

Personal Social Services Survey of Adult Carers in England (SACE)

2016-17

Published 03 August 2017

This report contains findings from the Survey of Adult Carers in England, 2016-17 (SACE). This national survey takes place every other year and is conducted by Councils with Adult Social Services Responsibilities (CASSRs). The survey seeks the opinions of carers aged 18 or over, caring for a person aged 18 or over, on a number of topics that are considered to be indicative of a balanced life alongside their unpaid caring role.

Key findings



71.0% of carers who received support or services were extremely, very or quite satisfied with the support or services they received

90.1% of carers aged 85 and over have caring responsibility for someone aged 75 or over



Of carers who have had a lot of financial difficulties caused by their caring responsibilities, 38.7% report having little social contact with people and feeling socially isolated

58.5% of carers spend more than 35 hours per week providing care. Over a third of carers (35.7%) provide care for over 100 hours per week



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These statistics provide useful insights into the lives and experiences of the members of our communities who provide informal care. They will be of use not just to people who plan, provide or use carers' services, but also more widely to all those who take an interest in the vital support that unpaid carers provide.

Introduction

This report contains findings from the Survey of Adult Carers in England, 2016-17 (SACE). In 2016-17 the eligible population changed so that in addition to including carers that have had a carer's assessment or review from the local authority in the 12 months prior to the survey taking place, carers are now also included who have not been assessed or reviewed during the previous 12 months. Under the Care Act (2014) councils have a duty to ensure relevant information and advice is made available to carers. This provides a clear rationale for including carers who were not assessed or reviewed during the year but who the local authority reports are in receipt of support. The survey seeks carer's opinions on a number of topics that are considered to be indicative of a balanced life alongside their caring role.

Due to the change in eligible population, comparisons have not been made to the 2014-15 survey data. Analysis was carried out to compare the new cohort as a whole to those that had a carers assessment or review to see if the results for this group were different. A summary of this analysis is included in the data quality statement.

Users of this report are encouraged to also consult the additional information published as part of this statistical release such as:

- Further information about the survey can be found in 'Methodological and Further Information' report.
- Information on validation methods and the quality of the data is provided in the data quality statement and the data quality annex file.
- Information on understanding surveys, including understanding the eligible population, sample sizes and the demographic profile of those that responded is available in the 'Understanding Surveys' document.

England level key findings are provided within this report.

Additional annex files containing data for all Councils with Adult Social Services Responsibilities (CASSRs) in England, further national level data and record level information is provided in a CSV file along with guidance documentation.

The additional information and annex files are available on the NHS Digital website: <https://digital.nhs.uk/pubs/psscarersurvey1617>.

Responses collected for the carers survey are also used to populate five of the measures within the Adult Social Care Outcomes Framework (ASCOF), these are:

- 1D: Carer-reported quality of life (Q7-12).
- 1I2: The proportion of carers who reported that they had as much social contact as they would like (Q11).
- 3B: Overall satisfaction of carers with social services (Q4).
- 3C: The proportion of carers who report they have been included or consulted in discussions about the person they care for (Q18).
- 3D2: The proportion of carers who find it easy to find information about support (Q16).

This report contains some analysis of the questions used to populate the ASCOF scores and which variables affect them.

Main findings

This report uses data collected from a sample of 55,705 carers who participated in the survey and these are weighted to make inferences (or estimates) about the whole weighted eligible population (341,515) of carers. As the numbers are estimates, the numbers quoted in this report are rounded to the nearest 50. All estimated numbers are also available in the accompanying annex file.

These estimates and findings are subject to a degree of uncertainty, therefore the charts presented include the standard errors, which are the measure of the statistical accuracy of the estimates and show the level of uncertainty in the value caused by only surveying a sample of carers.

Weights are also used to calculate national, regional and council type estimates. CASSR level weights were applied to the record level data to ensure different response rates between CASSRs did not unduly influence the England, regional and council type estimates. The weighted totals match the eligible population.

Details on the number of respondents and the percentage distribution of the responses can be found in the accompanying annex table¹.

Further information on calculating standard errors, weightings and analysis is provided in the “Methodological and Further Information report”².

This report contains information about the carers themselves and further detailed analysis specifically focusing on the questions used to populate the Adult Social Care Outcomes Framework (ASCOF) indicators and which variables affect them.

The main findings cover the following sections:

1) Information about the Carer and their role

- Age of Carer
- Support Needs
- Carers Health
- Time Providing Care

2) Detailed Question Analysis

- **Satisfaction with the support or services received from Social Services**
 - Satisfaction with support or services (Q4) and other caring responsibilities (Q13)

¹ <http://digital.nhs.uk/pubs/psscarerssurvey1617>

² <http://digital.nhs.uk/pubs/psscarerssurvey1617>

- Satisfaction with support or services (Q4) and financial difficulties (Q15)
- **Social contact and isolation**
 - Social contact and Isolation (Q11) and other caring responsibilities (Q13)
 - Social contact and isolation (Q11) and financial difficulties (Q15)
 - Social contact and isolation (Q11) and how long spent each week looking after or helping the person cared for (Q22)
 - Social contact and isolation (Q11) and number of children the carer has parental responsibility for (Q25)
- **How easy it is to find information about support**
 - How easy it is to find information about support (Q16) and satisfaction with the support and services (Q4)
 - How easy it is to find information about support (Q16) and social contact and isolation (Q11)
 - How easy it is to find information about support (Q16) and financial difficulties (Q15)
- **Discussions about the support or services provided to the person cared for**
 - Discussions about the support or services provided to the person cared for (Q18) and satisfaction with the support or services received (Q4)
 - Discussions about the support or services provided to the person cared for (Q18) and social contact and isolation (Q11)
 - Discussions about the support or services provided to the person cared for (Q18) and time to care for other people (Q13)
 - Discussions about the support or services provided to the person cared for (Q18) and financial difficulties (Q15)
- **Carer Reported Quality of Life Score**
 - Quality of Life Score and gender
 - Quality of Life Score and caring responsibilities (Q13)
 - Carer Reported Quality of Life Score and financial difficulties (Q15)
 - Quality of Life Score and how long spent each week looking after or helping the person cared for (Q22)

1) Information about the Carer and their role

The following concentrates on providing some context and understanding about who carers are and the support they provide. All the information presented within this section of the report, including the data tables used from the annex file, are provided as part of this statistical release which can be found at:

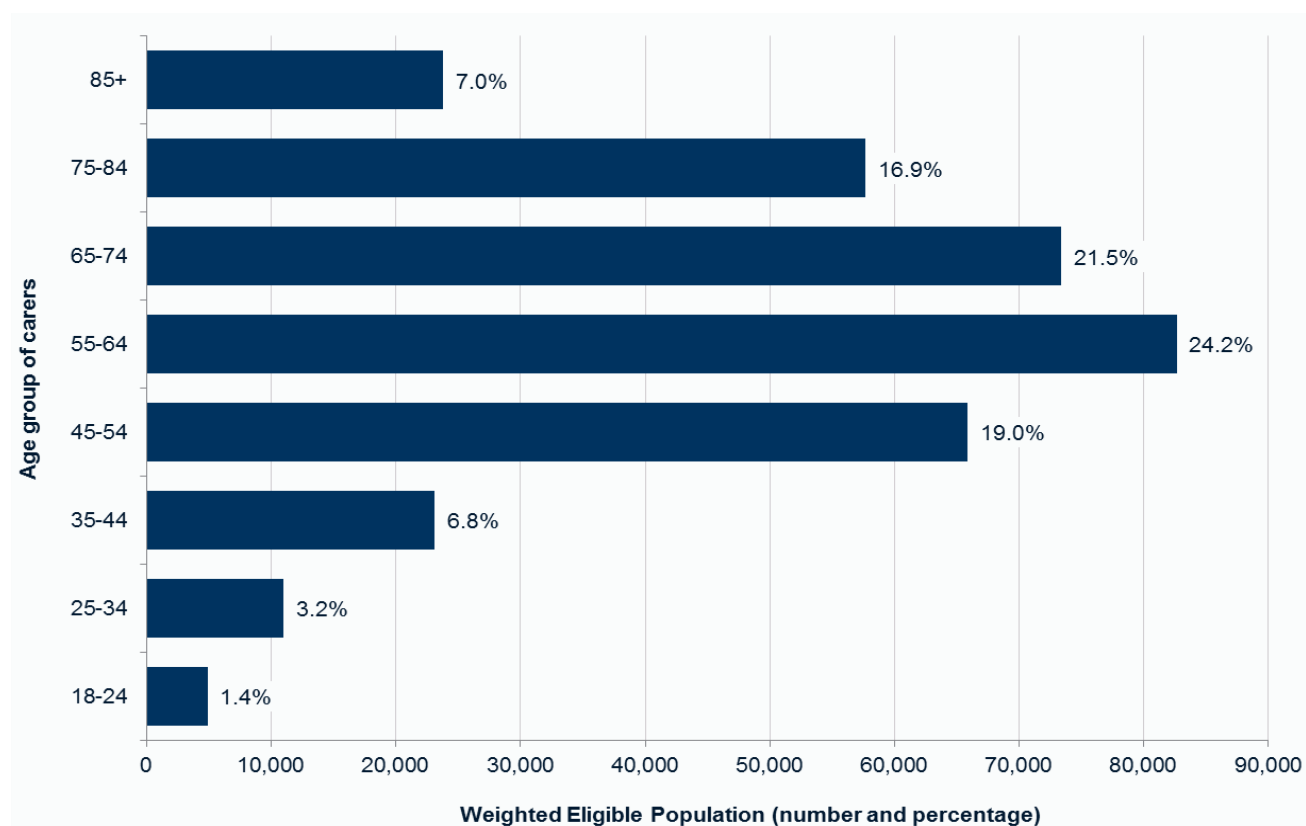
<https://digital.nhs.uk/pubs/psscarersurvey1617>

Age of Carer

There is a weighted eligible population of 341,515 people who are carers, the age profile of these individuals are spread across age groups.

- The largest proportion of carers are aged 55-64 (24.2 per cent) or approximately 82,750 people
- Carers aged 18-24 represent the smallest group at 1.4 per cent or approximately 4,850

Chart 1.1: Carers age group profile



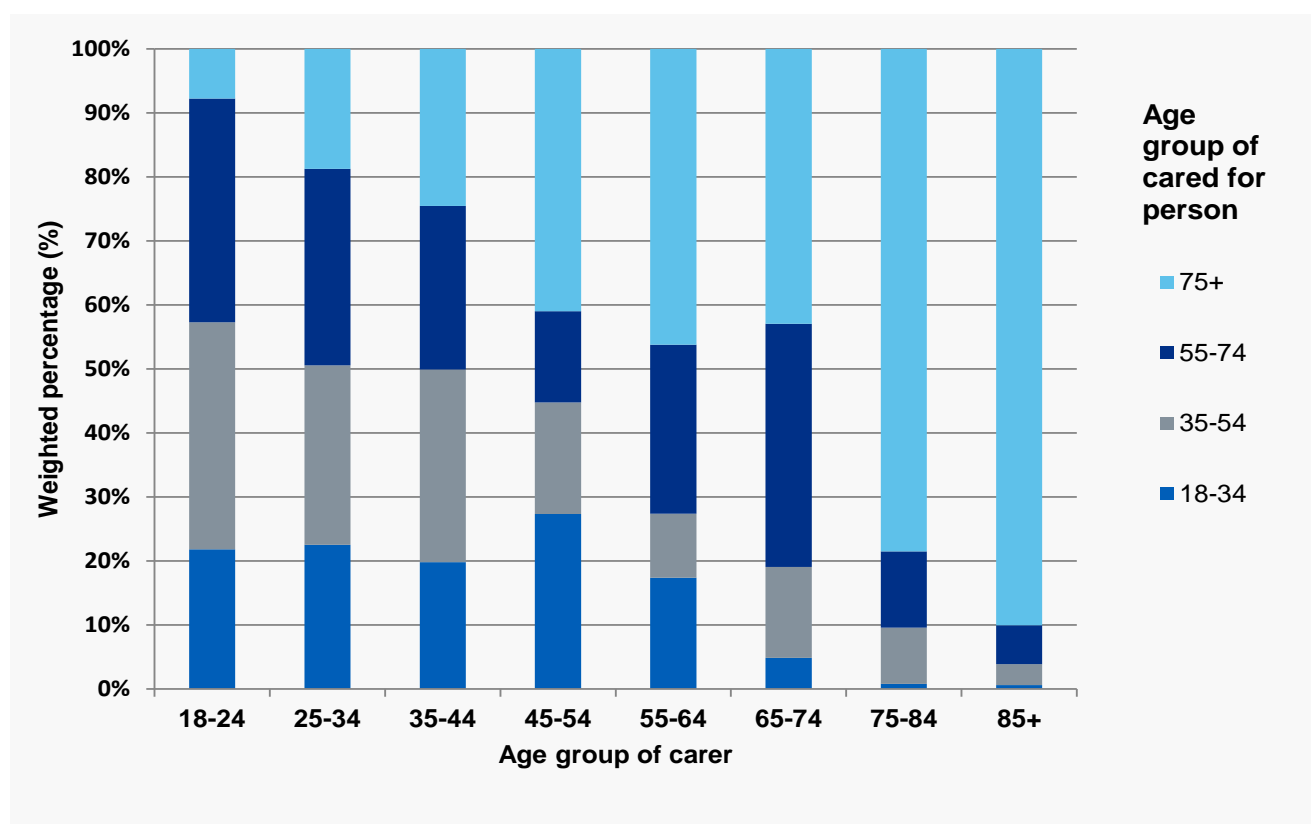
Source: SACE, NHS Digital

The age of the carer is generally indicative of age of the person the individual is caring for, e.g. husband or wife cares for their spouse / partner which represent the largest proportions. Additionally, some carers are children who care for their parent(s) or parents caring for their children.

