49	42%	33	47%	35	55%
No	229	47%	10	26%	75	43%	69	58%	37	53%	29	45%
Mean hour reduction	6.15		5.19		5.51		5.62		10.36		5.7	
<b>Reduced leisure</b>												
Yes	395	82%	33	87%	135	78%	96	81%	64	91%	55	86%
No	89	18%	5	13%	39	22%	22	19%	6	9%	9	14%
Mean hour reduction	10.99		9.07		11.75		6.85		16.38		9.93	

# 7 Caring and carer health

In the survey we also wanted to look at the association between caring and carer health. Various studies have reported that carers are themselves at increased risk of poor mental and physical health. As part of the survey participants were asked about their use of selected health services over the previous 3 months. Table 7.1 summarises findings for selected health services. 71% of carers had been in contact with primary care doctors (GPs) in the previous 3 months. Carers who had been in contact with their GP in the previous three months reported a higher number of weekly caring hours (46.5 versus 39.6) but this difference was not significant ( $p=0.166$ ). Across all categories in the table service contacts were greatest in Spain, where 85% of carers had been in contact with a GP and 46% had been in touch with hospital outpatient or accident and emergency services.

In addition, we also asked carers about their own mental and physical health status. 104 carers indicated that they had no health problem and 22 preferred not to disclose this information. A further 280 carers indicated that they had one or more health problems. In the overall study sample, 99 (27%) of all carers reporting their health in the survey reported having depression and/or anxiety disorders. Musculoskeletal health problems were also frequent with 86 (23%) of carers reporting having arthritis and 95 (26%) back pain.

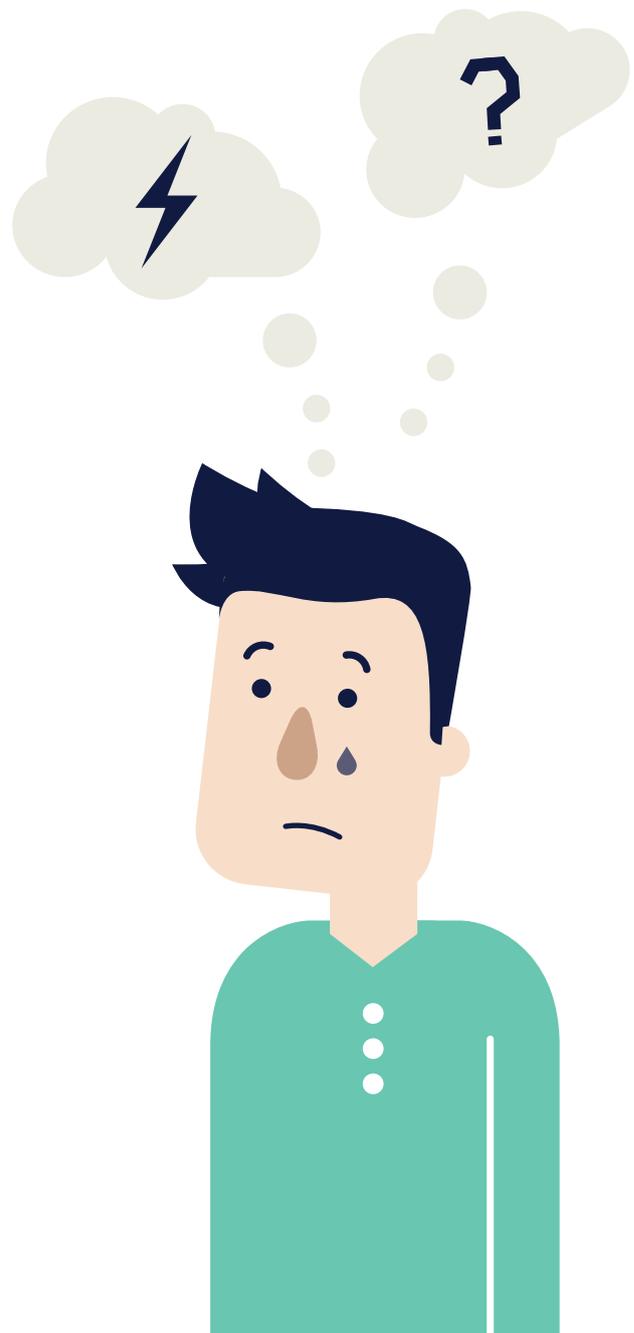


Table 7.1 Reported used of selected health care services by carers in previous 3 months

	Overall	%	Canada	%	Denmark	%	France	%	Spain	%	UK & Ireland	%
<b>GP contact</b>												
Yes	315	71%	27	79%	104	66%	81	75%	50	85%	48	79%
No	126	29%	7	21%	54	34%	27	25%	9	15%	13	21%
<b>Psychologist</b>												
Yes	103	23%	9	26%	51	32%	33	31%	33	56%	7	11%
No	339	77%	25	74%	107	68%	75	69%	27	46%	54	89%
<b>Hospital Outpatient Visit</b>												
Yes	82	19%	5	15%	27	17%	20	19%	27	46%	21	34%
No	358	81%	29	85%	131	83%	88	81%	31	53%	40	66%
<b>Hospital Stays</b>												
Yes	23	5%	0	0%	6	4%	8	7%	8	14%	6	10%
No	418	95%	34	100%	152	96%	100	93%	51	86%	55	90%

# 8 Caring and Loneliness

## 8.1 Reported levels of loneliness

Carers are at risk of losing contact with their social networks if the level of care they provide becomes onerous. They can become socially isolated. They can also become lonely. Loneliness is associated with higher risks of poor physical and mental health and is increasingly examined in studies looking at carer health and wellbeing (9, 10). It is also an issue considered more by policy makers, with strategies to tackle loneliness being developed in several European countries.

As part of our survey we included the 3 item short form UCLA-3 loneliness instrument, which has been used in a number of population surveys in Europe and beyond (7). It contains three questions on how often respondents feel that they lack companionship, are left out and perceive themselves to be isolated. The options for each question are 'hardly ever', 'some of the time' and 'all of the time'. Each of the three questions carries the same weight and UCLA-3 scores range from 3 (the lowest level of loneliness) to 9 (the highest levels of loneliness). There is no specific consensus on score that indicates substantive loneliness, although scores of 6 and above are often thought to indicate substantive loneliness.

Table 8.1 shows the overall mean loneliness score in our survey is 5.88. This compares with scores seen in a general population survey using the UCLA-3 of more than 10,500 adults in Finland, Poland and Spain of 3.51, 3.79, and 3.74 respectively (11). 1,000 bootstraps of a one-sample t-test confirms that this difference in scores is significant ( $p=0.001$ ). Our UCLA-3 scores are also significantly higher than those seen in general adult population over the age of 50 in England, measured in the English Longitudinal Survey of Ageing where the latest mean loneliness score was 4.0 (12). We can also see from Table 8.1 that mean loneliness score are much higher in Spain at 6.64; scores in the UK and Ireland are also above 6.

## 8.2 Factors associated with loneliness

We looked at whether levels of loneliness in carers differ by condition; caring for someone who does not have a psychotic disorder is associated with significantly higher levels of loneliness compared to carers where the care recipient has a psychotic disorder – scores of 6.18 versus 5.67  $p=0.004$ . Figure 8.1 also provides mean loneliness scores for different clusters of disorder. Mean scores are higher for each non-psychotic cluster, but it

Figure 8.1 Loneliness Scores by Disorder

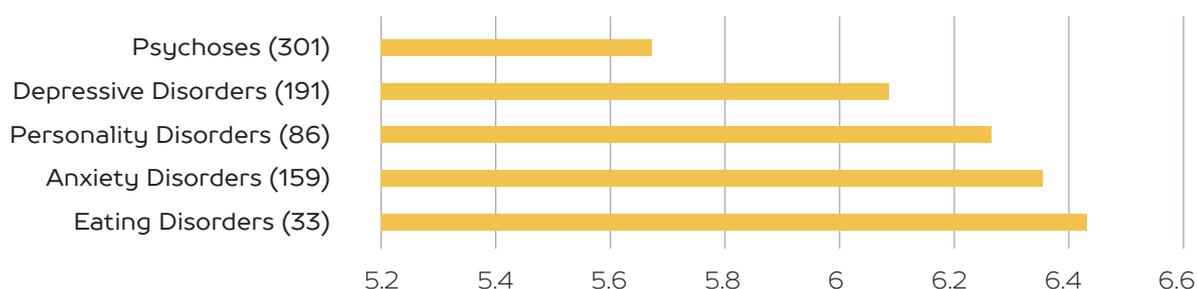


Table 8.1 Summary of overall and country-specific UCLA-3 loneliness impacts

	Overall	%	Canada	%	Denmark	%	France	%	Spain	%	UK & Ireland	%
<b>Lacking Companionship</b>												
Hardly ever	157	30%	13	33%	60	32%	47	38%	9	12%	18	25%
Some of the time	215	41%	18	46%	80	43%	42	34%	30	39%	37	51%
All of the time	148	28%	8	21%	48	26%	35	28%	37	49%	17	24%
<b>Feeling Left Out</b>												
Hardly ever	178	34%	14	36%	78	41%	46	37%	19	25%	11	15%
Some of the time	217	42%	18	46%	72	38%	51	41%	25	33%	44	61%
All of the time	125	24%	7	18%	38	20%	27	22%	32	42%	17	24%
<b>Feeling Isolated</b>												
Hardly ever	158	30%	12	31%	71	38%	34	27%	18	24%	16	22%
Some of the time	202	39%	13	33%	66	35%	45	36%	32	42%	37	51%
All of the time	160	31%	14	36%	51	27%	45	36%	26	34%	19	26%
<b>Mean UCLA 3 Loneliness Score</b>	5.88		5.74		5.62*		5.84*		6.64*		6.11	

\* Spanish UCLA-3 scores are significantly greater than those of France ( $p=0.041$ ) and Denmark ( $p=0.001$ ) Bonferroni post hoc test.

