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The impact of social care services on carers' quality of life

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Abstract: Unpaid care is an important part of long-term care systems. It is increasingly recognised that carers have their own health and wellbeing needs. Carer-specific interventions, as well as support for the care-recipient, may enable carers to maintain their own health and wellbeing alongside caring. This study seeks to establish whether and how community-based care services affect carers' QoL. The ASCOT-Carer interview (INT4) was used to capture carers' social care-related quality of life in qualitative interviews and a survey of carers' in England to provide insights into the impact of community-based care services on carers' QoL outcomes.

Key words: Quality of life; caregiver; social care; ASCOT-Carer

Word count: 8,162 words

Introduction

Unpaid care provided by family and friends of adults living with long-term health conditions, disability or age-related impairments comprises an estimated 80% of all long-term care provided across Europe (Hoffmann and Rodrigues, 2010). The decline in intergenerational co-residency, fertility rates and family size, and women's increased participation in the labour market are projected to contribute to a shortfall in informal care availability over the next two decades as demand for long-term care increases with ageing populations and increased multi-morbidity (Kingston et al, 2018; Pickard, 2015). In light of this challenge and in recognition of potential negative effects of caregiving on carers' health and wellbeing, policy developments in the UK, Europe and beyond have sought to establish legal entitlements and support for carers, even if there is considerable variation in type, availability and eligibility by country (Courtin et al, 2014; Brimblecombe et al, 2018). Support for carers includes, for example, formal care services for the person with care needs ('replacement care'), cash benefits, flexible working or paid care leave, psychological therapy or training interventions and support groups. There is emerging evidence of the effectiveness of flexible support and multi-dimensional interventions that adapt to the specific needs of the care-recipient and the carer's circumstances (Brimblecombe et al, 2018).

There are competing perspectives of the relationship between informal care and formal long-term care services (also known as social care in the UK, which refers to services for people with needs related to illness, disability or older age, e.g. residential care, home care). Carers may be viewed as the default source of care (*resources*), as partners enabled and encouraged by social care services (*co-workers*) and/or as individuals with support needs in their own right (*co-clients*) (Twigg, 1989). The perspective of carers as *co-clients* has been especially informed by the evidence that caregiving may have a negative impact on health (Brouwer et al, 2004; Van Houtven and Norton, 2004; Schmitz and Westphal, 2015), life satisfaction (van den Berg et al, 2014) and ability to maintain everyday activities, e.g. employment (King and Pickard, 2013). The policy strategy in England has primarily sought to position carers on an equal footing with care-recipients with their own needs (*co-clients*), yet also recognise and promote the concept of partnership between carers and care services (*co-workers*) (Department of Health and Social Care, 2018). The perspective of carers as co-clients is reflected also in the Care Act (2014), which places a responsibility on local authorities to address outcome needs of carers (e.g. to maintain social relationships, leisure activities and employment) as clients in their own right.

The Carers Action Plan in England highlights the importance of carer-specific support. In England, carer-specific services are commissioned by local authorities and may be delivered through local carers' or other voluntary organisations (Department of Health and Social Care, 2018). Even though carers in England have a legal right to assessment and support for eligible needs (Care Act, 2014), only an estimated 6% of carers receive support from local authority adult social services (National Audit Office, 2018). Furthermore, the evidence of the effectiveness of carer-specific interventions to improve carers' QoL is relatively weak due to methodological constraints – specifically, in terms of suitable outcome measures (Pickard, 2004). Studies tend to use carer-specific or generic measures to capture burden/strain, health-related quality of life or psychological outcomes; however, these may not be sensitive to the effect of social care interventions. The development of the Adult Social Care Outcomes Toolkit for carers (ASCOT-Carer) seeks to address this by measuring aspects of quality of life valued by carers that may be improved by social care services, or *social care-related quality of life* (SCRQoL) (see Table 1) (Rand et al, 2012; Rand et al, 2015). The tool was developed in England and has been translated for use in (cost-)effectiveness studies or carers' need assessment in Finland, Austria and Japan (Trukeschitz et al, 2018; Linnosmaa et al, 2019; Yamaguchi and Rand, 2019).