Chart 1.2 shows the age group of the carer and the age band of the people they are caring for as a percentage:

- 90.1 per cent of older carers, those aged 85 and over have caring responsibility for someone aged 75 or over
- For all carers aged over 45, the highest percentage of the people they care for are aged 75 or over

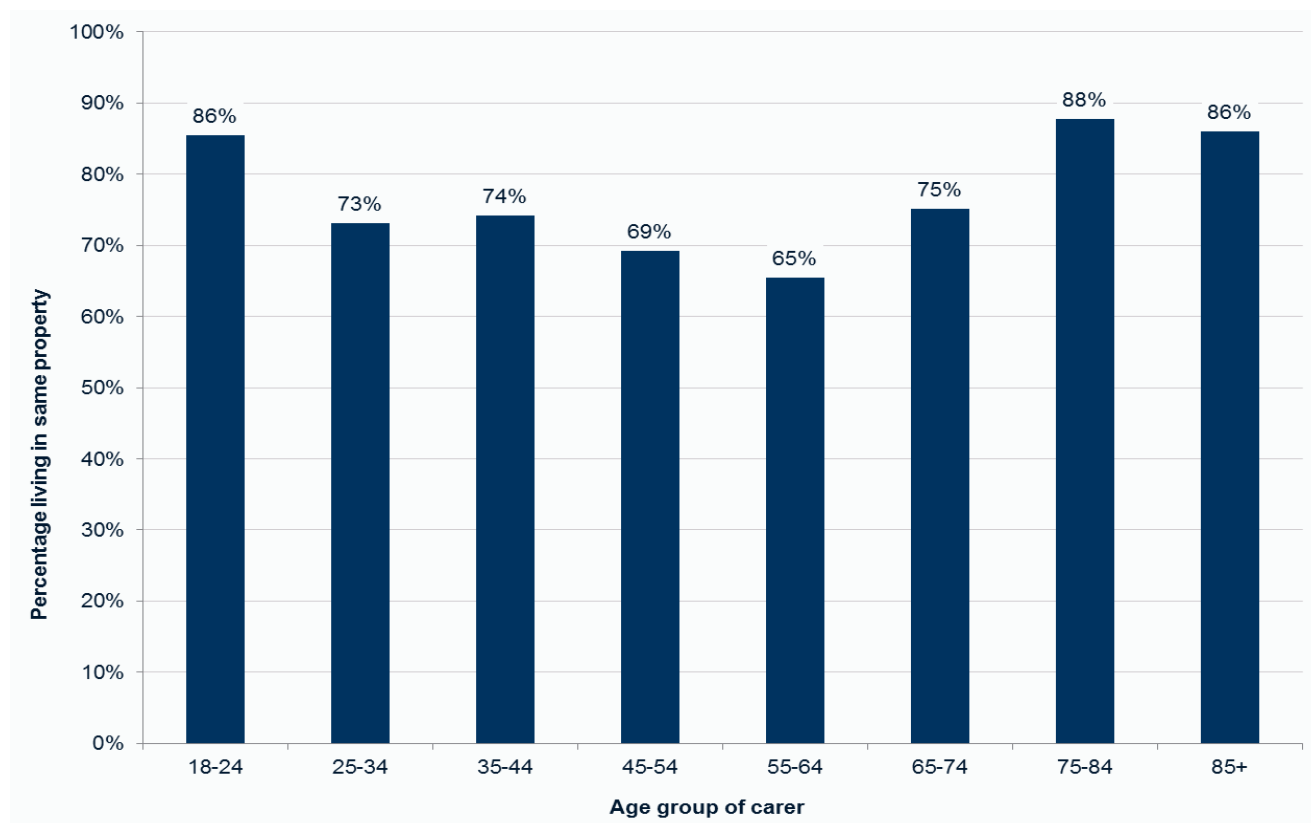
Chart 1.2: Age group of carer by age group of the person they care for



Source: SACE, NHS Digital

For the majority of carers the person they are caring for usually lives with them in the same property, generally this is around 77 per cent varying slightly across the age groups.

Chart 1.3: Percentage of carers living in the same property as the person they care for, by carer age group



Source: SACE, NHS Digital

At opposite ends of the age profiles, older and younger carers show they are amongst the highest percentages (around 86 per cent) where the carer and the person they are caring for are living together.

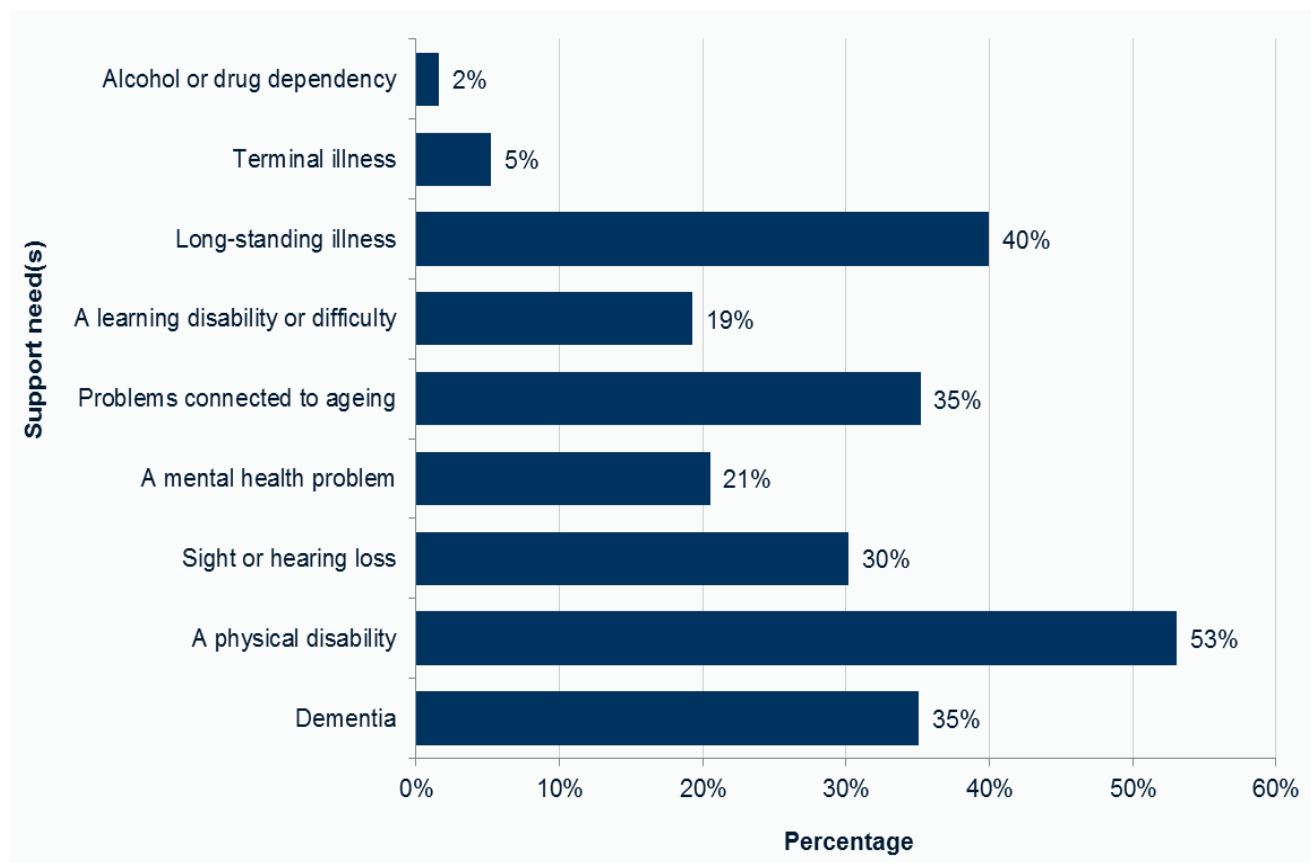
Support Needs

The support needs required will be very specific to each individual and the carers will often have to manage multiple support needs for the person they are caring for.

These complex needs might mean that an individual is managing multiple conditions such as dementia and problems connected to ageing.

- Most carers (53.1 per cent) reported that they were caring for a person with a physical disability;
- Carers are less likely to be caring for people with alcohol or drug dependency (1.6 per cent)

Chart 1.4: The support needs of the cared for person

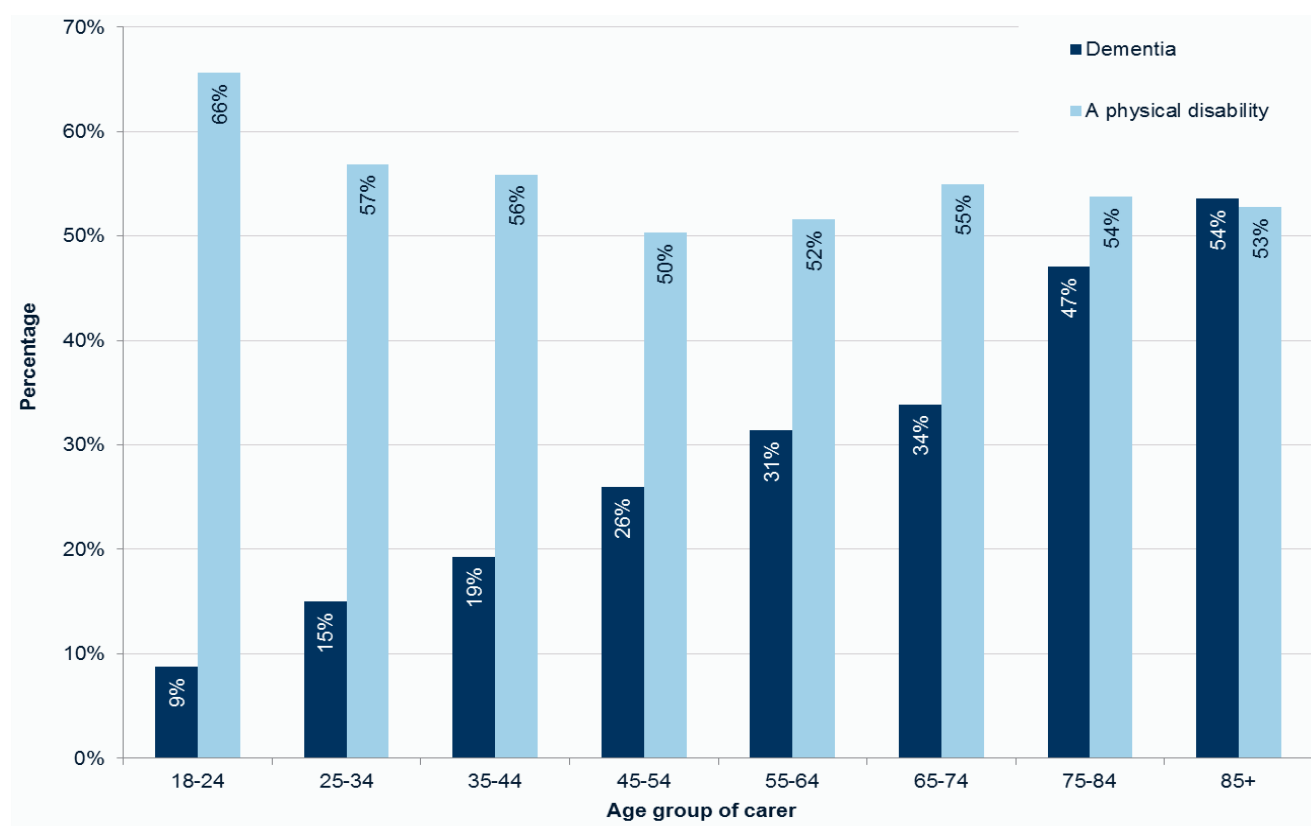


Source: SACE, NHS Digital

The level to which carers provide support for various or multiple needs is different across the carer age groups. Younger carers, those aged 18-24, are less likely to be caring for a person with dementia (8.8 per cent) but are most likely to be caring for someone with a physical disability (65.6 per cent).

Older carers, those aged 85 and over, are most likely to be a carer for someone with dementia (53.6 per cent). For over 50 per cent of this age group they are also supporting care needs related to physical disabilities, therefore is likely that the cared for person has multiple needs.

Chart 1.5: Dementia and Physical Disability support needs of the cared for person, by carer age group

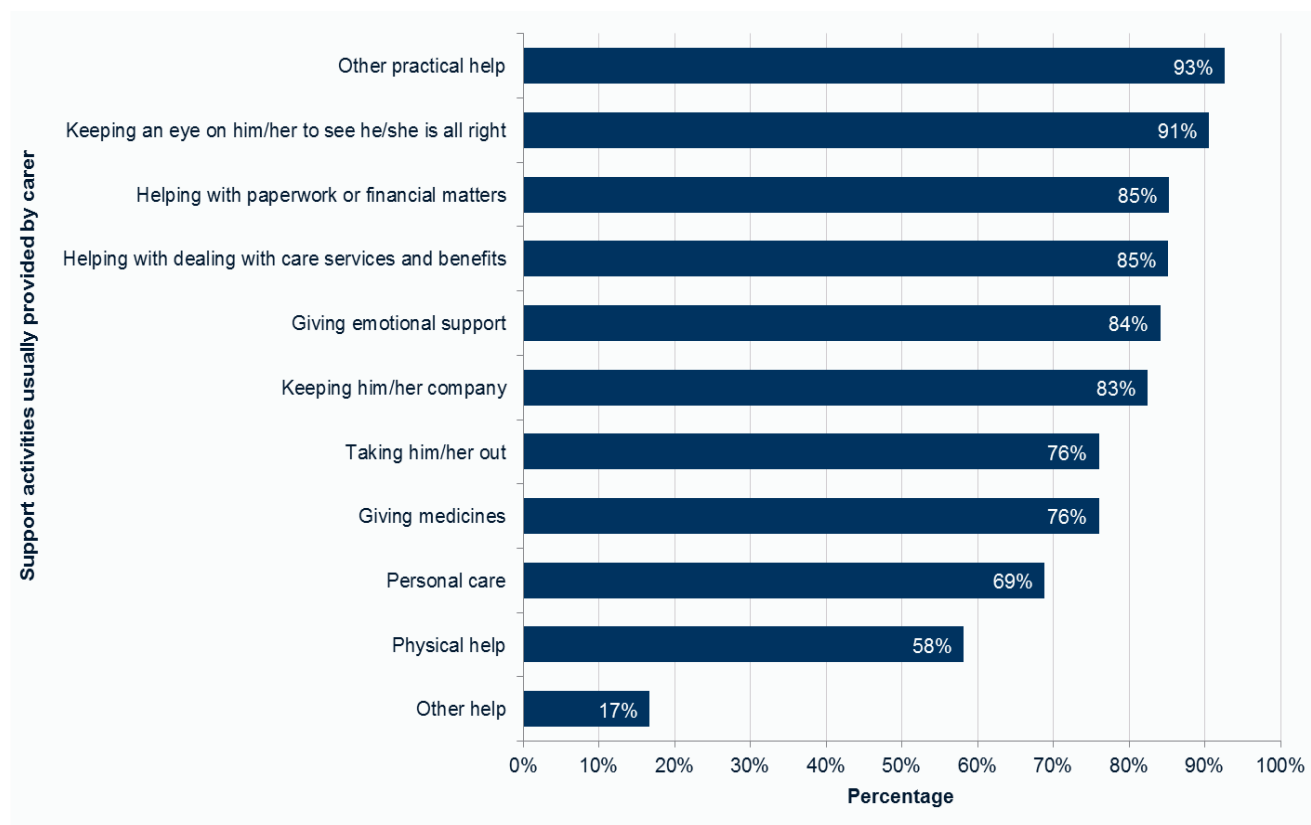


Source: SACE, NHS Digital

There are often multiple support activities provided by the carer, ranging from providing emotional support to ensuring medicines are administered to managing finances.