Table 8.2 Loneliness Score and multi-morbidity

Number of morbidities	N	Mean	Std. Deviation	Std. Error	95% Confidence Interval for Mean		Minimum	Maximum
					Lower	Upper		
1.00	261.00	5.62	1.99	0.12	5.38	5.86	3.00	9.00
2.00	118.00	5.99	2.12	0.20	5.60	6.38	3.00	9.00
3.00	82.00	6.10	1.98	0.22	5.66	6.53	3.00	9.00
4.00	31.00	6.45	1.86	0.33	5.77	7.13	3.00	9.00
5.00	16.00	6.25	2.08	0.52	5.14	7.36	3.00	9.00
6.00	8.00	7.50	2.07	0.73	5.77	9.23	3.00	9.00
7.00	3.00	6.00	1.00	0.58	3.52	8.48	5.00	7.00
8.00	1.00	8.00					8.00	8.00
<b>Total</b>	520.00	5.88	2.03	0.09	5.71	6.06	3.00	9.00

should be noted that many of the carers in those clusters are caring for someone with psychosis plus another disorder, which may contribute to the higher loneliness scores seen in Figure 8.1. The reasons why carers supporting people with a psychotic disorder have significantly lower levels of loneliness need further explanation; one possibility is that many carers are supporting someone with longstanding psychosis where there may be fewer acute episodes. However, our survey also indicates no association between

care recipients having to be hospitalised in the previous three months for mental health issues and loneliness.

We also looked at the relationship between multi-morbidity in care recipients and levels of loneliness in Table 8.2. Loneliness scores were lowest when care recipients only had one mental morbidity at 5.62 rising to 5.99 for 2 morbidities and being over 6 for all additional levels of morbidity.

Table 8.3 Factors influencing loneliness scores

Factors	Coef.	Std. Err.	t	P>t	95% CI	
<b>Carer age</b>	-0.011	0.006	-2.050	0.041	-0.022	0.000
<b>Carer gender</b>	-0.086	0.158	-0.550	0.585	-0.396	0.223
<b>Living together</b>	-0.419	0.161	-2.600	0.009	-0.735	-0.103
<b>Happiness</b>	-0.018	0.004	-4.980	0.000	-0.026	-0.011
<b>Carer role</b>	-0.034	0.056	-0.620	0.537	-0.143	0.075
<b>carer_hour</b>	0.009	0.002	5.130	0.000	0.006	0.013
<b>Quality of Life</b>	-0.029	0.004	-6.980	0.000	-0.037	-0.021
<b>_cons</b>	9.638	0.551	17.480	0.000	8.555	10.722

We also ran regression analysis (Table 8.3) that looked further at potential factors that influence loneliness levels in carers. In our initial model we considered carer age and gender, the number of hours caring per week and carer quality of life as potential factors that could impact on loneliness scores. We found that older carers were less affected than younger carers. For every one-year increase in age, loneliness scores decreased by 0.011 ( $p=0.041$ ). Perhaps one reason for this might be that older carers may be more experienced

and have better developed coping strategies, they may also have fewer other caring responsibilities than younger carers. When carers lived with their loved ones, people felt more lonely ( $p=0.009$ ). When caregivers had higher levels of happiness measured using the CQOL happiness instrument, they were less lonely ( $p=0.000$ ). As carers spent more time on caring activities, there was an increase in loneliness levels ( $p=0.000$ ).

# 9 Caring and quality of life

## 9.1 Overall impact on quality of life

As part of our survey information on carer quality of life was collected using the CarerQOL-7D, a validated quality of life instrument developed in the Netherlands that has been tested and validated in a number of European countries (3). The instrument is also available in all languages used in this survey. Table 9.1 shows the 7 domains used in the instrument. A weighting is attached to the different levels of each domain and used to calculate a quality of life score, where 0 represents the worst possible carer quality of life and 100 indicates that caring has no detrimental impacts on carer quality of life.

As Table 9.2 shows, the mean overall quality of life score is 60.29, with the highest mean and median carer quality of life score found in Denmark, (63.09 and 67.9) and the lowest found in Spain (51.15 and 53.00). Quality of life scores in Spain are significantly lower than in Denmark, France and the UK & Ireland. Quality of life scores for carers who live with the person they care for are also significantly lower than for carers who live separately from the person they care for (56.17 versus 63.78  $p=0.000$ ).

Table 9.1 Domains of the CarerQOL-7D

I have	no   some   a lot of	fulfilment from carrying out my care tasks
I have	no   some   a lot of	relational problems with the care receiver (e.g. he/she is very demanding or he/she behaves differently; we have communication problems)
I have	no   some   a lot of	problems with my own mental health (e.g. stress, fear, gloominess, depression, concern about the future)
I have	no   some   a lot of	problems combining my care tasks with my daily activities (e.g. household activities, work, study, family and leisure activities)
I have	no   some   a lot of	financial problems because of my care tasks
I have	no   some   a lot of	support with carrying out my care tasks when I need it (e.g. from family, friends, neighbours, acquaintances)
I have	no   some   a lot of	problems with my own physical health (e.g. more often sick, tiredness, physical stress)

Table 9.2 Mean and median CarerQOL-7D quality of life scores

	Overall	Canada	Denmark*	France*	Spain*	UK & Ireland*
Mean	60.29	57.79	63.09	60.46	51.15	62.01
Median	63.8	61.9	67.9	61.2	53	66.4
Range	0-100	0-100	0-100	0-92.7	0-98.8	0-95.9

\* Mean CareQOL-7D scores in Spain are significantly lower than in France ( $p=0.026$ ), Denmark ( $p=0.000$ ) and the UK/Ireland ( $p=0.015$ ).

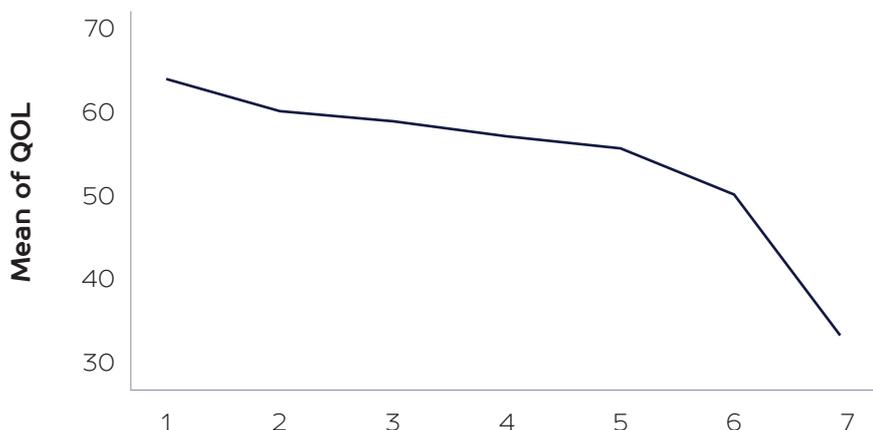
## 9.2 Multi-morbidity and quality of life

We also looked at the relationship between quality of life scores and the number of diagnosed mental disorders of care recipients. We can in Figure 9.1 see that overall, mean quality of life scores decline as the number of conditions increases.

Figure 9.2 highlights mean quality of life score where the care recipient only had one type of mental disorder, e.g. only a mood disorder or only a psychotic disorder. These quality of life scores are generally illustrative only, as with the exception of psychosis, very small numbers of care recipients live with mental disorders in just one

of these clusters. For instance, while the quality of life scores for carers of people with eating disorders are very low indeed at 25, there are only three individuals living with an eating disorder alone. Carers of people living with psychotic disorders alone have higher levels of quality of the life than the overall study average; but this is because the overall study average reflects quality of life scores for a survey population where nearly 50% of respondents are caring for someone with 2 or more conditions.

Figure 9.1 Mean quality of life scores and number of care recipient mental morbidities



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Unlike Figure 9.2, Figure 9.3 reports mean quality of life scores where care recipients are in at least one mental disorder cluster, for instance the mean score of 62.03 for psychosis, includes all 295 care recipients with psychosis, including 125 who are in at least one other mental disorder cluster. This is lower than the quality of life score for carers supporting someone living with just

psychotic disorder alone. Similarly, 140 of the 154 care recipients with an anxiety disorder also have at least one other disorder. This combination of anxiety plus other disorders leads to a much lower quality of life score of 58.35 compared to 68.75 for the very small number of care recipients who only had an anxiety disorder.