The ASCOT-Carer also offers a way of capturing the wider benefit of social care services on carers. In healthcare, there is increasing awareness of the 'spill-over effects' in (economic) evaluation studies of interventions on carers and (more broadly) families and households, alongside the effect on patients (Basu and Meltzer, 2005; Goodrich et al, 2012; Hoefman et al, 2013; Al-Janabi et al, 2016). It has been argued that considering spillover effects may have unintended effects on access to healthcare and also not adequately account for those individuals or groups who would bear the opportunity cost (McCabe, 2018). Despite these potential pitfalls, there are compelling arguments for the inclusion of spillover effects to consider the wider societal impact of healthcare, if applied with appropriate caution to address the identified issues of equitable access to healthcare and potential displacement (Brouwer, 2018). Indeed, these issues are already part of the growing literature on how to estimate spillover effects to take into account the displacement of funding of one intervention over another (Al-Janabi et al, 2016) and avoiding the reinforcement of existing social inequality – especially with regard to the absence of family or household members (Basu and Meltzer, 2005). The discussion of spillover effects in healthcare also apply to social care, with the added complexity that carers are viewed as *co-clients* (patients) in their own right.

In conceptualising spillover effects, there are two aspects: (1) the effect of caregiving for someone (the *caregiving effect*) and (2) the effect of caring about someone (the *family effect*) (Bobinac et al, 2010, 2011; Brouwer, 2006). The latter may apply to households and families – regardless of caregiving responsibilities – whereas the former only applies in the case where someone is providing informal care to the care-recipient. These concepts may also be applied to the impact of social care services on carers' QoL. Unlike in healthcare, where it has been argued that there is a need to disentangle the *caregiving* from the *family effect* to avoid overestimating the intervention effect (Bobinac et al, 2011), it may be argued that the *family effect* is within the remit of social care interventions, especially in psychosocial interventions (e.g. carer support worker).

Interventions for the care-recipient (e.g. home care) may reduce time spent on caregiving tasks, either overall or for emotionally burdensome tasks (e.g. personal care), thereby, limiting an adverse *caregiving effect* on QoL. Indeed, this is supported by evidence of substitution between the amount of professional care and informal care received by older adults (Bonsang, 2009) and that higher care-recipient QoL is associated with reduced time spent on care tasks and increased carer QoL (Dixon et al, 2006). By contrast, the *family effect* captures the way in which someone's QoL may influence the QoL of the people around them because they *care about* the person. Here, the impact of social care services may be through the impact on the care-recipient (e.g. home care may improve the care-recipient's QoL and, thereby, also the carer's QoL) via the mutual dependence in utility between the cared-for person and their carer (Becker, 1981; Van Houtven and Norton, 2004; Rand et al, 2017). The impact of social care on carers' QoL through the *family effect* may also be as a direct effect of services that mediate the carer's emotional response to *caring about* the care-recipient. This may be an intended direct effect of an intervention (e.g. carers' support workers, who encourage carers to self-care) or an indirect effect (e.g. emotional support from domiciliary care workers).

In this study, we sought to establish whether and how community-based social care services affect carers' QoL in qualitative interviews and a survey of carers in England using the ASCOT-Carer interview (INT4). The ASCOT-Carer INT4 is a measure of carers' social care-related QoL that uses a novel counterfactual self-estimation method to estimate the effect of services on carers' QoL (Rand et al, 2012, 2015). This counterfactual self-estimation method was initially developed and tested with the service user (care-recipient) version of the ASCOT (Malley et al, 2019). The aim of the study was to determine whether and how community-based social care services have spillover effects on carers' QoL as a way of understanding the wider impact of social care.

Methods

Qualitative interviews

The aim of identifying whether and how social care services affect carers' SCRQoL was addressed through a secondary analysis of qualitative interviews conducted as part of the *Identifying the Impact of Adult Social Care* (IIASC) study. These qualitative interviews were originally conducted to inform the development of the ASCOT-Carer interview (INT4) questionnaire, which is reported elsewhere (Rand et al, 2012). The study inclusion criteria were: adult carers aged 18 years or over, who supported someone with a physical disability or sensory impairment, learning disability or mental health condition in receipt of fully or partly publicly-funded social care services. Three local authorities in England and two carers' organisations within those areas supported recruitment. The local authorities distributed a letter of invitation to eligible carers identified from their social care records. The two carers' organisations advertised the study in their newsletters. In response, 37 carers indicated their interest. Of those, 31 carers completed an interview of 40 to 70 minutes' duration. The interviews were conducted between April and July 2012 by one researcher (SR) and took place at the participant's home or another convenient location. Two interviews were excluded from the analysis due to poor quality audio recording with incomplete transcription (*n*=1) or the length of time since the carer had been in contact with the care-recipient (*n*=1).