- Physical help is one of the least provided support activities, but still provided by 58.2 per cent of carers.
- Over 90 per cent ensure they are 'keeping an eye on him/her to see he/she is all right'

Chart 1.6: Proportions of activities usually provided by carer



Source: SACE, NHS Digital

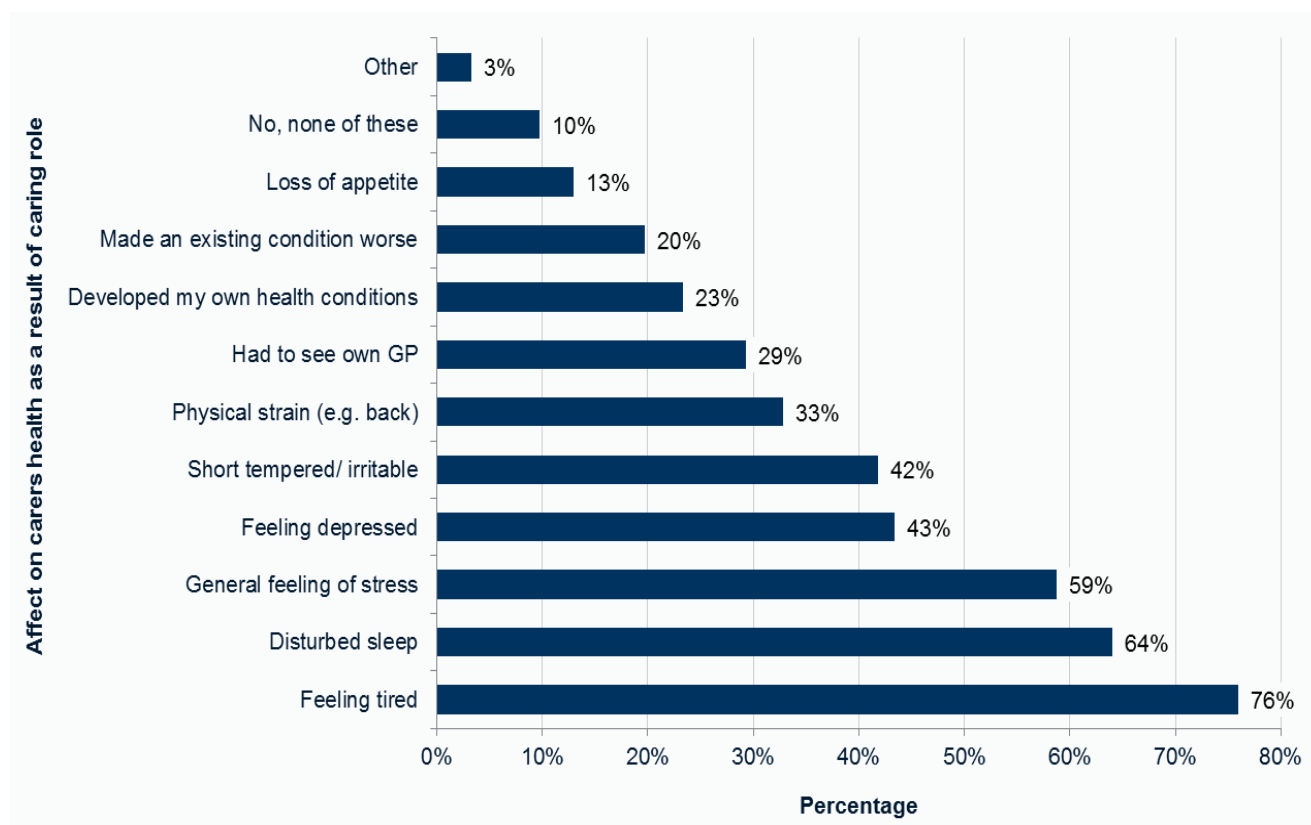
Carers Health

Providing care and support can have a detrimental impact on the health of the carer themselves, indeed nearly 20 per cent of carers reported that in the last 12 months, their health had been adversely affected by their caring role and made an existing condition worse.

There are other ways in which the carer's health is directly impacted as a result of their carer role:

- 76.0 per cent reported 'feeling tired' and 64.0 per cent of carers reported they experienced 'disturbed sleep' as a result of their caring role
- A third of carers reported feeling the 'physical strain' of caring
- Nearly 60 per cent reported a 'general feeling of stress' and 43.4 per cent stated they were 'feeling depressed'

Chart 1.7: Impact on health reported by carers due to their caring role



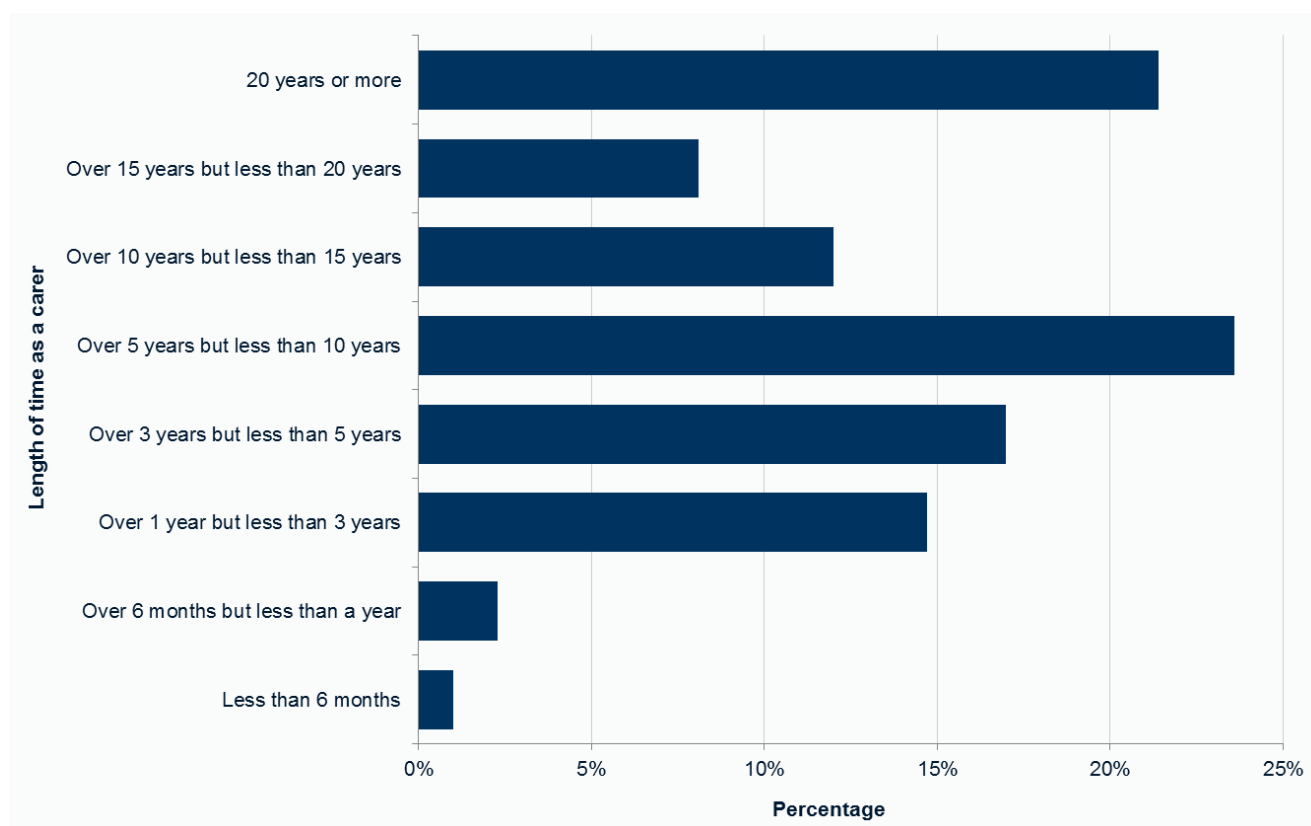
Source: SACE, NHS Digital

Time Providing Care

Depending on the reason the support is being provided by the carer, this will inevitably influence how long the carer has been providing care. Where they are in a caring role for someone with a long-term condition such as a learning disability, they may have been a carer for many years. Where the caring role is related to a predominately degenerative condition such as dementia then it's likely the period of the caring being provided maybe much shorter.

- 65.2 per cent of carers have been providing support and care for 5 or more years
- 21.4 per cent have been carers for over 20 years

Chart 1.8: Length of time carers have spent in their caring role

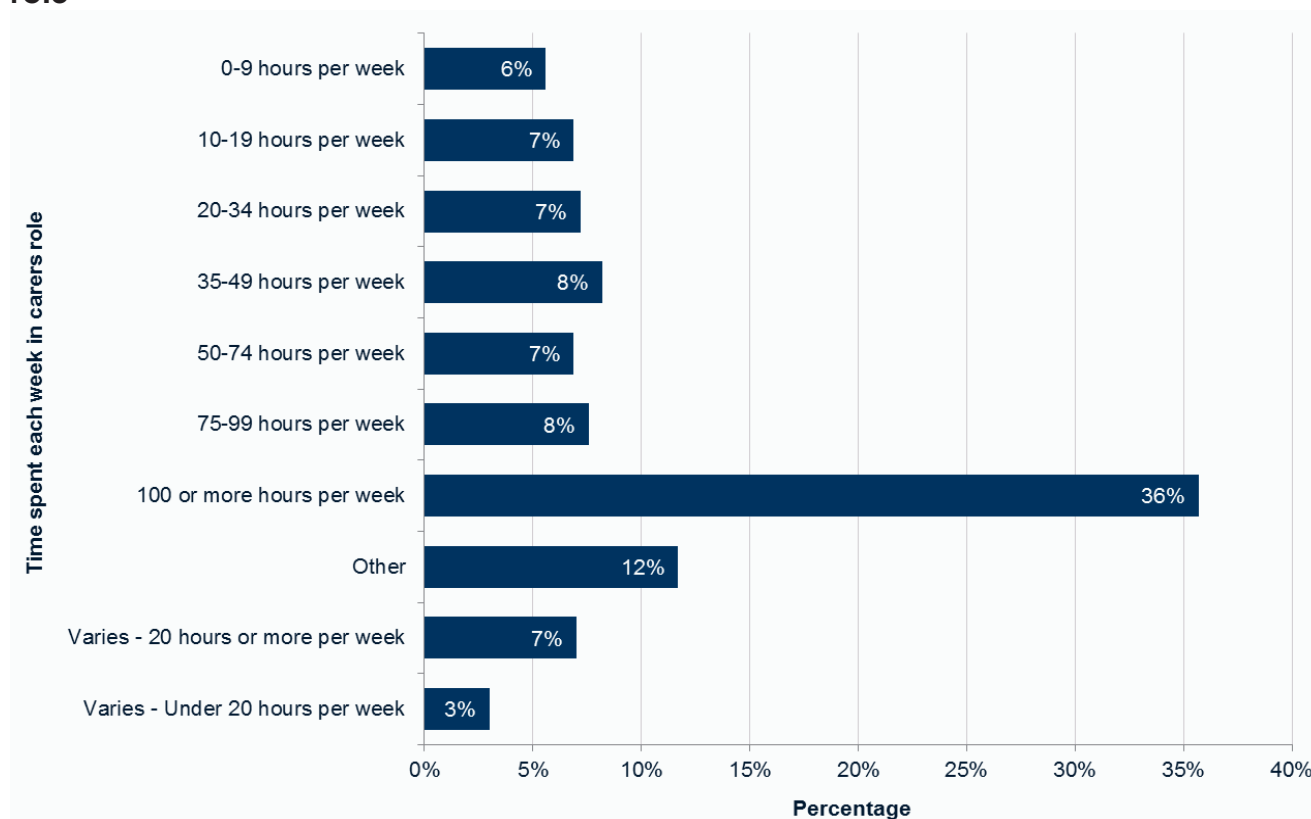


Source: SACE, NHS Digital

Less than a quarter (23.8 per cent) of carers are in paid employment (either part-time, full-time or self-employed). Of these carers, less than half are employed on a full-time basis (Q19). 21.0 per cent of carers feel unable to work because of their carer responsibilities (Q20).

The majority of carers (58.5 per cent) spend more than 35 hours per week providing care. Over a third of carers (35.7 per cent) provide care for over 100 hours per week.

Chart 1.9: Amount of hours carers spend each week in their caring role



Source: SACE, NHS Digital

2) Detailed Question Analysis

Further to the above analysis on the profile of the carer, we have undertaken additional in-depth analysis of the underlying survey data collected and weighted this to the eligible population of 341,515.

Responses to survey questions have been examined in the context of responses to other questions within the survey.

Significance testing was carried out to evaluate the key findings from the 2016-17 survey. The term 'significant' refers to statistical significance at the 95 per cent confidence level and is not intended to imply substantive importance. The main findings presented within this report only contain analysis of variables which are considered statistically significant.

Further information on significance testing is provided in the "Methodological and Further Information report"³.

Satisfaction with the support or services received from Social Services

Satisfaction with support or services is directly linked to a positive experience of care and support.

Question 4 of the survey asked carers "Overall, how satisfied or dissatisfied are you with the support or services you and the person you care for have received from Social Services in the last 12 months?"

Overall, for carers who received support or services along with the person they care for, 71.0 per cent were extremely, very or quite satisfied with the support or service they received. This compares to 13.4 per cent who were extremely, very or quite dissatisfied and 15.5 per cent that were neither satisfied nor dissatisfied.

Question 4 of the survey responses received are used as the underlying data to calculate ASCOF measure 3B, "Overall satisfaction of carers with social services". The following section looks at the response for question 4 alongside other variables.

Considering how satisfied the user and survey respondent was with the support or service they received, we also looked to see how this correlated with:

- Other caring responsibilities (Q13) and
- Financial difficulties (Q15)

71.0%

of carers who received support or services were extremely, very or quite satisfied with the support or services they received.

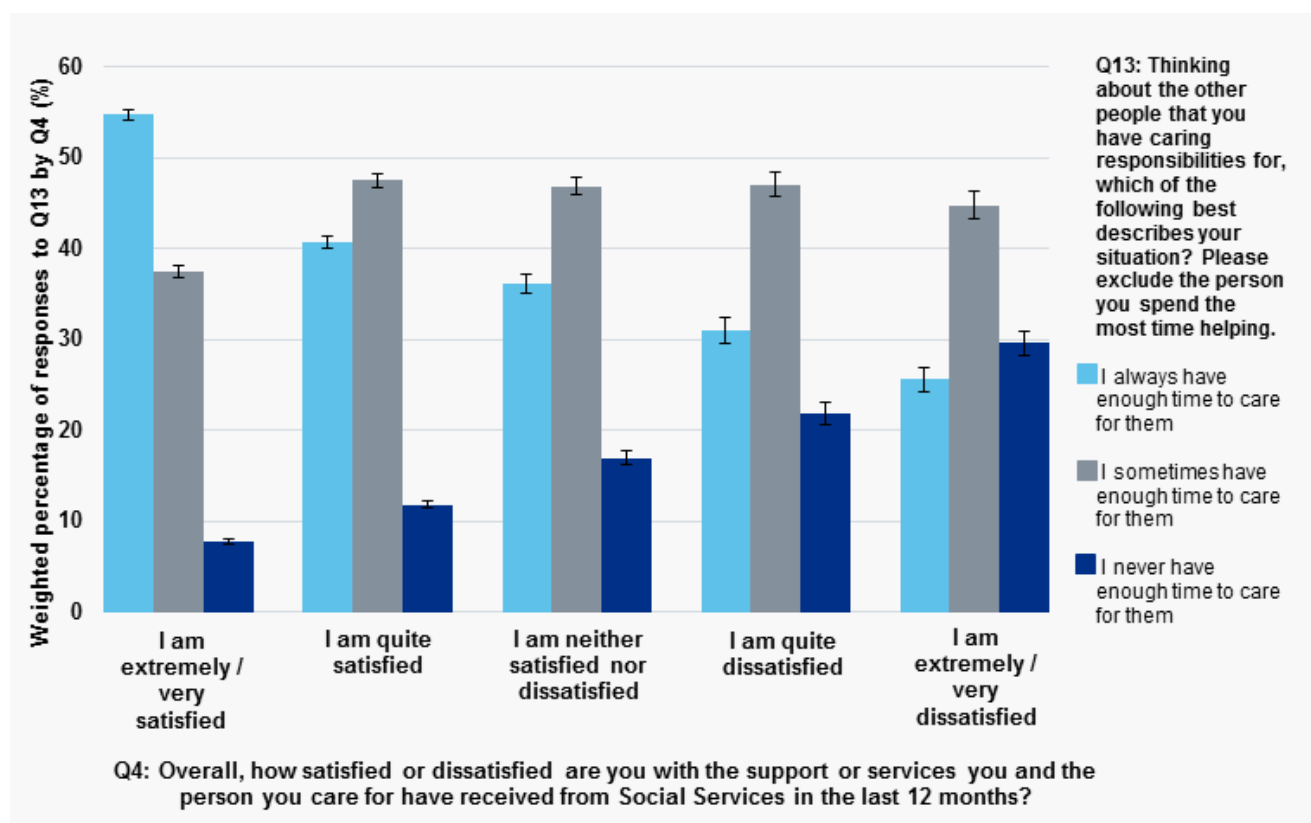
³ <http://digital.nhs.uk/pubs/psscarerssurvey1617>

Satisfaction with support or services (Q4) and other caring responsibilities (Q13)

39.0 per cent of carers were either extremely or very satisfied with the services or support they had received.