Figure 9.2 Quality of life score where care recipients only are in one mental disorder cluster

Carer Quality of Life Score (max 100 & 0 lowest)

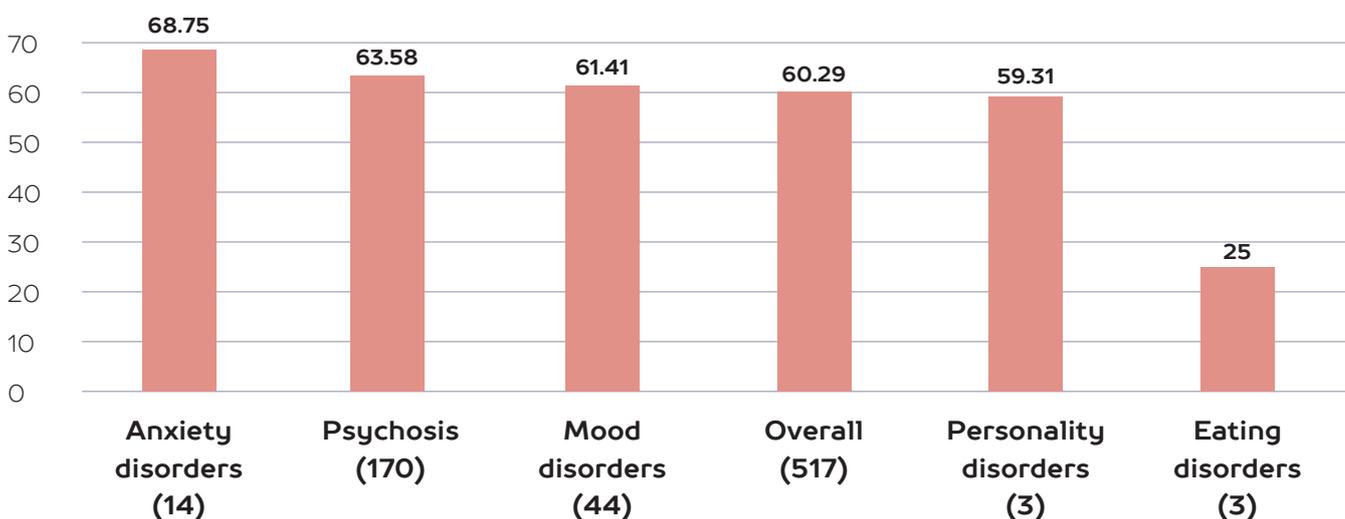
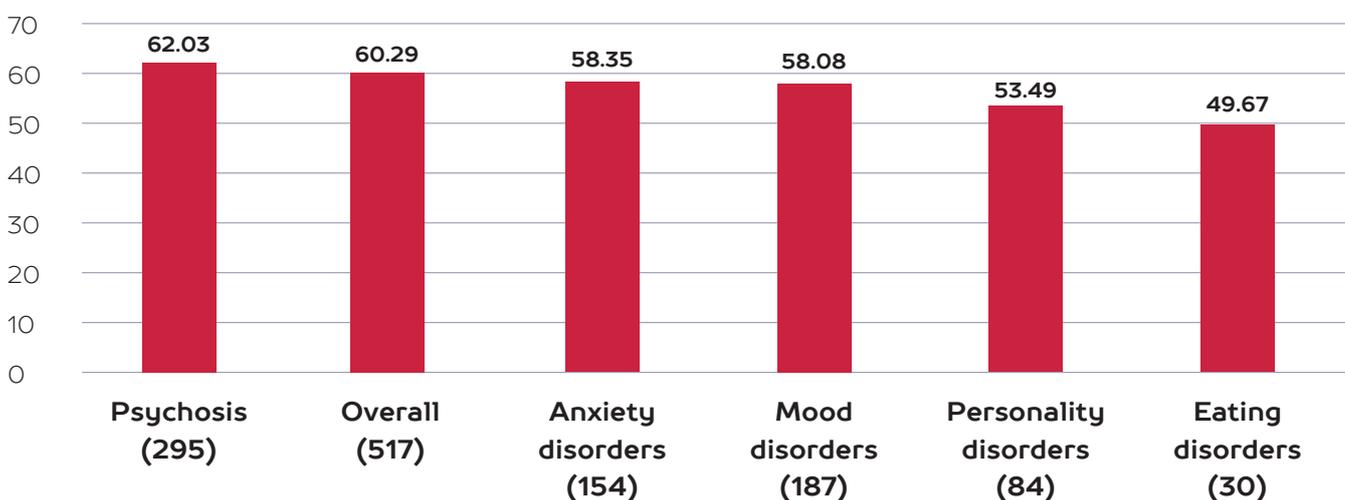


Figure 9.3 Quality of life score where care recipients are in at least one mental disorder cluster

Carer Quality of Life Score (max 100 & 0 lowest)



# 10 Health of care recipient

Another area that we examined is the association between the health of the care recipient and impacts on caregivers. The demands on carers will be dependent on the mental health needs of the person they are supporting. We asked carers to rate the mental health of the person they were supporting on a scale from 0 to 100 where 100 is the best mental health state and 0 is the worst. 352 carers provided responses which are shown in Figure 10.1. There were no significant differences in mental or physical health between country clusters. Physical health scores were consistently higher, but all values are low, indicating poor levels of physical as well as mental health of care recipients.

Our survey included some questions on the use of health services by care recipients. 81 (23%) of 358 responding carers said that the person they care for had been admitted to hospital because of their mental health in the previous 3 months. On average they had 4.5 hospital admissions

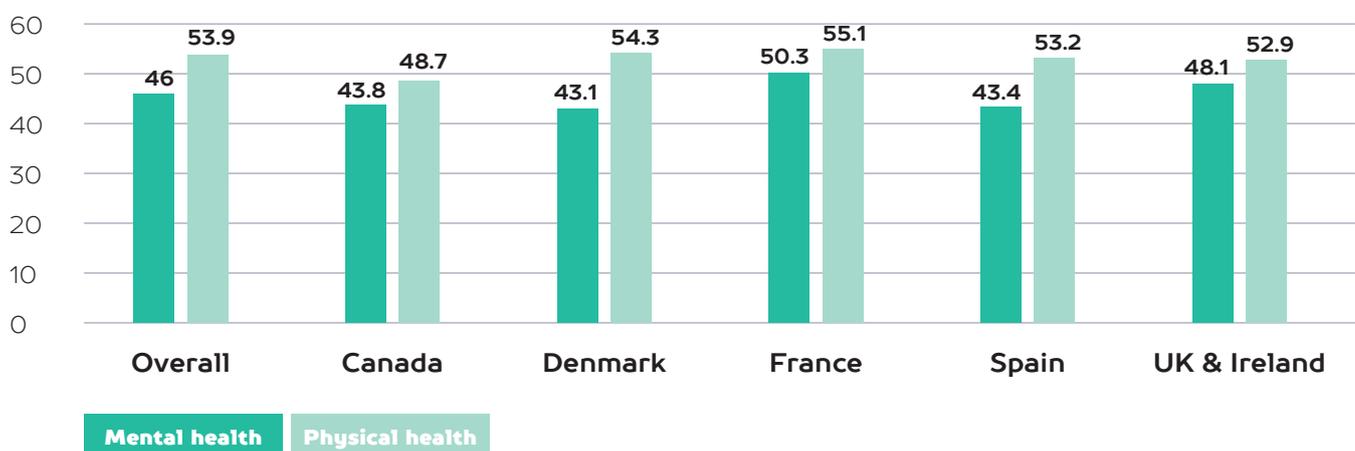
during this period, spending an average of 9 nights in hospital. 68% of all care recipients who were admitted to hospital had psychosis but the number of admissions and nights in hospital did not differ significantly between care recipients with and without psychosis.

258 (86%) of 356 responding carers also indicated that their care recipient had experienced unplanned hospital admissions since they had started providing care support. The most frequent cause of unplanned admissions was stated to be a psychotic episode (26%) followed by suicide or self-harm behaviour (17%) and depression (9%).

273 (77%) of 356 responding carers stated that the person they care for experiences periods of agitation, with 46% saying that this was very frequent, occurring at least once a week. If the care recipient needed urgent / emergency care for agitation, on average this would be for more than 9.5 hours.

Figure 10.1 Perceived mental and physical health of care recipients

Perceived mental and physical health of care recipient



# 11 Estimating the economic value of caring

**This report has highlighted the substantial time and other impacts of informal care. We can see that these impacts are substantial for all carers regardless of the specific health needs of their care recipients. This support from informal carers has tremendous economic value. Without support from informal carers, health and social care systems will have to invest in more formal services to support people with mental health needs. If they fail to do this, they run the risk of poor recovery trajectories and increased likelihood of crisis events occurring, which in turn might lead to extra costs to health, social welfare and other services.**

## 11.1 Value of caring time

There are different ways in which the value of caring can be estimated. One approach we have used in this survey is to ask carers how much they would either be willing to pay for someone else to provide an extra hour of caring tasks or how much money they would be willing to accept to themselves provide an extra hour of caring tasks. This methodology reflects the values placed on care by carers with lived experience of the caring process, rather than simply estimating the replacement costs if informal care were to be replaced by formal care provided at a specific hourly wage rate.

Table 11.1 reports mean willingness to pay and willingness to accept values per hour of informal care provision. Carers would on average have to receive €28.75 to provide one extra hour of care themselves; they would be willing to pay €23.62 for someone else to provide an extra hour of care. Table 11.1 also shows country specific

values of informal care. The highest values are reported in Spain, which again may reflect the higher level of adverse impacts of caring felt by Spanish carers. In Denmark, where the impacts on loneliness and carer quality of life are lowest, the willingness to pay for someone else to provide care, or willingness to accept (be paid) to provide additional care is lower. These values for an hour of informal care can be attached to hours of care provided per week to provide an estimate of the economic value of caring.

## 11.2 Travel time and cost

Another aspect of the value of caring is the travel cost associated with caring, particularly where carers live separately from the person they are caring for. Carers who live separately from the person they care for have much lower mean hours of care per week, although they do have additional travel time costs and expenses. In our survey, on average, carers spent 3.3 hours every week on caring related travel. Our survey also indicates that the mean cost of a return journey for carers to visit the person they support is €12.33, with a mean of 4.08 trips per week. The mean annual value of time spent travelling was €6,053 with mean travel expenses of €1,932. We have added these travel costs, plus the value of travel time to overall time spent caring, adjusted to assume that only those carers that live apart from the person they care for incur these travel costs.

As Figure 11.1 illustrates, the weekly value of caring overall is €1,441 using the willingness to accept approach or €1,164 using the willingness to pay approach. The country specific weekly value of hours of caring depends on both the number of

hours of care provided and carers' own estimate of the value of each hour of care in each country. In our survey the mean weekly value of care, using the willingness to accept approach, ranges from €763 in Canada to €3,471 in Spain. These values are lower across all countries using the willingness to pay approach.

We also estimated the weekly costs of care for carers who live with or separately from the person they care for. Living with the person being cared for leads to significantly increased costs; overall using the willingness to accept approach the mean weekly value of caring would be €2,223 compared with €774 for carers who live separately. These figures using the willingness to pay methodology are €1,758 and €652 respectively.

Figure 11.2 shows the annual value of caring hours, if mean costs per week are extrapolated across an entire year. Overall, the average value of caring hours range between €74,907 or €61,026 depending on whether the willingness to accept or pay methods are used.

The monetary value of hours of caring represents just a part of the true value of care. In addition, there are also adverse impacts on quality of life. These impacts are not easy to value economically;

many carers may even feel that it is inappropriate to try and put a monetary value on them. That said, it is common to place a monetary value on adverse impacts on quality of life. Here we have assumed that impacts on quality of life are constant and for illustrative purposes conservatively value each year of perfect quality of life at €30,000. This annual value is similar to that seen in health economic studies in the UK and Spain (13). In Figure 11.3 if we include these impacts then the total average economic impact of caring increases from €74,907 (using the willingness to accept value of carer hours) to €86,819, with mean annual costs of lost quality of life ranging between €11,074 in Denmark to €14,654 in Spain. This potentially may still be an underestimate of costs; even though we identified high levels of loneliness in carers we are not able to put a monetary value on these outcomes, nor can we assume that quality of life captures the impacts of loneliness, or even capture the stigma that may be associated with caring. We have also not included any costs associated with increased use of health care services by carers; these again may not be captured by changes in quality of life. We also have not attached any monetary value to lost long term career opportunities.

Table 11.1 Value per hour of informal care €'s

	Overall	Canada	Denmark	France	Spain	UK & Ireland
WTP	23.62	22.02	21.91	23.03	28.62	22.09
WTA	28.75	21	27.15	29.87	37.07	25.68

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Figure 11.1 Overall and country estimated weekly value of care per carer

Weekly value of care

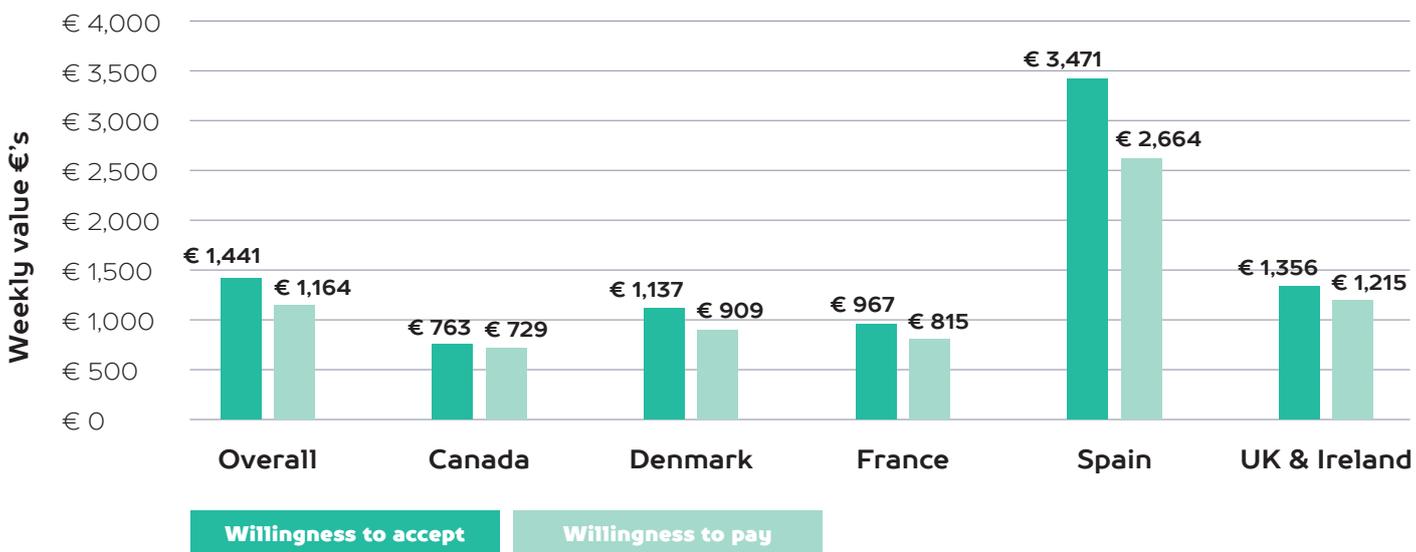


Figure 11.2 Overall and country estimated annual value of care per carer

Annual value of informal caring (€'s)