Of the carers who were very or extremely dissatisfied with the support or services they or the person they care for received from Social Services in the last 12 months, a higher proportion also reported that they never have enough time to care for the other people they have caring responsibilities for (29.6 per cent or 3,300 of the 11,150 carers).

Chart 2.1: Other caring responsibilities by satisfaction with support or services received

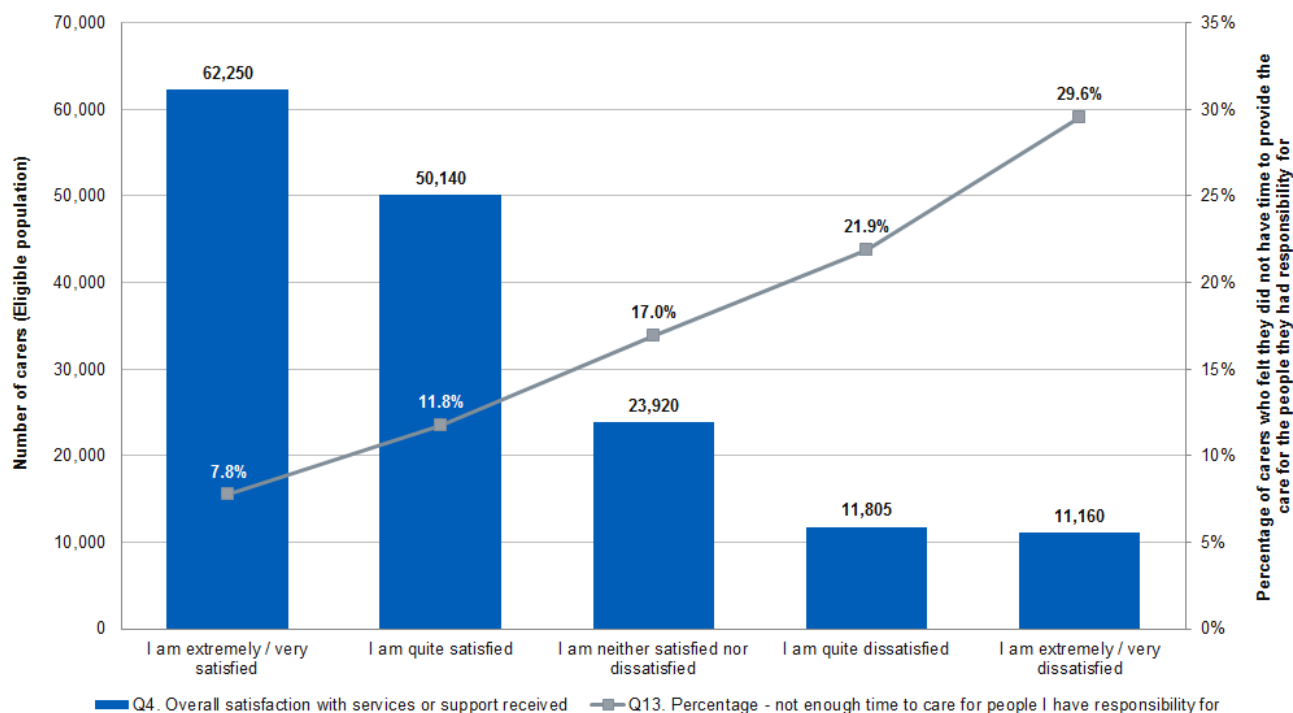


Source: SACE, NHS Digital

In contrast, for carers that were extremely or very satisfied with the support or services received, 7.8 per cent (4,850 carers of the 62,250) felt they never had enough time to care for the other people they have caring responsibilities for.

For carers that were extremely or very dissatisfied with the support or services received, 25.6 per cent (2,850 carers of the 11,150) felt they always had enough time to care for the other people they have caring responsibilities for. This compares to 54.8 per cent (or 34,100 of the 62,250) of the carers which were extremely or very satisfied with the support or services.

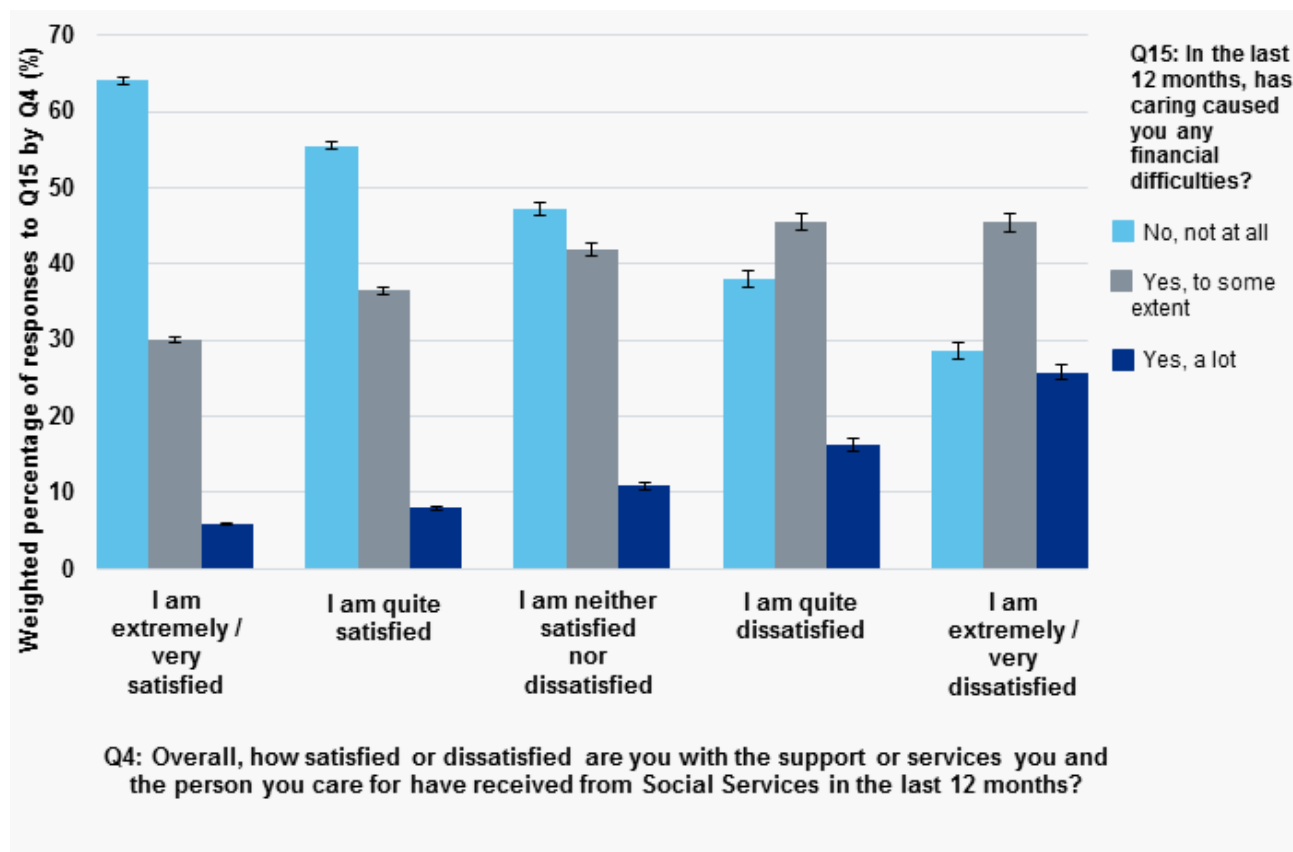
Chart 2.2: The number of carers by satisfaction with support or services received by percentage who did not feel they had enough time to provide care



Satisfaction with support or services (Q4) and financial difficulties (Q15)

Carers that are very or extremely dissatisfied with the support or services they and the person they care for have received from Social Services also report the highest proportion who have had a lot of financial difficulties caused by their caring responsibilities.

Chart 2.3: Financial difficulties by satisfaction with support or services received



Source: SACE, NHS Digital

Chart 2.3 shows that for carers who report they are extremely or very dissatisfied with the support or services they and the person they care for have received from Social Services in the last 12 months, 25.8 per cent (4,200 of the 16,200 carers) also report having lots of financial difficulties in the last 12 months caused by their caring responsibilities. In contrast, for carers that are extremely or very satisfied with the support or services received, 5.9 per cent (5,900 of the 100,450 carers) reported they had a lot of financial difficulties caused by their caring responsibilities.

For carers that are extremely or very dissatisfied with the support or services received, 28.6 per cent (4,650 of the 16,200 carers) had no financial difficulties caused by their caring responsibilities. For carers that were extremely or very satisfied with the support or services received, 64.1 per cent (64,350 of the 100,450 carers) reported they did not have any financial difficulties caused by their caring responsibilities.

Social contact and isolation

Loneliness is linked to poor mental and physical health. A key aspect for social care is for it to tackle loneliness and social isolation.

Question 11 of the survey asked carers “Thinking about how much social contact you’ve had with people you like, which of the following statements best describes your social situation”.

Overall 35.5 per cent of carers reported they have as much social contact as they want with people they like, 48.3 per cent have some social contact but not enough and 16.2 per cent reported they have little social contact and feel socially isolated.

Question 11 of the survey responses received are used as the underlying data to calculate ASCOF measure 1I2, the “Proportion of carers who reported that they had as much social contact as they would like”. The following section looks at the response for question 11 alongside other variables where there are differences.

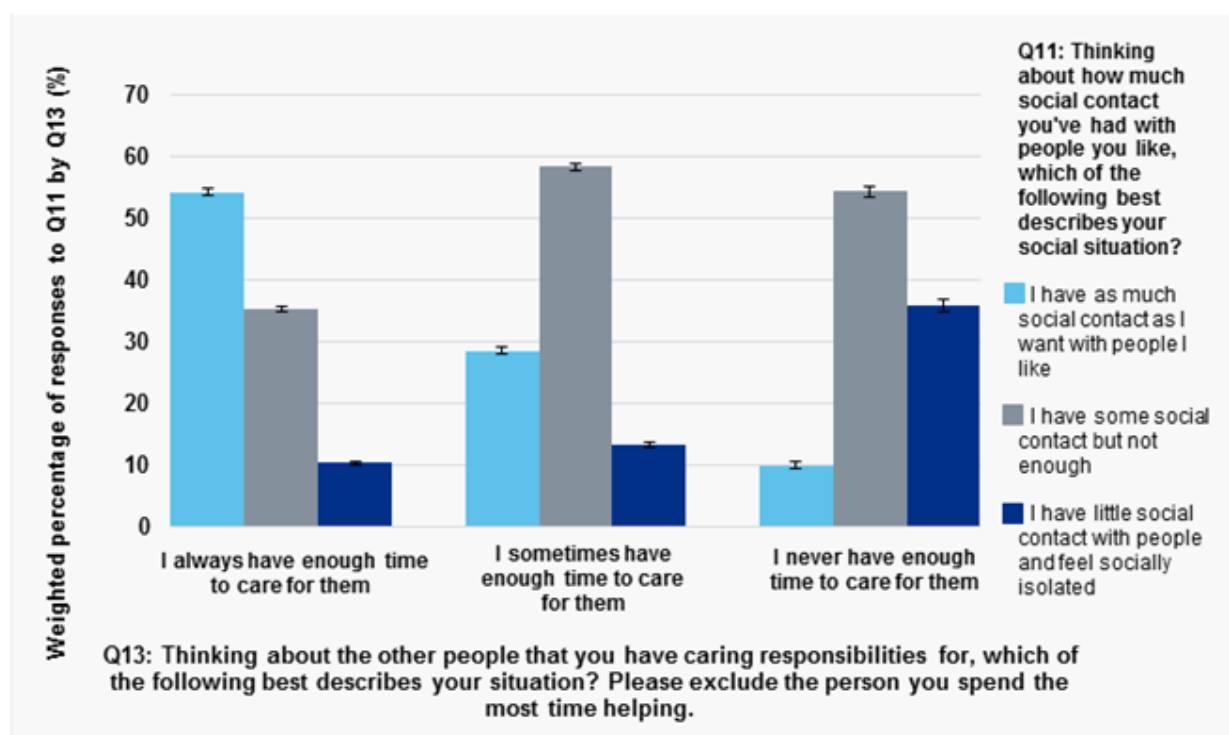
16.2%
of carers
reported they
have little social
contact and feel
socially isolated.

Social contact and isolation (Q11) and other caring responsibilities (Q13)

27.6 per cent of carers reported always having enough time to care for other people they have caring responsibilities for, 26.2 per cent sometime have enough time, 7.8 per cent never have enough time and 38.3 per cent do not have other caring responsibilities.

Of the carers that report they never have enough time to care for other people they have caring responsibilities for, a higher proportion also reported they have little social contact with people and feel socially isolated (35.8 per cent or 9,550 carers).

Chart 2.4: Social contact and isolation by other caring responsibilities



Source: SACE, NHS Digital

In contrast, for carers that reported they always have enough time to care for the other people they have caring responsibilities for, 10.4 per cent (9,750 of the 93,200 carers) reported having little social contact with people and feeling socially isolated.

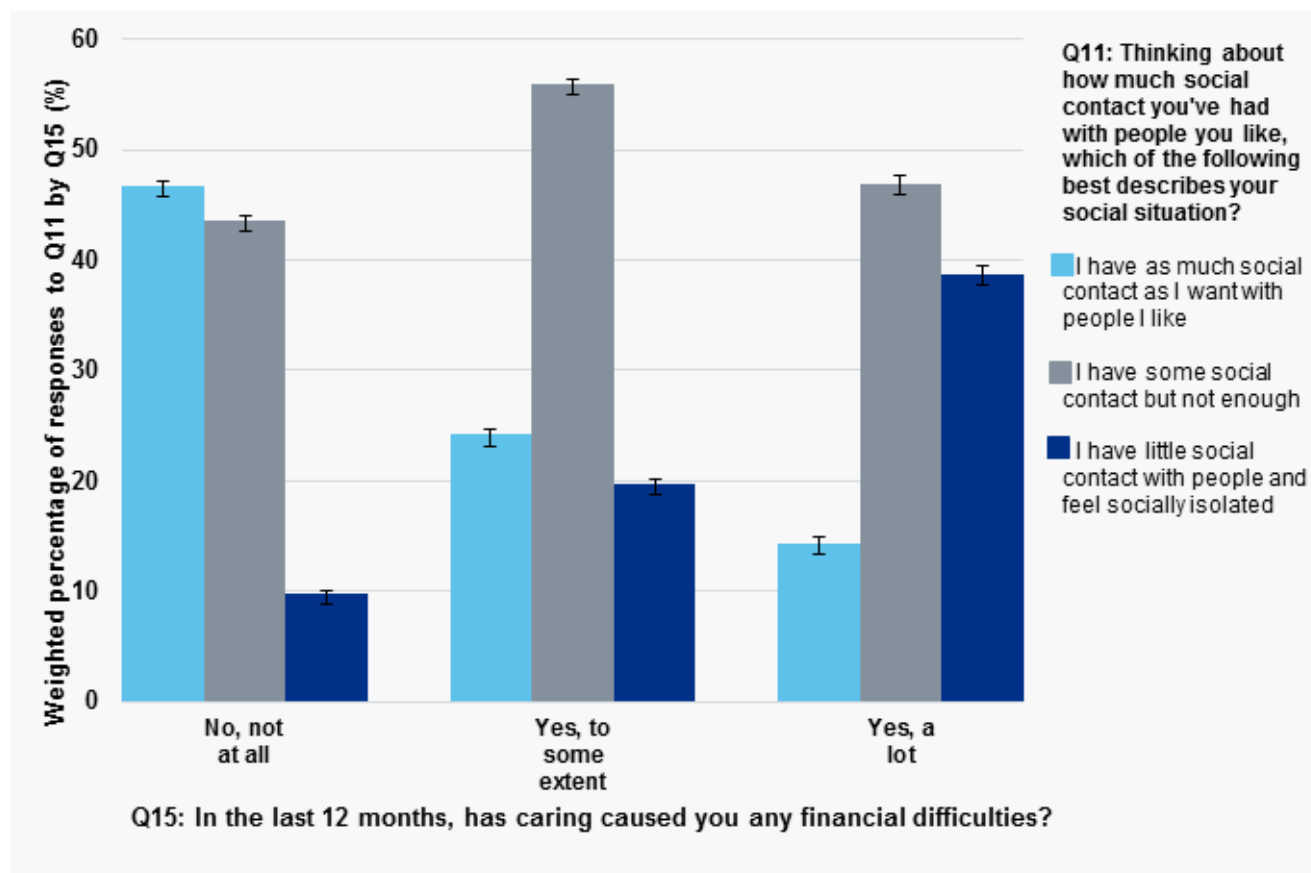
For carers that reported they never have enough time to care for the other people, 9.9 per cent (2,600 of the 26,600 carers) felt they have as much social contact as they want, this compares to 54.2 per cent (50,550 of the 93,200 carers) for carers that always have enough time to care for the other people they care for.