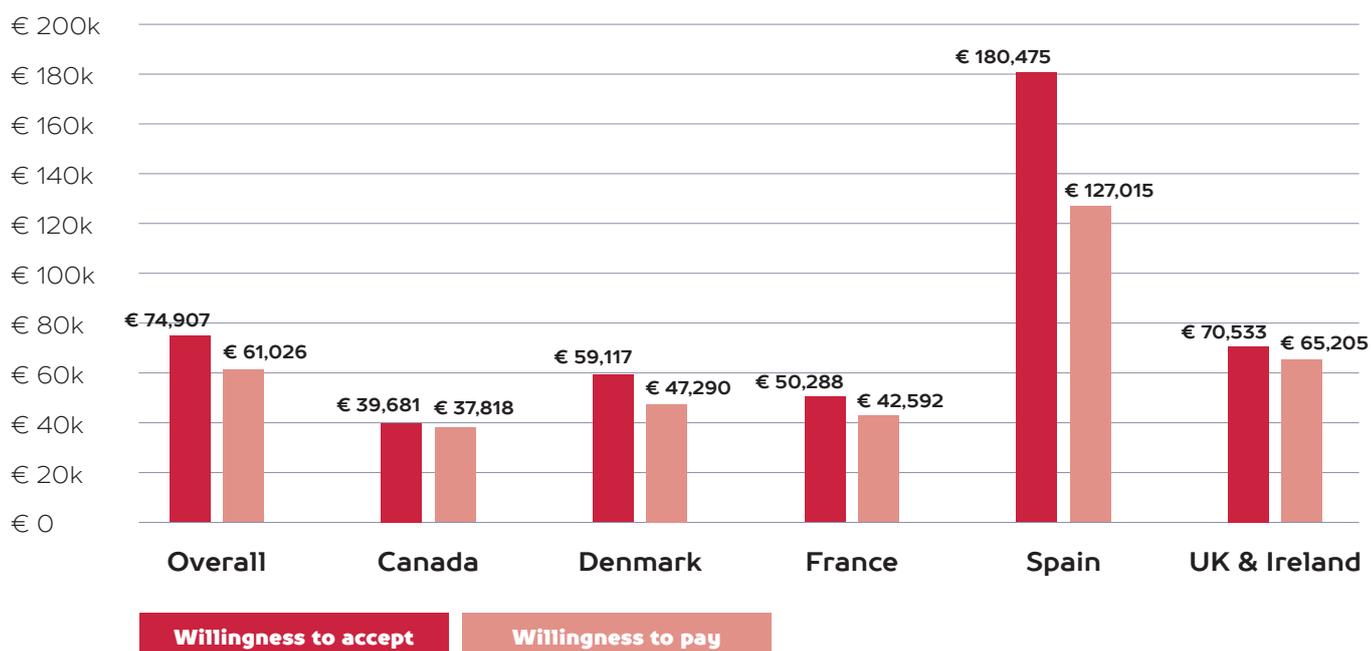
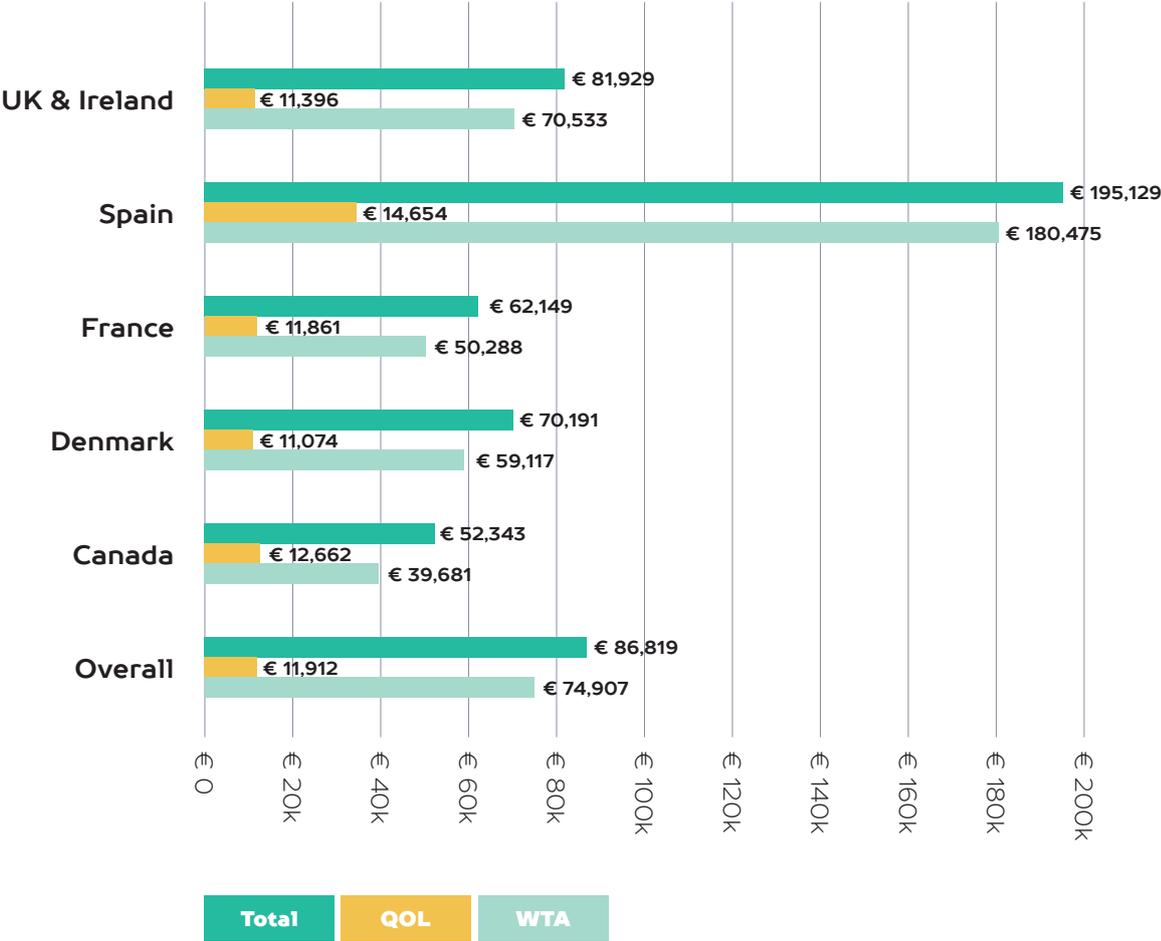


Figure 11.3 Annual value of informal care including quality of life impacts (€'s)



# 12 Carer support and carer needs

## 12.1 Carer identified support needs

Although the main purpose of our report is to estimate the economic value associated with caring, as well as identify other potential impacts, we also asked carers to choose their top three support needs from a list of ten possible options. Overall, Figure 12.1 indicates that 162 carers prioritised more emotional support; 98 prioritised help in responding to challenging behaviours, 97 prioritised respite through help with supervision / monitoring and 92 prioritised access to psychosocial care. Help with practical and financial concerns, as well as transport, were only seen as important by a small minority of participants.

Figure 12.2 shows the mean ranking of each support need where selected by respondents, with 1 being the highest ranked level of priority and 3 being the third highest level of priority. Again, emotional support and access to carer respite are among the most highly valued support needs. Support with health care coordination ranks highly, but as Figure 12.1 shows this was not among the support needs were frequently chosen by survey respondents.

Figure 12.1 Number of top 3 responses for each support need

Priorities ranked by number of top 3 responses

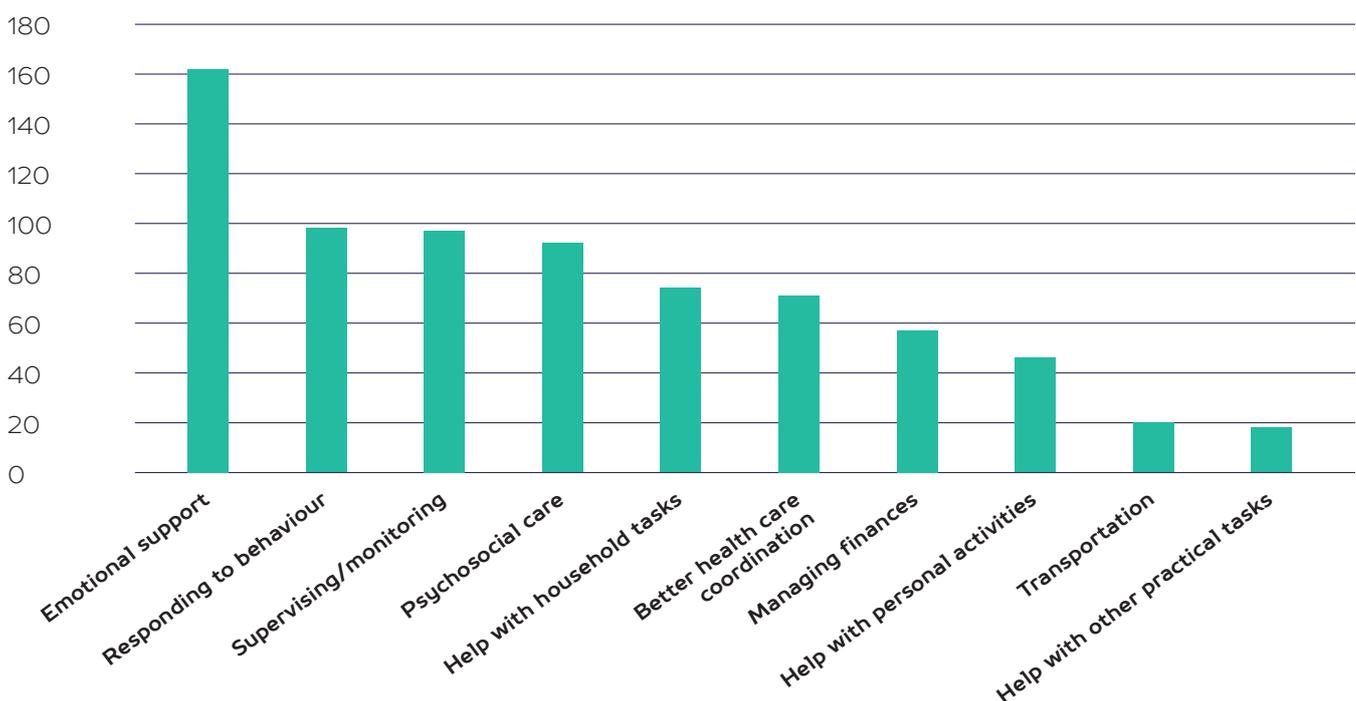
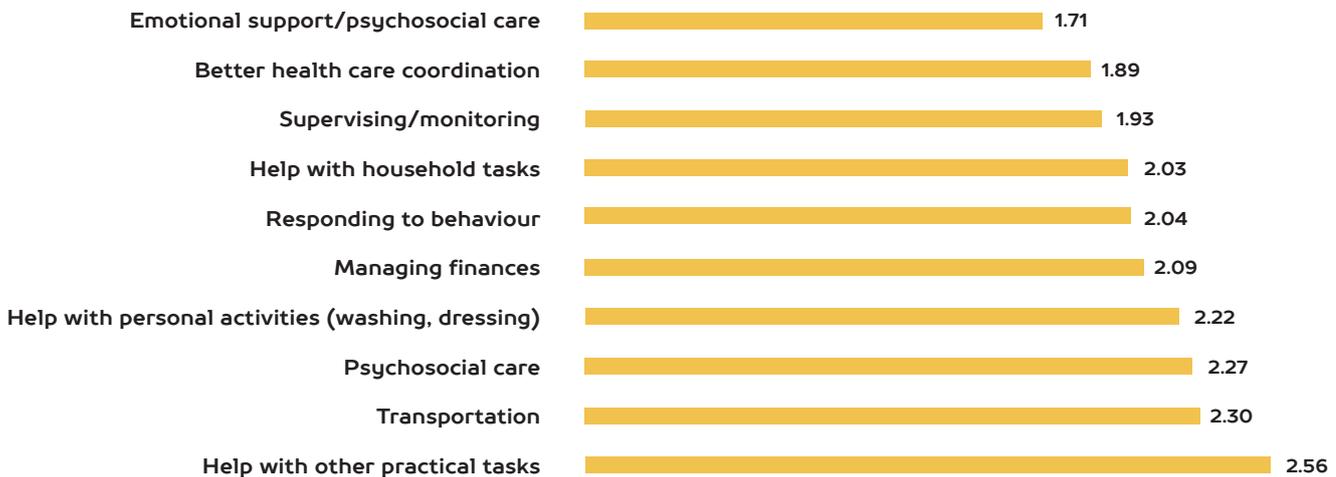


Figure 12.2 Mean ranking of each carer priority selected by survey respondents

Mean ranking of support needs when selected by carers



## 12.2 Carer support services received by carers

We also asked survey respondents in all countries about different types of support that they might receive. Table 12.1 summarises survey findings. In all settings very few carers in our survey were receiving help from paid carers. Overall, only 15% of carers are complemented by paid carers, on average receiving 4 hours of paid care per week. 43% of care recipients attended some regular external activity, on average 2.6 days every week, with each of these activities on average lasting 75 minutes, thus also potentially providing some brief respite for carers. One third of carers also indicate receiving some other form of additional support. Peer support for carers can be vital in protecting mental health and wellbeing; 45% of carers were involved in peer support groups for an average of 2 hours per week. Similar rates of peer group support participation were seen across all country groups.