Social contact and isolation (Q11) and financial difficulties (Q15)

In the last 12 months, 54.4 per cent of carers reported that caring has not caused them any financial difficulties, 36.0 per cent have reported some and 9.6 per cent reported a lot.

Carers who have had a lot of financial difficulties caused by their caring responsibilities report the highest proportion having little social contact with people and feeling socially isolated compared to carers who have not had financial difficulties.

Chart 2.5: Social contact and isolation by financial difficulties



Source: SACE, NHS Digital

Chart 2.5 shows that for carers who have had a lot of financial difficulties caused by their caring responsibilities, 38.7 per cent (12,550 of the 32,400 carers) report having little social contact with people and feeling socially isolated. In contrast, for carers that had no financial difficulties caused by their caring responsibilities, 9.8 per cent (17,850 of the 182,400 carers) report having little social contact with people and feeling socially isolated.

For carers that have had a lot of financial difficulties, 14.4 per cent (4,650 of the 32,400 carers) reported they have as much social contact as they want, this compares to 46.7 per cent (85,100 of the 182,400 carers) for carers that have not had any financial difficulties.

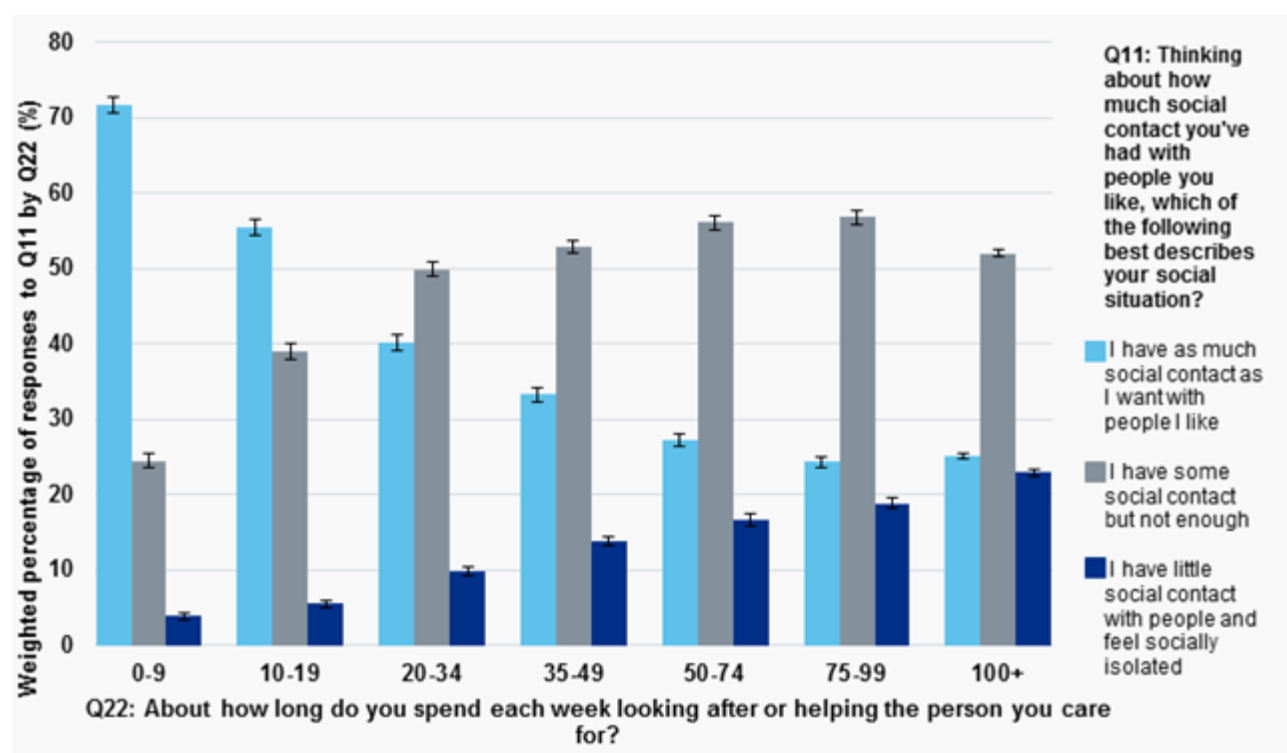
Social contact and isolation (Q11) and how long spent each week looking after or helping the person cared for (Q22)

In the section below the number of hours 0-9, 10-19, 20-34, 35-49, 50-74, 75-99 and 100 hours or more a week are included in the analysis. The response options “varies – under 20 hours per week”, “varies – 20 hours or more a week” and “other” were not included in the analysis.

Chart 1.9 shows the amount of hours carers spend each week in their caring role.

Carers who report the highest number of hours spent a week looking after or helping the person they care for have a higher proportion who report they have little social contact with people and feel socially isolated.

Chart 2.6: Social contact and isolation by number of hours per week carer spends looking after cared for person



Source: SACE, NHS Digital

Chart 2.6 shows for carers who spend less than ten hours a week looking after or helping the person they care for, 3.8 per cent (700 of the 18,850 carers) report feeling they have little social contact with people and feel socially isolated. In contrast, for carers that spend 100 or more hours a week looking after or helping the person they care for, 22.9 per cent (27,500 of the 120,050 carers) report feeling they have little social contact with people and feel socially isolated.

For carers that spend less than ten hours a week looking after or helping the person they care for, 71.7 per cent (13,500 of the 18,850 carers) report having as much social contact as they want with people they like, this compares to 24.3 per cent (6,250 of the 25,600 carers) who spend 75 to 99 hours a week and 25.1 per cent (30,100 of the

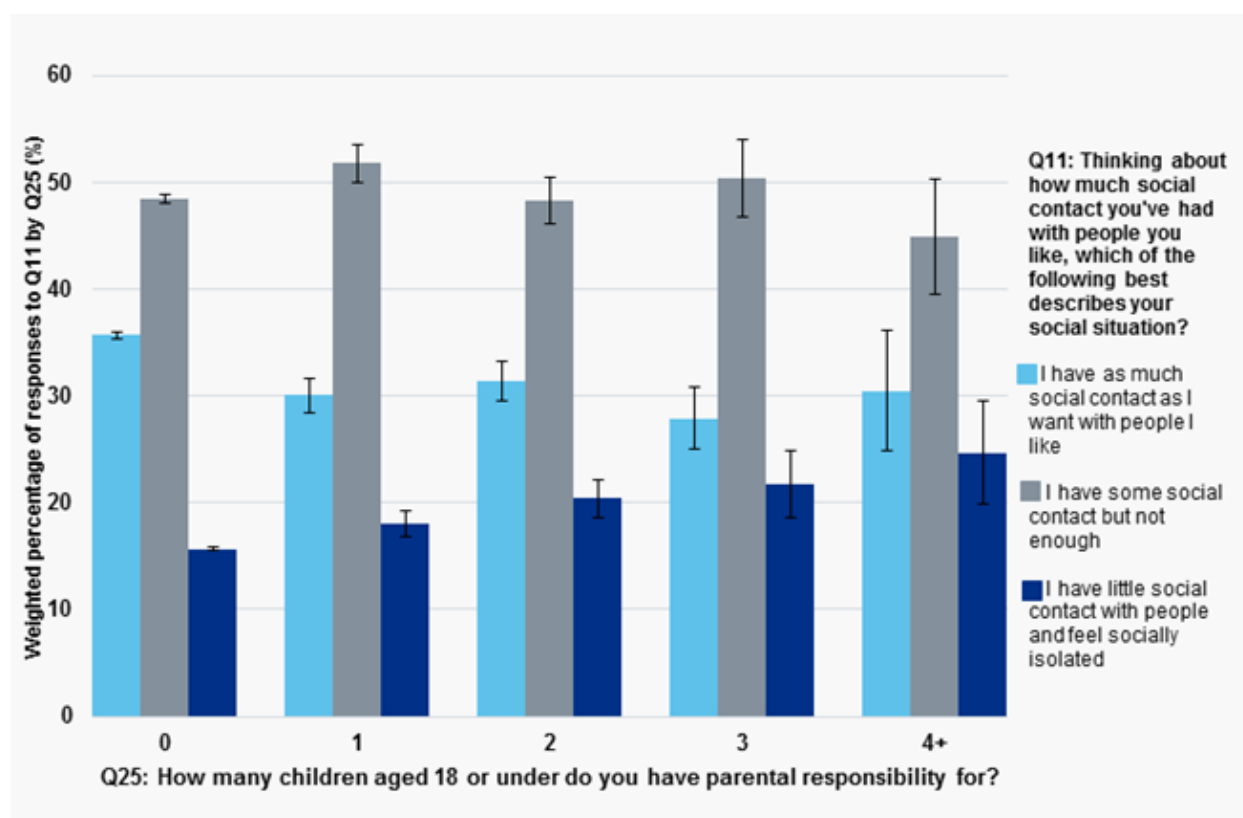
120,050 carers) that spend 100 or more hours a week looking after or helping the person they care for.

Social contact and isolation (Q11) and number of children the carer has parental responsibility for (Q25)

83.4 per cent of carers do not have children under 18 for whom they have parental responsibility for, 9.4 per cent have one child, 4.9 per cent have two, 1.4 per cent have three and 0.9 per cent (3,100) have four or more children.

Carers with no children under 18 for whom they have parental responsibility are also the lowest proportion reporting that they have little social contact with people and feel socially isolated.

Chart 2.7: Social contact and isolation by number of children carer has parental responsibility for



Source: SACE, NHS Digital

Chart 2.7 shows that for carers with no children aged under 18 for whom they have parental responsibility, 15.7 per cent (43,600 of the 277,150 carers) reported having little social contact with people and feeling socially isolated. In contrast, for carers with four or more children aged 18 or under for whom they have parental responsibility, 24.7 per cent (750 of the 3,100 carers) reported having little social contact with people and feeling socially isolated.

For carers with no children under 18 for whom they have parental responsibility, 35.7 per cent (99,050 of the 277,150 carers) reported they have as much social contact as they want with people they like.

This compares to 27.9 per cent (1,300 of the 4,750 carers) who have three children and 30.5 per cent (950 of the 3,100 carers) with four or more children.

How easy it is to find information about support

Access to information benefits carers and the people they support by helping them to have greater choice and control over their lives.

Question 16 of the survey asked carers “In the last 12 months, have you found it easy or difficult to find information and advice about support, services or benefits?”

Overall excluding those that did not try to find information and advice, 17.0 per cent of carers found it very easy to find 47.2 per cent found it fairly easy, 23.7 per cent found it fairly difficult and 12.1 per cent found it very difficult to find.

Question 16 of the survey responses received is used as the underlying data to calculate ASCOF measure 3D, “The proportion of people who use services and carers who find it easy to find information about support”. The following section looks at the response for question 16 alongside other variables where there are differences.

64.2%

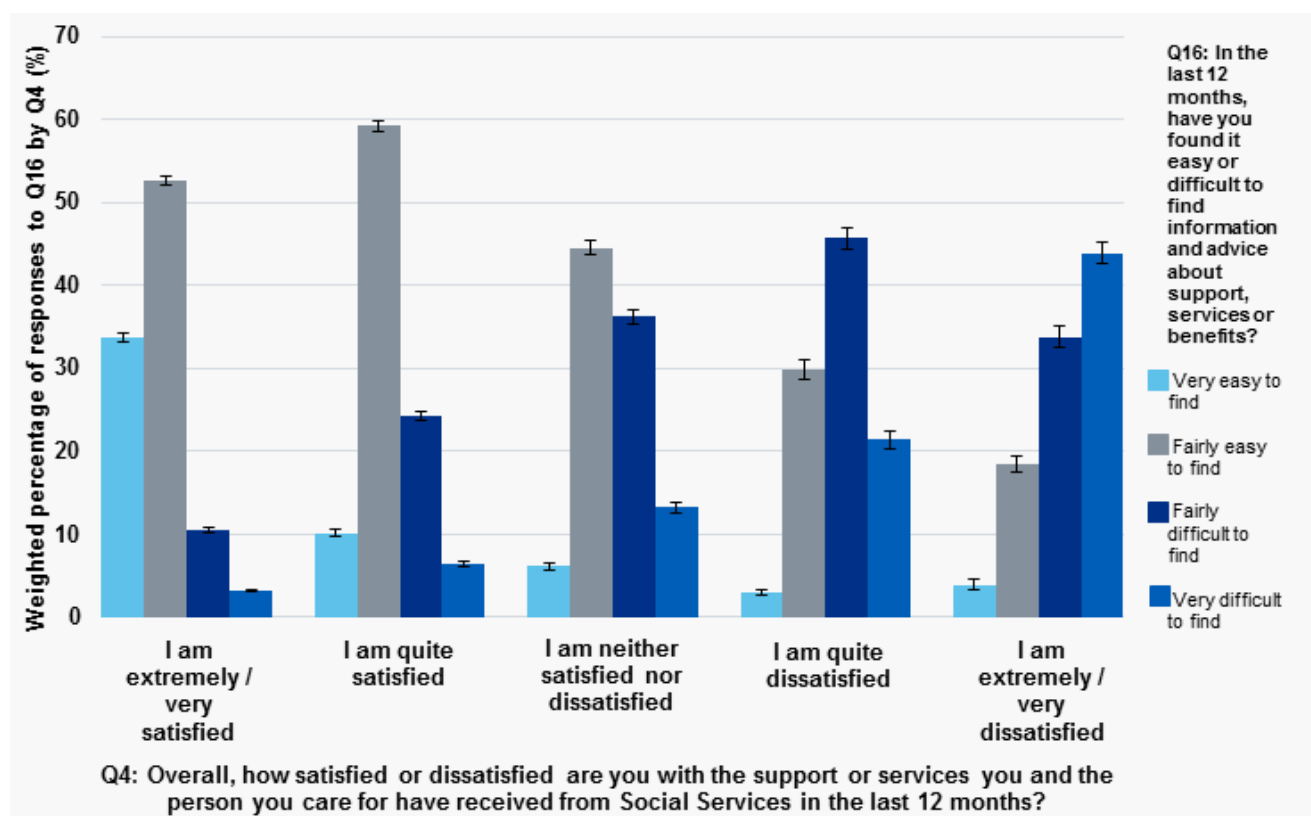
of carers reported they found it very or fairly easy to find information and advice about support, services or benefits.

How easy it is to find information about support (Q16) and satisfaction with the support and services (Q4)

Excluding carers that reported they hadn't received any support or services from Social Services in the last 12 months, 24.2 per cent were very satisfied with the support received. 32.0 per cent were quite satisfied, 15.6 per cent were neither satisfied nor dissatisfied, 7.0 per cent were quite dissatisfied, 2.8 per cent were very dissatisfied and 3.5 per cent were extremely dissatisfied with the support or services received.