We asked survey respondents in all countries (except Denmark) about whether they had requested a formal assessment of their care

needs. Carer assessments are an important way to identify needs and also to help prevent crisis events occurring which could lead to the breakdown of caring relationships. Perhaps most critically carer assessment provides an opportunity to determine whether a carer may benefit from access to respite services. Overall, 23% of respondent carers had requested or had such as assessment, including 62% in Spain, 22% in the UK and Ireland, 8% in France and 6% in Canada. Carer assessments may also be a way of identifying welfare benefits that carers may be able to claim. Only 11% of carers (excluding Denmark) said they were claiming welfare benefits.

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Table 12.1 Support services received by carers

Support	Overall	%	Canada	%	Denmark	%	France	%	Spain	%	UK & Ireland	%
<b>Carer Assessment</b>												
Yes	63	23%	2	6%	NA		8	8%	36	62%	13	22%
No	211	77%	31	94%	NA		97	92%	22	38%	47	78%
<b>Carer Welfare Benefits</b>												
Yes	30	11%	3	9%	NA		14	13%	9	16%	4	7%
No	243	89%	30	91%	NA		91	87%	49	84%	56	93%
<b>Paid Carer Support</b>												
Yes	63	15%	4	12%	26	18%	19	18%	7	12%	5	8%
No	359	85%	29	88%	121	82%	86	82%	51	88%	55	92%
<b>Recipient external activity</b>												
Yes	182	43%	8	24%	76	51%	45	43%	22	38%	24	39%
No	242	57%	25	76%	73	49%	59	57%	36	62%	37	61%
<b>Carer Peer Support group</b>												
Yes	190	45%	12	36%	78	53%	50	48%	22	39%	24	40%
No	231	55%	21	64%	69	47%	55	52%	35	61%	36	60%
<b>Carer Other Support</b>												
Yes	141	33%	8	24%	71	47%	33	32%	7	12%	17	29%
No	280	67%	25	76%	79	53%	70	68%	51	88%	42	71%

# 13 What does the literature tell us about the value of informal care?

A systematic mapping review was also undertaken to map what is known about the value and impacts of providing informal care to people living with poor mental health. The primary focus was on identifying estimates of the monetary value of informal care, predominantly in terms of how time spent caring is valued. Again we also searched for additional impacts on carers, not only lost opportunities to participate in paid work, but also lost career opportunities, impacts on their own physical and mental health, other adverse impacts on quality of life, loneliness and social exclusion, as well as the the additional out of pocket costs associated with caring.

Our primary review question was to determine what is known about the economic value of informal care. Our secondary questions were:

- a. To look at how the value of informal care differs by population group, e.g. different diagnoses of people being cared for, gender, age group and country.
- b. To assess the extent to which impacts beyond the value of time spent caring are included in economic analyses.
- c. To assess trends in valuation of informal care studies.
- d. To look at developments in measures of the value of informal care.

## **Inclusion criteria**

Studies looking at any aspect of the costs/value of informal care. Our review here was restricted to studies from any high-income country; we included all countries classified by the World Bank as high-income countries, as well as all current member countries of the OECD.

## **Search methods for identification of studies**

Searches were conducted in the following databases: PubMed/MEDLINE, EMBASE, PsycINFO and CINAHL. This was supplemented by a limited search of Google Scholar. We also examined citations of relevant papers (forward and backward citations). There were no language restrictions and no date restrictions were applied to searches. The searches were last updated and run in May 2020.

## **Appraisal and data extraction**

All records identified were initially imported into Endnote X9 and then transferred to Covidence a software platform used in conducting systematic reviews. Title and abstracts of records were double screened; disagreements were resolved through discussion. We then aimed to obtain the full texts of all articles that were included after initial screening; these again were double screened. All records that met inclusion criteria were then coded in a number of different ways

and a systematic map of trends in costing studies over time produced. The quality of costing methods used has been assessed using the costing elements has also been assessed using the Consensus on Health Economic Criteria checklist (14).

### Summary of Results

Our detailed review results are being submitted for publication separately, but some messages from key studies are noted here. In short there are few published estimates of the cost of informal care, mainly focused on schizophrenia, although there is an extensive literature on other aspects of caregiver burden. One study in Spain highlighted that informal care accounted for 47% of all costs of care for schizophrenia(15), with a similar finding in a small study in Germany (16). A more recent study in Italy modelled the annual costs of schizophrenia; unfortunately it only included mean costs of days out of normal role so annual mean costs were only estimated to be €148 per carer (17).

There is also considerable variation in estimates of hours spent on care. This may be due to differences in methods used; most of the studies we have identified have focused on carers of people with schizophrenia. Recent analysis in Australia looking at time spent caring by family carers for a range of mental health problems had similar findings to this study; they estimate that primary carers provide on average about 36 hours of care per week, with 38% caring for 40 or more hours per week (18, 19). In the Basque country a survey of more than 200 carers supporting

people with eating disorders, depression and schizophrenia respectively, reported that 44%, 68% and 33% of carers were in contact with the person they support for more than 35 hours per week (20). Caregivers of people with schizophrenia in seven countries (Australia, Czech Republic, France, Italy, Russian Federation, Spain and Turkey) were asked about caring hours; in Italy the median number of hours of care per week was 53 compared to 19 in Spain (21).

There are also examples of studies that report on aspects of the costs of caring, but do not report the overall costs of care. Analysis of the experience of caring for someone with schizophrenia and caring for other (physical health) client groups has previously been compared across five countries. It found that family caregivers for people with schizophrenia were more likely to take time off work and had significantly greater contact with primary and secondary services than other carers. However, this study did not compare schizophrenia caring with caring for people with other mental health problems (22). A similar study in Sweden also reported that parental carers of people with schizophrenia were much more likely to need specialist care for their own mental health, and more likely to lose employment, compared to parental carers of people with rheumatoid arthritis, multiple sclerosis and epilepsy (23). In summary, however, the existing evidence base is limited, using very different methodologies, making comparisons difficult.

# 14 Discussion

**Our survey of more than 700 caregivers across Europe and Canada highlights the tremendous and too often hidden value of caregiving. Potentially without the input of these (mainly close family) carers undoubtedly some of this support would need to be provided instead by health and social care systems. In short, informal carers are fundamental to the functioning of any health and social care systems; it is critical therefore to invest in measures to support these caregivers and identify potential risk factors that might lead to a breakdown in caregiving support.**

There are important health, wellbeing and economic gains to be made from providing more support to carers, and in particular providing support for carers who live with the person they care for, as well as those carers supporting people with more complex multiple mental health problems. Highlighting the economic value of informal care and some of the potential costs that would have to be borne by governments if informal care was not provided may help strengthen the case for action to support these carers.

As part of our study we also undertook a review of the literature, finding relatively few studies looking at carers of serious and common mental disorders, compared to studies focused on dementia caregivers. Despite the importance of caring for carers and understanding the value of caring, more can be done to highlight this issue for policy makers. In the case of dementia raising awareness of the value of caring has been very important; the increased focus on this topic over the last

two decades has directly led to the development of supportive policies for carers in many European countries.

In our report we have highlighted that the average caring week is much longer than the working week, and that this is over 60 hours per week for carers who live with the person that the care for. We have highlighted major detrimental effects on carer quality of life, as well as high levels of loneliness. We have also noted that more than a quarter of all carers have a depression or anxiety disorder. We have seen wider adverse impacts on potential career and education prospects as well as financial worries.

Our report provides therefore some ammunition to help facilitate policy and practice change, although there are important limitations in our methodology so these findings must be treated cautiously. This is a cross-sectional survey, meaning that we have only collected responses



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from caregivers at one point in time. Longitudinal studies that follow up the same carers over time are needed to understand how caring experiences change, and also how any potential interventions may reduce any of the challenges associated with caregiving. The scale of surveys also needs to increase, with approaches used to obtain a fully representative sample of the caregiver population. This is not something that was possible with our study design. Larger surveys (or replication surveys within countries) would also allow more definitive statements to be made about caring experiences at individual country level.