Carers who are extremely or very dissatisfied with the support or services they receive and the person they care for have received from Social Services in the last 12 months report the highest proportion who also found it very difficult to find information and advice about support, services or benefits.

Chart 2.8: How easy carers find information about support by satisfaction with the support and services



Source: SACE, NHS Digital

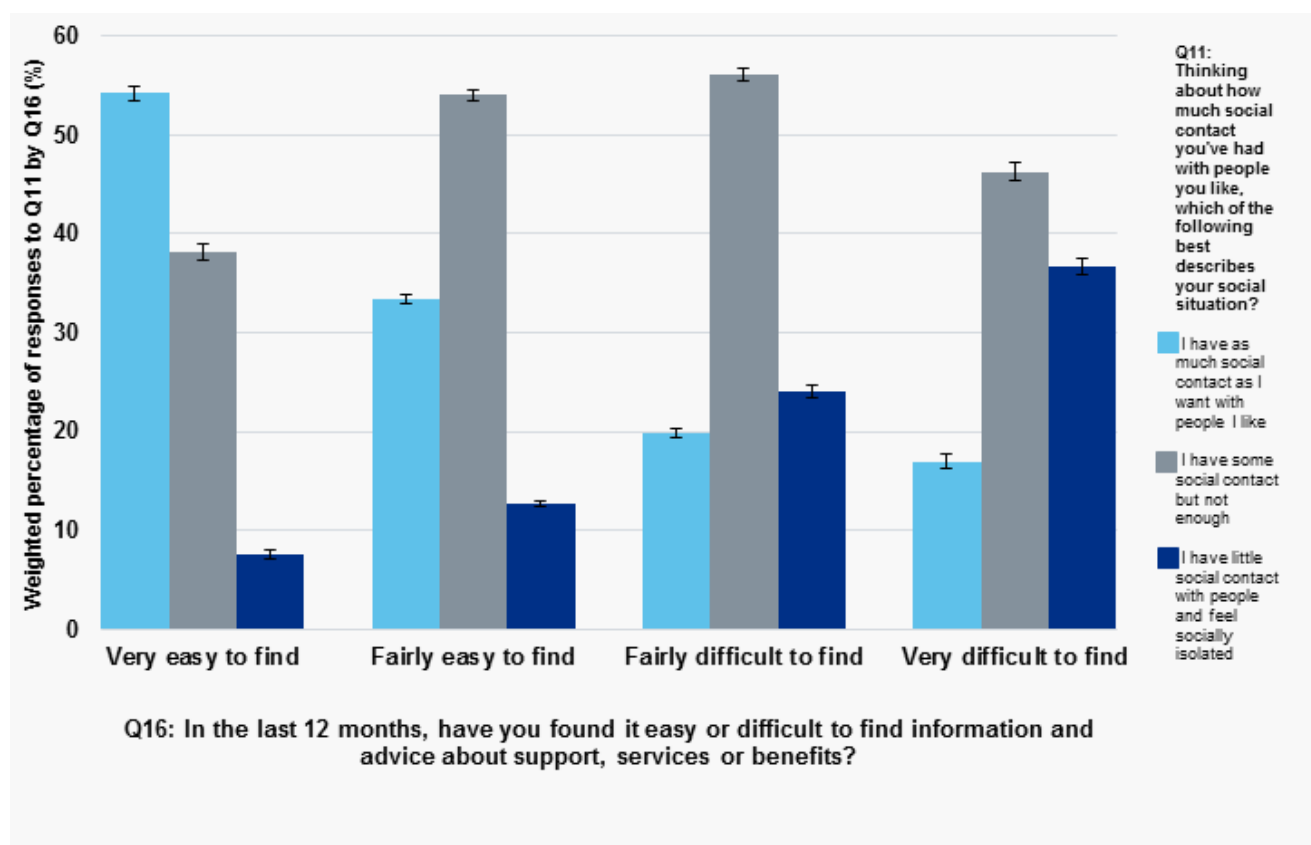
Chart 2.8 shows that for carers who are extremely or very satisfied with the support or services they receive or the person they care for have received from Social Services in the last 12 months, 3.2 per cent (2,350 of the 72,000 carers) report that they find it very difficult to find information and advice about support, services or benefits. In contrast, for carers who are extremely or very dissatisfied with the support or services received, 43.9 per cent (5,950 of the 13,550 carers) report that they find it very difficult to find information and advice about support, services or benefits.

For carers that are extremely or very satisfied with the support or services they receive, 33.7 per cent (24,250 of the 72,000 carers) report that they find it very easy to find information and advice about support, services or benefits, this compares to 3.0 per cent (450 of the 14,700 carers) who are quite dissatisfied and 3.9 per cent (550 of the 13,550 carers) who are extremely or very dissatisfied with the support or services received.

How easy it is to find information about support (Q16) and social contact and isolation (Q11)

Carers that find it very difficult to find information and advice about support, services or benefits also have the highest proportion that report having little social contact with people and feeling socially isolated.

Chart 2.9: Social contact and isolation by how easy carers find information about support



Source: SACE, NHS Digital

Chart 2.9 shows that for carers who find it very difficult to find information and advice about support, services or benefits, 36.7 per cent (14,900 of the 40,550 carers) report having little social contact with people and feeling socially isolated. In contrast, for carers who find it very easy to find information and advice, 7.6 per cent (4,350 of the 57,100 carers) report having little social contact with people and feeling socially isolated.

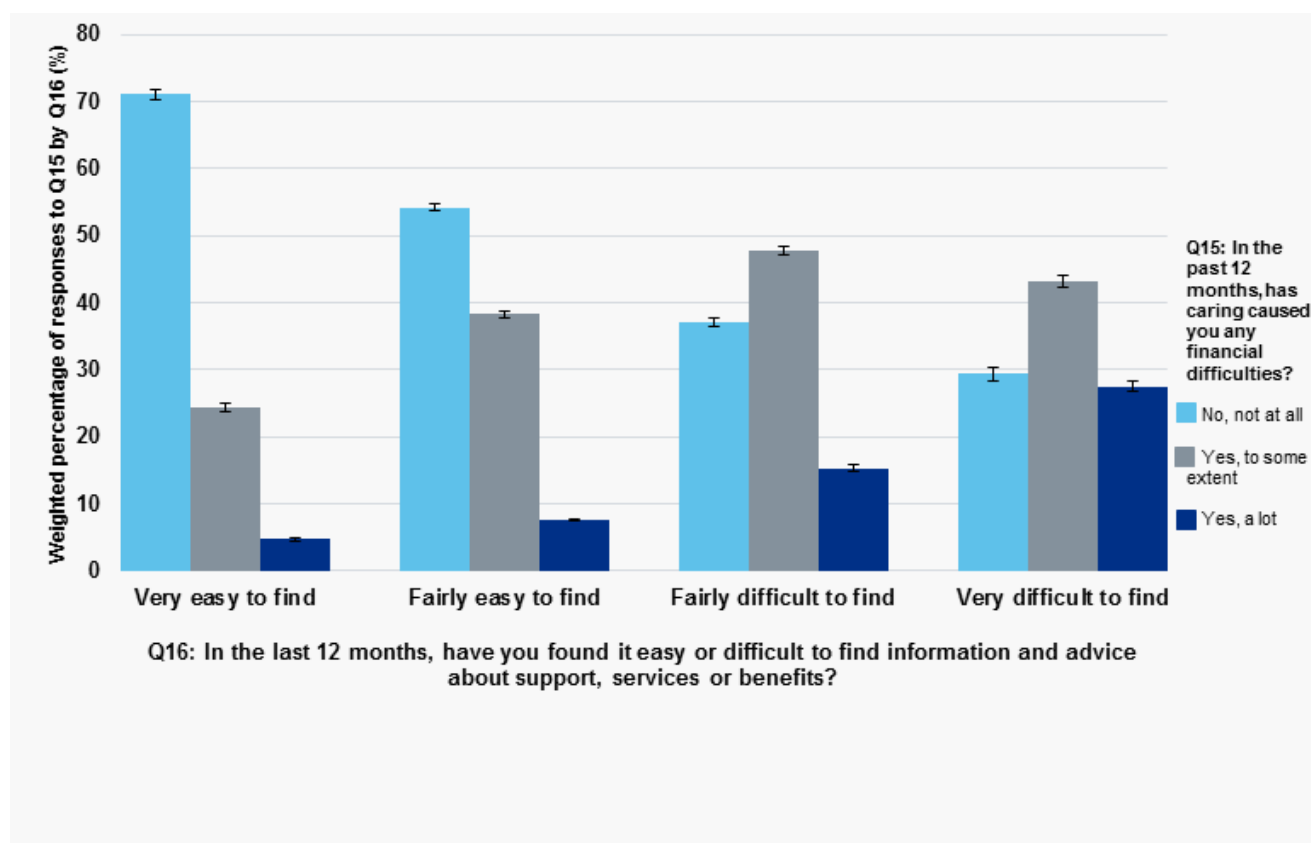
For carers who find it very difficult to find information and advice, 17.0 per cent (6,900 of the 40,550 carers) report having as much social

contact as they want, this compares to 54.2 per cent (30,950 of the 57,100 carers) who find it very easy to find information and advice.

How easy it is to find information about support (Q16) and financial difficulties (Q15)

Carers who found it very difficult to find information about support, services or benefits also had the highest proportion that reported they had lots of financial difficulties in the last 12 months caused by their caring responsibilities.

Chart 2.10: Financial difficulties by how easy carers find information about support



Source: SACE, NHS Digital

Chart 2.10 shows that for carers that found very difficult to find information and advice about support, 27.5 per cent (11,100 of the 40,350 carers) had a lot of financial difficulties caused by their caring responsibilities in the last 12 months. In contrast, for carers that found it very easy to find information and advice about support or benefits, 4.7 per cent (2,650 of the 56,700 carers) reported they had a lot of financial difficulties caused by their caring responsibilities in the last 12 months.

For carers that found it very difficult to find information and advice, 29.3 per cent (11,850 of the 40,350 carers) reported they did not have any financial difficulties, this compares to 71.0 per cent (40,250 of the 56,700 carers) who found it very easy to find information and advice.

Discussions about the support or services provided to the person cared for

Carers should be respected as equal partners in service design for the individuals for whom they care for, this improves outcomes for both the carer and the cared for person.

Question 18 of the survey asked carers “In the last 12 months, do you feel you have been involved or consulted as much as you wanted to be, in discussions about the support or services provided to the person you care for?”

Excluding carers that reported there had been no discussions that there were aware of, 39.4 per cent reported they always felt involved or consulted, 31.2 per cent usually felt involved or consulted, 21.7 per cent sometime felt involved or consulted and 7.7 per cent never felt involved or consulted.

Question 18 of the survey responses received are used as the underlying data to calculate ASCOF measure 3C, the “The proportion of carers who report that they have been included or consulted in discussion about the person they care for”. The following section looks at the response for question 18 alongside other variables where there are differences.

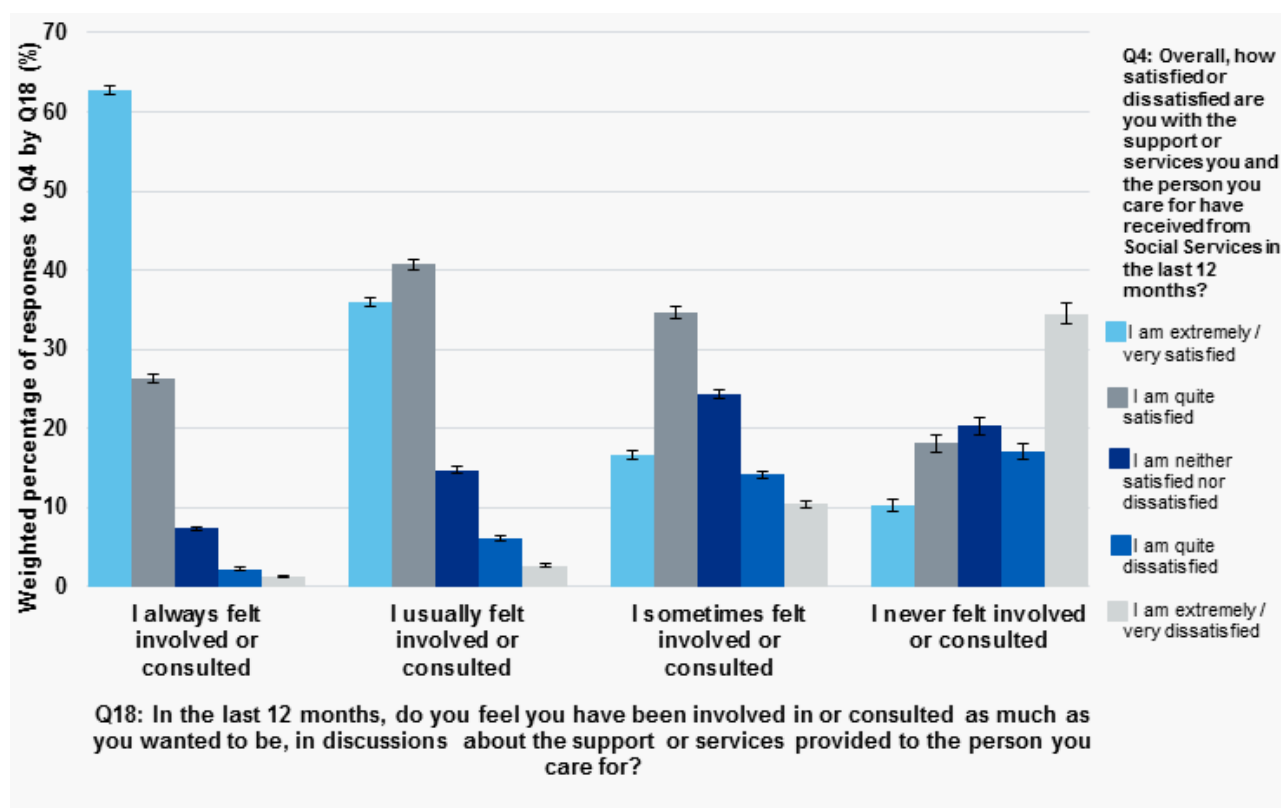
70.6%

of carers reported they usually or always felt involved or consulted in discussion about the support or services provided to the person they care for.

Discussions about the support or services provided to the person cared for (Q18) and satisfaction with the support or services received (Q4)

Carers that felt they were never involved or consulted in discussions about the support or services provided to the person they care for also had the highest proportion that reported they were extremely or very dissatisfied with the support or services they and the person they care for have received from Social Services in the last 12 months.

Chart 2.11: Satisfaction with the support or services received by discussions about support or services provided to the person cared for



Source: SACE, NHS Digital

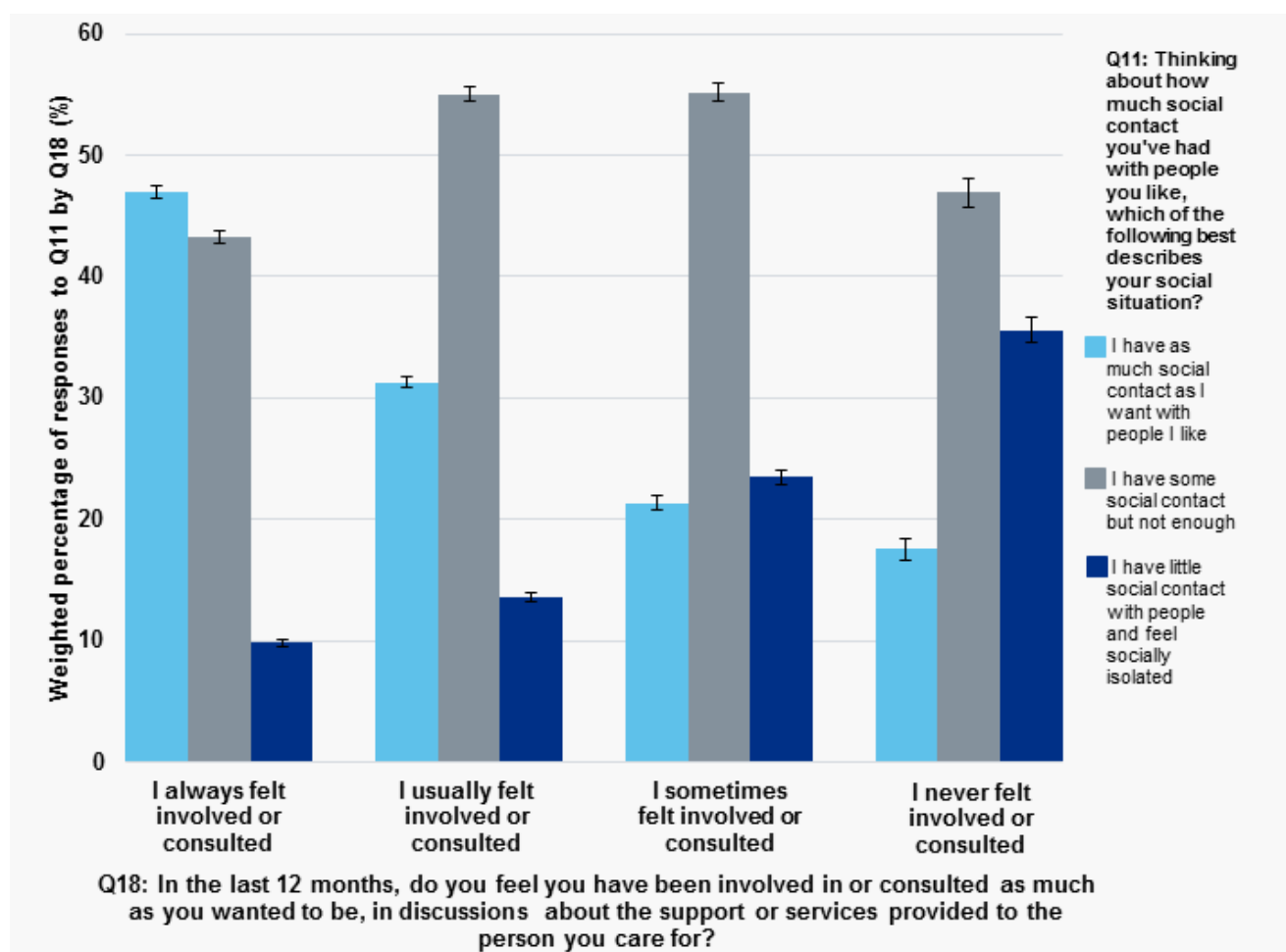
Chart 2.11 shows that for carers that felt they are never involved or consulted in discussions about the support or services provided to the person they care for, 34.5 per cent (6,650 of the 19,250 carers) felt extremely or very dissatisfied with the support or services they and the person they care for have received from Social Services in the last 12 months. In contrast, for carers that always felt involved or consulted in discussions, 1.3 per cent (1,600 of the 117,500 carers) felt extremely or very dissatisfied with the support or services received.

For carers that never felt involved or consulted in discussions, 10.2 per cent (1,950 of the 19,250 carers) reported being extremely or very satisfied with the support or services received, this compares to 62.8 per cent (73,850 of the 117,500 carers) who always felt involved or consulted in discussions.

Discussions about the support or services provided to the person cared for (Q18) and social contact and isolation (Q11)

Carers that never felt involved or consulted in discussions about the support or services provided to the person they care for had the highest proportion who felt they have little social contact with people and feel socially isolated.

Chart 2.12: Social contact and isolation by discussions about support or services provided to the person cared for



Source: SACE, NHS Digital

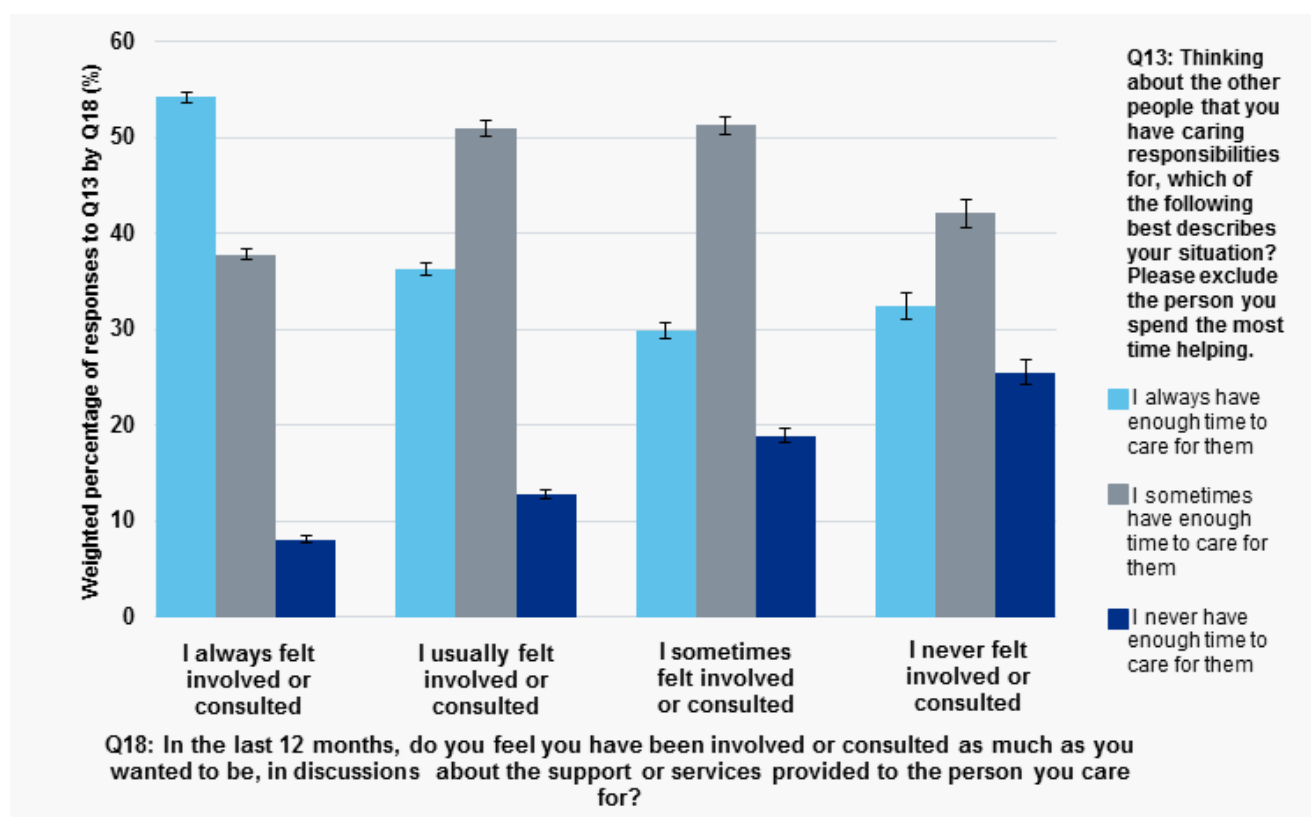
Chart 2.12 shows that for carers that never felt involved or consulted in discussions about the support or services provided to the person they care for, 35.6 per cent (9,150 of the 25,750 carers) reported having little social contact with people and feel socially isolated. In contrast, for carers that always felt involved or consulted in discussions, 9.8 per cent (13,050 of the 132,350 carers) reported they have little social contact with people and feel socially isolated.

For carers that never felt involved or consulted in discussions, 17.5 per cent (4,500 of the 25,750 carers) reported having as much social contact as they wanted, this compares to 47.0 per cent (62,150 of the 132,350 carers) who always felt involved or consulted in discussions.

Discussions about the support or services provided to the person cared for (Q18) and time to care for other people (Q13)

Carers that felt they were never involved or consulted in discussions about the support or services provided to the person they care for also had the highest proportion that reported they never have enough time to care for the other people they have caring responsibilities for.

Chart 2.13: Other caring responsibilities by discussions about support or services provided to the person cared for



Source: SACE, NHS Digital

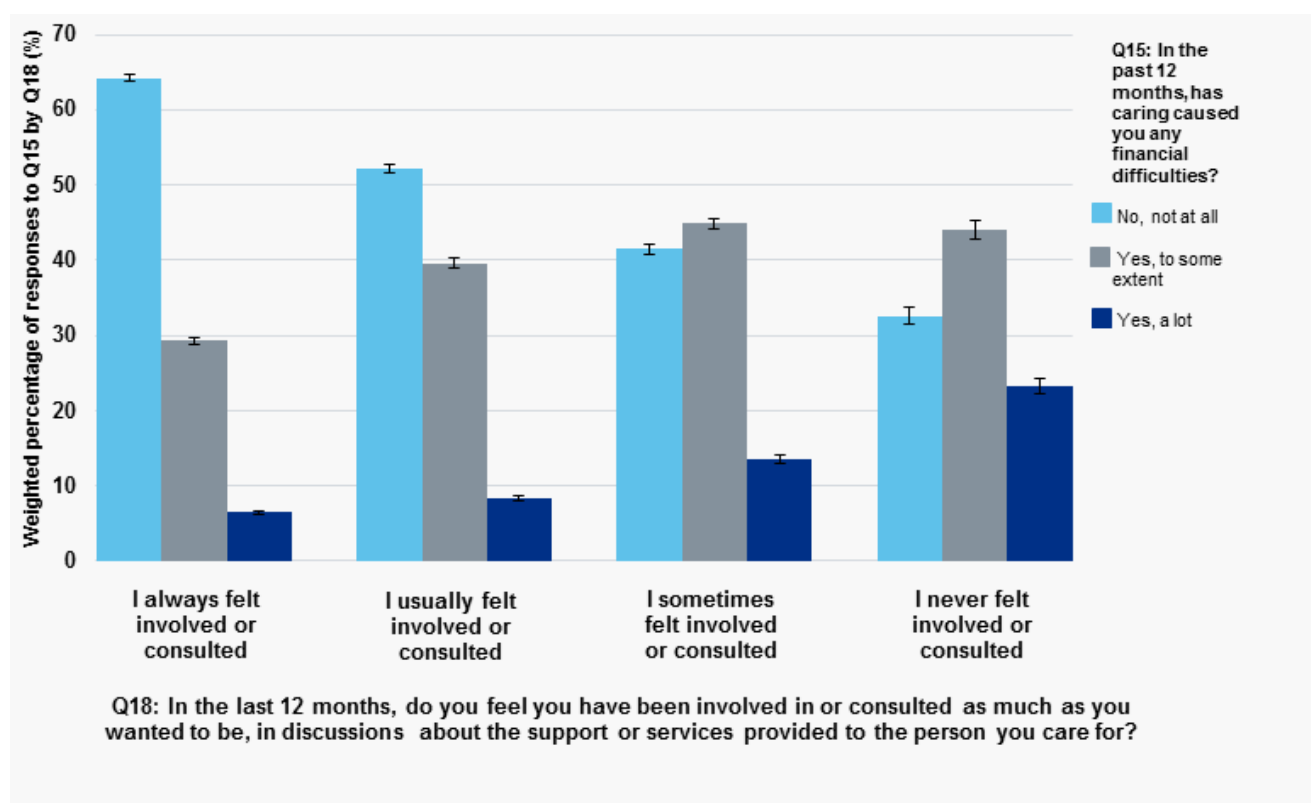
Chart 2.13 shows that for carers that always felt involved or consulted in discussions about the support or services provided to the person they care for, 8.1 per cent (6,650 of the 82,200 carers) felt they never had enough time to care for other people they have caring responsibilities for. In contrast, for carers that never felt involved or consulted in discussions about the support or services provided to the person they care for, 25.5 per cent (3,950 of the 15,550 carers) reported never having enough time to care for other people they have caring responsibilities for.

For carers that always felt involved or consulted in discussions about the support or services provided to the person they care for, 54.2 per cent (44,550 of the 82,200 carers) reported always having enough time to care for other people they have caring responsibilities for, compared to 29.9 per cent (13,200 of the 44,200 carers) for those that sometimes felt involved or consulted and 32.4 per cent (5,050 of the 15,550 carers) for those that never felt involved or consulted.

Discussions about the support or services provided to the person cared for (Q18) and financial difficulties (Q15)

Carers who always felt involved or consulted in discussions about the support or services provided to the person they care for reported a higher proportion of carers that did not have any financial difficulties in the last 12 months caused by their caring responsibilities.

Chart 2.14: Financial difficulties by discussions about support or services provided to the person cared for



Source: SACE, NHS Digital

Chart 2.14 shows that for carers that always felt involved or consulted in discussions about the services or support provided to the person they care for, 64.2 per cent (84,450 of the 131,450 carers) did not have any financial difficulties caused by their caring responsibilities. In contrast, for carers that never felt involved or consulted in discussions about support or services, 32.6 per cent (8,300 of the 25,500 carers) did not have any financial difficulties caused by their caring responsibilities.

For carers that that always felt involved or consulted in discussions, 6.5 per cent (8,500 of the 131,450 carers) reported they had lots of financial difficulties caused by their caring responsibilities, this compares to 23.2 per cent (5,900 of the 25,500 carers) that never felt involved or consulted in discussions.

Carer-Reported Quality of Life Score

The Carer-reported quality of life score gives an overarching view of the quality of life of carers. The measure combines individual responses to six questions measuring different outcomes relating to overall quality of life. The outcomes map to six domains; occupation, control, personal care, safety, social participation and encouragement and support. Details of which questions are used to calculate the quality of life score are provided in the Adult Social Care Outcomes Framework Handbook of Definitions⁴.

The Carer- reported quality of life score is ASCOF measure 1D. Details of the ASCOF scores at CASSR, regional and national level are provided in the ASCOF CSV alongside this publication⁵. The England level quality of life score in 2016-17 was 7.7 out of a maximum score of 12.

The following section looks at the Carer-reported quality of life score alongside other variables where there are differences.

7.7
the Carer-
reported quality
of life score (out
of 12) for
England in 2016-
17.