Despite these limitations, we believe that this report can act as a catalyst for action. This is even more important now than when this study was commissioned. The reliance on family carers will probably have increased, while challenges faced by caregivers and the risks of isolation may well be heightened during the ongoing COVID-19 pandemic.

### **Key findings arising from this report**

In the earlier Summary section of this report – Section 1.1 Key Findings, we have set out our key findings.

### **Recommendations arising from this report**

We have drafted recommendations arising from the report and they are set out in the summary part of this report in Section 1.2 – Recommendations.

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# 16 Appendix

## EUFAMI CARING SURVEY – UK VERSION

### INFORMATION SHEET

We are inviting you to participate in this online survey of your experiences of caring for a person with poor mental health. The survey has been commissioned and is being conducted by EUFAMI, the European Federation of Associations of Families of People with Mental Illness, Leuven, Belgium. The London School of Economics and Political Science, in London, UK are working with EUFAMI to analyse and summarise the findings.

The results will be used to help estimate all of the value to society of informal caring for people with mental health needs to inform national and local policymaking, strengthen public awareness of the contribution of informal carers and advocate for greater recognition of mental health carers and their support needs.

All information you provide will be treated in a confidential manner and will be kept securely by EUFAMI for up to 10 years. You do not have to finish the survey in one go; your responses are automatically saved and you can come back to complete within a week. You can also go back and change any of your answers at any time until you submit the questionnaire, but once this is submitted it will no longer be possible to change your responses.

More information on this survey as well as an option to print and post the survey instead are available on the EUFAMI website <http://eufami.org/economic-case-survey/> . If you have any questions or concerns please feel free to contact Margaret Walker, Executive Director at EUFAMI. Email: [executive.director@eufami.org](mailto:executive.director@eufami.org) Telephone: + 32 468 17 71 48

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To be eligible to participate in the survey you should:

- 1. Be 18 years or older;**
- 2. Care for someone aged 18 years or older with at least one severe mental health condition** (other than dementia and learning difficulties). You do not have to be their main carer or live at the same address.
- 3. Not be employed to provide your caring role** (i.e. formally paid a wage for caring). You can still participate in the study if you receive a government benefit such as the Carer's Allowance.

This study has received ethical clearance from the London School of Economics and Political Science. There are no specific risks to your health and wellbeing associated with participation in this survey. You can change your responses until you have clicked the "Submit" button at the end of the survey. Once submitted your responses cannot be changed.

### STATEMENT OF INFORMED CONSENT

If you select "**I AGREE**" this means that you have read this information sheet, understand the purpose and nature of the survey and are participating voluntarily. If you do not wish to participate in the research study, please decline participation by selecting "**I DISAGREE**".

- I AGREE (1)
- I DISAGREE (2)

*Skip To: End of Survey If To be eligible to participate in the survey you should: 1) Be 18 years or older; 2) Care for som... = I DISAGREE*

**In which country do you currently reside?**

▾ England (1) ... Zimbabwe (199)

**Which of the following best describes your role as a carer? (Here we are referring to unpaid informal care only)**

- I am the only unpaid caregiver (1)
- I share caring responsibilities with others, but I am the main unpaid caregiver (2)
- I share caring responsibilities equally with other unpaid carers (3)
- I share caring responsibilities, but someone else is the main unpaid caregiver (4)
- Other (5)

**The person I care for is my**

▾ Partner / Spouse (1) ... Other (7)

**What is your gender?**

- Male (1)
- Female (2)
- Other (4)

**What is your age?**

Age in Years (1)

▾ 10 (1) ... 109 (100)

**What is your marital status**

▾ Single (1) ... Prefer not to say (7)

**Which of these categories best describes your current status?**

▾ Employed (6) ... None of the above (5)

**The person I care for is**

- Male (1)
- Female (2)
- Other (8)

**How old is the person you care for?**

Age in years (4)

▾ 18 (1) ... 109 (92)

**Does the person you care for live with you?**

- Yes (1)
- No (2)

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### How long have you been caring because of his/her mental health needs?

▾ 0 – 3 months (1) ... More than 3 years (9)

### Has the person you care for been diagnosed with one or more of the following mental health conditions? Select ALL that apply.

- Schizophrenia (1)
- Schizoaffective Disorder (2)
- Other Psychosis (3)
- Bipolar Disorder (Manic Depression) (4)
- Depression Major Depressive Disorder) (5)
- General Anxiety Disorder (6)
- Panic Disorder (with or without agrophobia) (7)
- OCD (Obsessive Compulsive Disorder) (8)
- PTSD (Post Traumatic Stress Disorder) (9)
- Social Phobia (10)
- Other Specific Phobia (11)
- Borderline Personality Disorder (BPD) (12)
- Other Personality Disorder (13)
- Anorexia or Bulimia (Eating Disorder) (14)
- Other (15)
- Dont know / Not had a diagnosis (16)

### What do you consider to be his/her main mental health condition?

▾ Schizophrenia (1) ... Other (15)

### In a typical week, how many hours in total do you spend providing care? This could range between 0 and 168 hours per week

	0	17	34	50	67	84	101	118	134	151	168
Total hours of care provided per week ()											

### We would like to know more about the impacts of caring on your social situation. Please select the choices that best reflect your situation

	Hardly ever (1)	Some of the time (2)	Often (3)
How often do you feel that you lack companionship? (1)			
How often do you feel left out? (2)			
How often do you feel isolated from others? (3)			



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**Imagine that the person you are caring for needs one extra hour of informal care per week and that the government will pay you for providing this extra hour of informal care. Which net amount from the government would you minimally want to receive in order to provide one extra hour of care?**

Net amount you would need to receive to provide an extra hour of care (1):

• Less than 5 pounds (1) ... More than 50 pounds (11)

**Imagine that you get the opportunity to give up one hour of informal care per week. Somebody else has offered to provide this hour of informal care instead, so the total number of hours of care will not change. How much would you personally be willing to pay to them so that you can provide one less hour of care per week?**

Amount you would be willing to pay for someone else to provide care (1) :

• Less than 5 pounds (1) ... More than 50 pounds (11)

**We would like to know about the impacts of caring on employment, education, volunteering and leisure time. Please select the options that best reflect your situation.**

	Yes (1)	No (2)
I have reduced time spent working (1)		
I have reduced time volunteering (2)		
I have reduced time in education (4)		
I have reduced my leisure time (5)		

**How many hours of work per week did you give up?**

Number of hours per week (7)

• 1 (1) ... 36+ (36)

**How many hours of volunteering per week did you give up?**

Number of hours per week (4)

• 1 (1) ... 36+ (36)

**How many hours of education per week did you give up?**

Number of hours per week (4)

• 1 (1) ... 36+ (36)

**How many hours of leisure time per week did you give up?**

Number of hours per week (4)

• 1 (1) ... 36+ (36)

**Suppose you did not have to provide informal care anymore. How would you spend this time?**

	Yes (1)	No (2)
More work (1)		
More volunteering (6)		
More education (7)		
More leisure (8)		

**How many extra hours of work per week would you like to do?**

Number of hours per week (4)

• 1 (1) ... 36+ (36)

**How many extra hours of volunteering per week would you like to do?**

Number of hours per week (4)

• 1 (1) ... 36+ (36)

**How many extra hours of education per week would you like to do?**

Number of hours per week (4)

• 1 (1) ... 36+ (36)

**How many extra hours of leisure per week would you like to have?**

Number of hours per week (9)

• 1 (1) ... 36+ (36)

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**Please indicate if you have been in contact with any of the following services because of your health in the last 3 months**

	Yes (1)	No (2)
GP (1)		
GP Practice Nurse (2)		
Psychologist (3)		
Physiotherapist (4)		
Occupational Therapist (5)		
Social Worker (6)		
Community Mental Health Team (7)		
Complementary / Alternative Medicine (e.g. Acupuncture, Mindfulness, Yoga etc) (8)		
Other therapist (9)		
Visits to hospital not involving an overnight stay (11)		
Visits to hospital involving an overnight stay (12)		

**Please indicate the number of visits to your GP in the last 3 months**

Number of visits (1)

• 0 (1) ... 36+ (37)

**Please indicate the average length of GP visit**

Average length of visit (minutes) (1)

• 15 (1) ... 300+ (12)

**Please indicate the number of contacts with GP Practice Nurses in the last 3 months**

Number of contacts with GP nurses (1)

• 0 (1) ... 36+ (37)

**Please indicate the average length of contacts with GP Nurses in the last 3 months**

Average length of contact with GP Nurses (minutes) (4)

• 15 (1) ... 300+ (12)

**Please indicate the number of contacts with psychologists in the last 3 months**

Number of contacts with psychologists (1)

▾ 0 (1) ... 36+ (37)

**Please indicate the average length of contact with psychologists**

Average length of contact (minutes) (4)

▾ 15 (1) ... 300+ (12)

**Please indicate the number of contacts with physiotherapists in the last 3 months**

Number of contacts with physiotherapists (1)

▾ 0 (1) ... 36+ (37)

**Please indicate the average length of contact with physiotherapists.**

Average length of contact (minutes) (4)

▾ 15 (1) ... 300+ (12)

**Please indicate the number of contacts with occupational therapists in the last 3 months**

Number of contacts with occupational therapists (1)

▾ 0 (1) ... 36+ (37)

**Please indicate the average length of contact with occupational therapists.**

Average length of contact (minutes) (4)

▾ 15 (1) ... 300+ (12)

**Please indicate the number of contacts in the last 3 months with community mental health teams.**

Number of contacts with community mental health teams (1)

▾ 0 (1) ... 36+ (37)

**Please indicate the average length of contact with community mental health teams.**

Average length of contact with community mental health teams (minutes) (1)

▾ 15 (1) ... 300+ (12)

**Please indicate the number of contacts with social workers in the last 3 months.**

Number of contacts with social workers (1)

▾ 0 (1) ... 36+ (37)

**Please indicate the average length of contact with social workers.**

Average length of contact with social workers (minutes) (4)

▾ 15 (1) ... 300+ (12)

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### Please indicate the number of contacts in the last 3 months with complementary / alternative medicine therapists.

Number of contacts with complementary / alternative medicine therapists (1)

• 0 (1) ... 36+ (37)

### Please indicate the average length of contact with complementary / alternative medicine therapists.

Average length of contact with complementary / alternative therapists (minutes) (4)

• 1 (1) ... 10+ ~ 120 (90)

### Please indicate the number of contacts in the last 3 months with other therapists.

Number of contacts with other therapists (1)

• 0 (1) ... 36+ (37)

### Please indicate the average length of contact with other therapists.

Average length of contact with other therapists (minutes) (4)

• 15 (1) ... 300+ (12)

### Please indicate the number of A & E, planned outpatient and other hospital visits that did not involve an overnight stay in the last 3 months

Number of A & E visits (1)	• 1 (undefined) ... 20 (39)
Number of of planned outpatient visits (6)	• 1 (undefined) ... 20 (39)
Number of other visits (e.g. for screenings / blood tests ) (7)	• 1 (undefined) ... 20 (39)

### Please indicate how many times you were admitted to hospital in the last 3 months.

Total number of hospital admissions (1)

• 0 (1) ... 36+ (37)

### Please indicate the total number of nights spent in hospital in the last 3 months

Total number of nights spent in hospital (4)

• 1 (1) ... 90+ (14)

**Please indicate which of these statements apply to you**

	Yes (1)	No (2)
I have requested or had a carer's assessment (1)		
I receive the Carer's Allowance (2)		
I receive support from paid carers (4)		
The person i care for attends support activities (6)		
I take part in a support group (5)		
I receive other support with caring (7)		

**Please indicate the weekly number of contacts with paid carers**

Number of weekly contacts with paid carers (1)

• 0 (1) ... 36+ (37)

**Please indicate the average length of contacts with paid carers**

Average length of contact (minutes) (4)

• 15 (1) ... 300+ (12)

**Please indicate how many days in a typical week the person you support attends external supported activities**

Number of days per week attending external activities (1)

• 1 (1) ... 7 (7)

**Please indicate the average length of external support activities for the person you care for**

Average length of contact for external activities (minutes) (4)

• 15 (1) ... 300+ (12)

**Please indicate how many hours you spend in peer support groups in a typical week**

Number of hours of peer support per week (1)

• 1 (1) ... 10+ ~ 5 hours + (120)

**Thinking about a typical week please indicate how many hours a week you spend on the following activities:**

Supervising and monitoring activities (1)	• 0 hours (1) ... More than 100 hours (37)
Emotional support and encouragement (encouraging, motivating, providing intensive emotional support and companionship) (4)	• 0 hours (1) ... More than 100 hours (37)
Responding to challenging behaviour (managing crises, managing inappropriate behaviours) (5)	• 0 hours (1) ... More than 100 hours (37)
Other emotional support or psychosocial care (6)	• 0 hours (1) ... More than 100 hours (37)
Household tasks (grocery shopping, preparing meals, housework, property maintenance) (7)	• 0 hours (1) ... More than 100 hours (37)
Health care coordination. (supervising or prompting medication, arranging supervision / outside services, assisting and liaising with health professionals, assisting with other aspects of treatment plans) (8)	• 0 hours (1) ... More than 100 hours (37)
Managing finances /paying bills, other paper work, reading and writing or communication (9)	• 0 hours (1) ... More than 100 hours (37)
Travel-related activities (getting to appointments, workplace) (10)	• 0 hours (1) ... More than 100 hours (37)
Other practical tasks (11)	• 0 hours (1) ... More than 100 hours (37)
Helping with activities of daily living. (can include personal hygiene, grooming, bathing and showering, dressing, eating and mobility) (12)	• 0 hours (1) ... More than 100 hours (37)

**Please identify the three activities where you would like to receive help, with 1 being the most important, 2 being the second most important and 3 being the third most important area for help.**

- \_\_\_\_\_ Supervising and monitoring (1)
- \_\_\_\_\_ Emotional support and encouragement (2)
- \_\_\_\_\_ Responding to behaviour (3)
- \_\_\_\_\_ Other emotional support or psychosocial care (4)
- \_\_\_\_\_ Household tasks (shopping, preparing meals etc) (5)
- \_\_\_\_\_ Health care coordination (6)
- \_\_\_\_\_ Managing finances/paying bills, other paper work, reading and writing, communication (7)
- \_\_\_\_\_ Transport (8)
- \_\_\_\_\_ Other practical tasks (9)
- \_\_\_\_\_ Activities of daily living (help with washing, dressing, eating etc) (10)

**In a typical week how much time do you spend travelling to and from the person you support's place of residence?**

Number of hours per week (4)

• 1 (1) ... 36+ (36)

**In a typical week how many times would you visit the person you support?**

Number of visits per week (4)

• 1 (1) ... 10+ (10)

**Please estimate your travel costs for a return journey to visit them?**

Costs for a return journey (£s) (4)

• Less than 5 pounds (1) ... More than 50 pounds (11)

**Thinking about your current circumstances how concerned are you about:**

	Not at all (1)	A little (2)	Moderately (3)	Quite a bit (4)	A lot (5)
Your finances (1)					
The finances of the person you care for (2)					
Extra regular costs of caring (4)					
Unexpected crisis costs of caring (5)					
Your career, including promotion opportunities (6)					
Your retirement income (7)					

**Thinking about your retirement do you think you have had or will have to postpone your retirement because of your caring responsibilities?**

- Yes (1)
- No (2)

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### Have your caring responsibilities had an impact on the quality of your relationship with your family?

- Strengthened a lot (1)
- Strengthened a little (2)
- No impact (3)
- Weakened a little (4)
- Weakened a lot (5)

### We would like to ask a few more questions about your situation. Are you caring for more than one person with mental health problems?

- Yes (1)
- No (2)

### How would you describe your ethnic origin?

▸ English/Welsh/Scottish/Northern Irish/British (1) ... Prefer not to say (18)

### We would like to know a little more about your own health and how this affects your ability to be a carer. Have you been diagnosed with any condition that impacts on your ability to care? (Select ALL that apply)

- No health condition (1)
- Arthritis (2)
- Back Pain (3)
- Cancer (4)
- Cardiovascular Disease (5)
- Diabetes (6)
- Epilepsy (7)
- Movement Disorders (e.g. Parkinson's Disease, Huntingdon's Disease, Cerebral Palsy) (8)
- Permanent Disabilities including Hearing Loss and Visual Impairment (9)
- Respiratory Disease (e.g. Asthma, Chronic Obstructive Pulmonary Disease – COPD) (10)
- Depression and / or Anxiety Disorders (13)
- Other (11)
- Prefer not to say (12)

### What is the highest level of qualification that you have received from school, college or since leaving education? Please include any work-based training.

▸ Degree level qualification (or equivalent) (1) ... No formal qualifications (8)

**We would like to know more about where you live.**

- o Owner occupied house or flat (1)
- o Privately rented house or flat (2)
- o Public sector or housing association/cooperative rented house or flat (3)
- o Other (4)

**Urban / Rural – Do you live in an area with**

- More than 125,000 people (1) ... Less than 3000 people (4)

**Which professional category best fits you?**

- Manager (1) ... Armed forces (10)

**What is your gross income from all sources before tax and national insurance?**

- Up to £100 per week (1) ... Dont know (13)

**We would like to know some more about the health of the person you care for and how this impacts on caring. Has the person you care for been diagnosed with any other physical health conditions that requires significant care? (Select ALL that apply)**

- o No, no other health condition (1)
- o Cancer (2)
- o Cardiovascular Disease (3)
- o Diabetes (4)
- o Dementia (5)
- o Epilepsy (6)
- o Movement Disorders (e.g. Parkinson's Disease, Huntington's Disease, Cerebral Palsy, etc.) (7)
- o Permanent disabilities including Hearing Loss and Visual Impairment (8)
- o Respiratory Disease (e.g. Asthma, Chronic Obstructive Pulmonary Disease – COPD) (9)
- o Other (10)
- o Dont know (11)

**Has the person you care for had an overnight stay in hospital in the last 3 months because of their mental health?**

- o Yes (1)
- o No (2)

**Please specify how many times they have been admitted to hospital in the last 3 months because of their mental health and the total number of nights spent in hospital**

Total number of hospital admissions (4)

- 0 (1) ... 36+ (37)