⁴

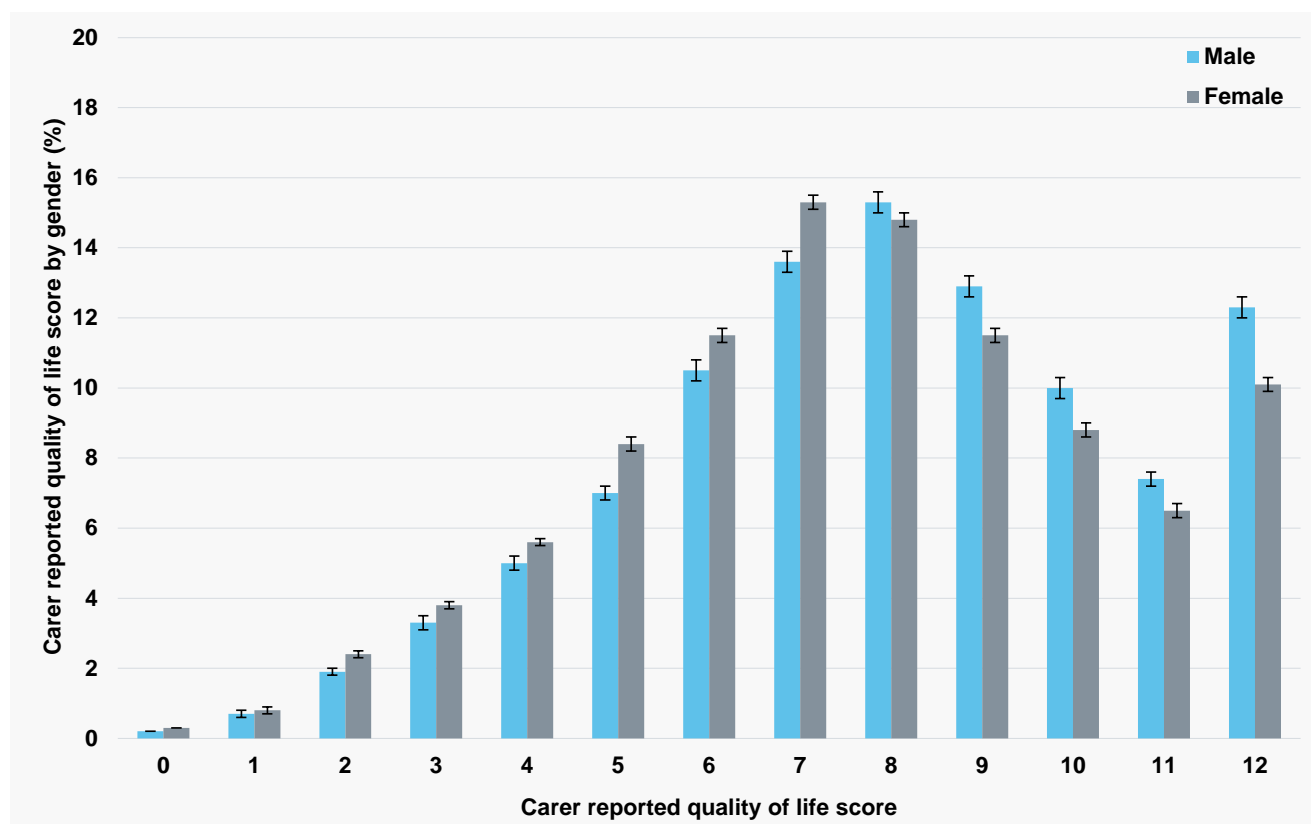
https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/416897/ASCOF.pdf

⁵ <http://digital.nhs.uk/pubs/psscscarersurvey1617>

Quality of Life Score and gender

There are a higher proportion of male carers reporting a high quality of life score compared to female carers.

Chart 2.15: Carer-reported quality of life score by Gender



Source: SACE, NHS Digital

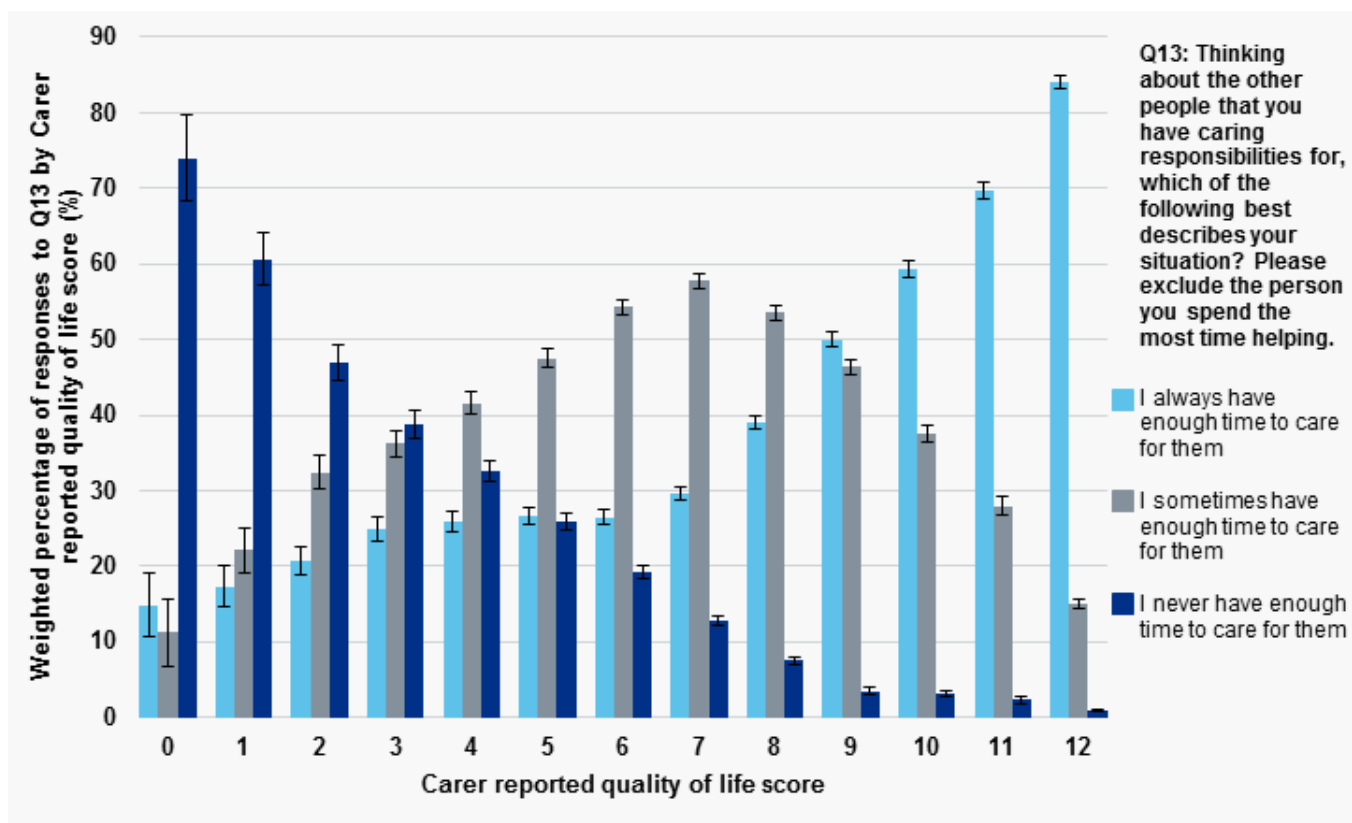
Chart 2.15 shows 12.3 per cent (13,800) of the 112,250 male carers reported the highest possible carer quality of life score, this compares to 10.1 (23,000) per cent of the 227,550 female carers.

- 2.8 per cent (3,150) of male carers reported a carer quality of life score of two or less, compared to 3.6 per cent (8,100) of female carers.

Quality of Life Score and caring responsibilities (Q13)

Carers with a high quality of life score have a high proportion of carers reporting always having enough time to care for the other people they have caring responsibilities for.

Chart 2.16: Other caring responsibilities by Carer-reported quality of life score



Source: SACE, NHS Digital

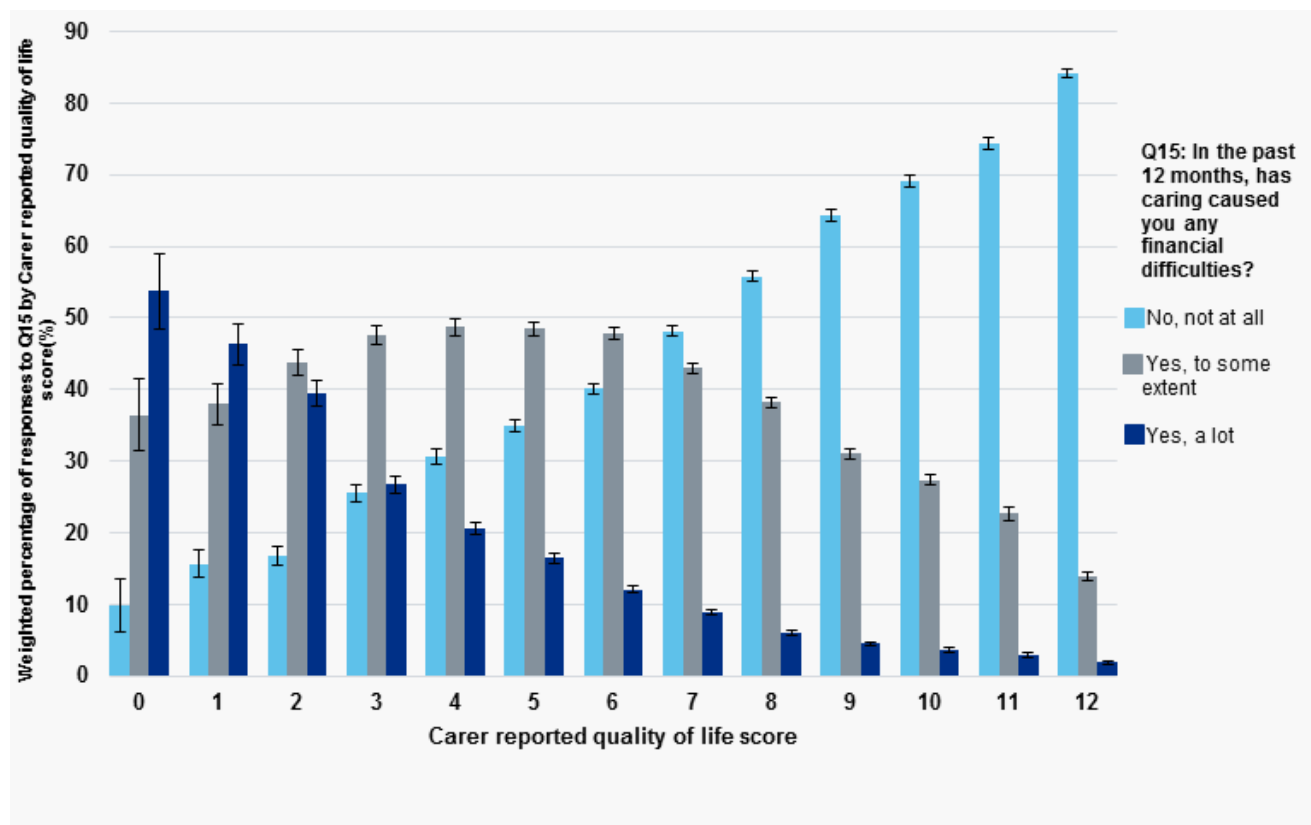
Chart 2.16 shows that for carers with the highest possible quality of life score, 84.0 per cent (19,550 of the 23,250 carers) report always having enough time to care for the other people they having caring responsibilities for. In contrast, for carers with the lowest quality of life score, 14.8 per cent (100 of the 500 carers) report always having enough time to care for the other people they having caring responsibilities for.

For carers with the highest quality of life score, 0.9 per cent (200 of the 23,250 carers) report never having enough time to care for the other people they have caring responsibilities for, this compares with 74.0 per cent (400 of the 500 carers) with the lowest quality of life score.

Carer Reported Quality of Life Score and financial difficulties (Q15)

Carers with a high quality of life score have a high proportion that report not having had financial difficulties caused by their caring responsibilities.

Chart 2.17: Financial difficulties by Carer-reported quality of life



Source: SACE, NHS Digital

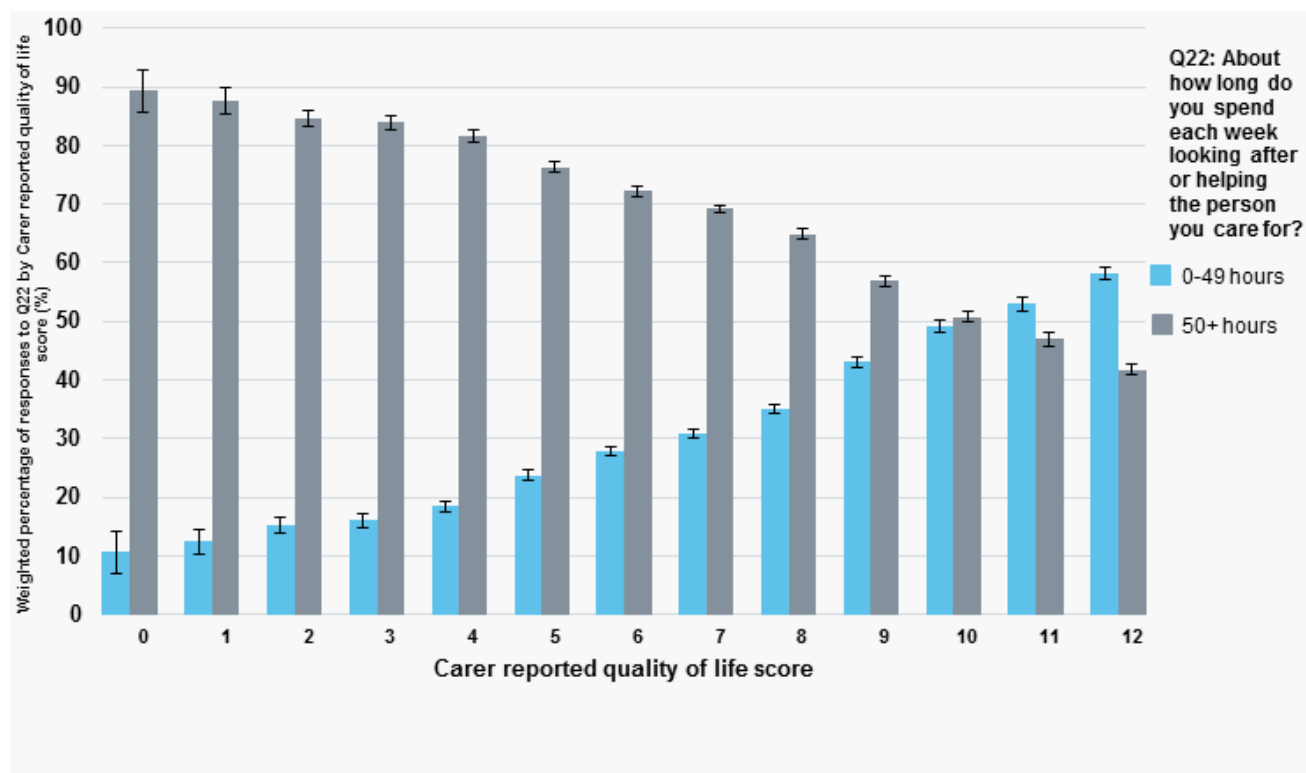
Chart 2.17 shows that for carers with the highest quality of life score, 84.1 per cent (28,900 of the 34,400 carers) reported they did not have any financial difficulties caused by their caring responsibilities. In contrast, for carers with the lowest quality of life score, 9.8 per cent (100 of the 900 carers) report they did not have any financial difficulties caused by their caring responsibilities.

For carers with the highest quality of life score, 1.9 per cent (650 of the 34,400 carers) reported they had a lot of financial difficulties caused by their caring responsibilities, this compares to 53.7 per cent (500 of the 900 carers) with the lowest quality of life score.

Quality of Life Score and how long spent each week looking after or helping the person cared for (Q22)

As carer reported quality of life scores increase, the proportion of carers that spend 50 hours a week or more looking after or helping the person cared for decreases.

Chart 2.18: Number of hours per week carer spends looking after cared for person by Carer-reported quality of life score



Source: SACE, NHS Digital

Chart 2.18 shows that for carers with the highest possible carer quality of life score, 41.8 per cent (10,450 of the 24,950 carers) spend 50 hours a week or more looking after or helping the person they care for. In contrast, for carers with the lowest carer quality of life score, 89.4 per cent (650 of the 700 carers) spend 50 hours or more a week looking after or helping the person cared for.

For carers with the highest possible carer quality of life score, 58.2 per cent (14,500 of the 24,950 carers) spend less than 50 hours a week looking after or helping the person cared for, this compares to 10.6 per cent (100 of the 700 carers) for carers with the lowest possible carer quality of life score.

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