The interviews were transcribed and imported into NVivo for analysis using the framework approach (Ritchie and Lewis, 2003). This involves familiarisation with the interview by listening to the audio file, reading transcripts and reviewing notes. The data were initially coded using *a priori* concepts (the ASCOT-Carer SCRQoL attributes, the effect of services on carers' QoL) and emerging themes (barriers to accessing social care, the meaning and value of the caring role). This analysis is reported elsewhere (Rand and Malley, 2014). Here, we present a secondary data analysis that focuses only on the effect of social care on carers' SCRQoL using the analytical framework outlined in Box 1.

Box 1. Analytical framework

Insert Box 1 here.

Survey of carers

The study aim of identifying whether and how community-based social care services affect carers' QoL was also addressed by analysis of data collected in a survey of service users and carers in 22 English local authorities. The study is reported elsewhere (Forder et al, 2016). Here, we focus on the data collected using the ASCOT-Carer INT4. The questionnaire uses a counter-factual self-estimation method to enable carers to self-report an estimate of the effect of social care services on QoL (Rand et al, 2012).

Study design and sample

Service users were identified from a non-stratified random sample of people in receipt of fully or partly publicly-funded support primarily due to a physical disability, mental health problems or intellectual disability and/or from respondents to the 2012/13 Adult Social Care Survey (ASCS), who had agreed to be contacted about further research. Interviews were completed between June 2013 and March 2014 (*n*=990). All participants were asked whether they received help and who provided that help in relation to a number of activities of daily living and instrumental activities of daily living (I/ADLs). If respondents received help from family or friends, they were asked to pass a study information pack to the carer who was reported to spend the most hours per week on care-related tasks by the service user.

A total of 387 carers were recruited and completed an interview. The interview was completed using the same mode of administration as the service user (i.e. by telephone or face-to-face). In the analysis presented here, we only consider the carers of people with physical disability or mental health conditions (*n*=316) because the interviews with adults with intellectual disabilities did not collect the detailed service use information for the calculation of cost-weighted intensity.

Questionnaire

The survey collected data on the carer (age, sex, educational level, employment status, self-rated health, mobility) and aspects of the caregiving situation (duration of caregiving, suitability of home design for caregiving). The carer’s wider social support was captured by rating of involvement with regular social groups and frequency of contact by telephone with friends and family. The potential availability of social care services for the carer’s own needs was indicated by asking whether the carer had ever completed a carer’s assessment. Items to ask whether the household was in receipt of means-tested benefits and to self-rate the household financial situation captured the financial resources available to the household.

The questionnaire also included the ASCOT-Carer INT4.[1] This instrument may be used to estimate three measures of carer SCRQoL (Rand et al, 2012, 2015). First, there is the ***ASCOT-Carer SCRQoL current***. This is the carers' self-rated SCRQoL for each of the seven ASCOT-Carer attributes (Table 1). Each attribute may be rated as the ideal state, no needs, some needs or high-level needs.

Second, there is ***ASCOT-Carer SCRQoL expected***. The ASCOT-Carer INT4 uses a counterfactual self-estimation method, which has been adapted from the ASCOT INT4 for service users (Malley et al, 2019). The counterfactual is an estimate of the carer's SCRQoL *in the absence of services* (Netten et al, 2012; Rand et al, 2012).The respondent was then asked whether services affected each SCRQoL attribute. If respondents answered yes or were unsure, they were also asked to self-estimate their counterfactual quality of life (Box 2), i.e. to imagine what life would be like without social care support whilst holding other factors constant. In this study, respondents were asked to self-estimate their counterfactual based on *all* social care services accessed by the care-recipient and carer. The same four response levels were applied as for the rating of ASCOT-Carer SCRQoL current (i.e. ideal state, no needs, some needs and high-level needs) (Box 2). Where the respondent said services did not have an effect, their ASCOT-Carer SCRQoL current score was applied as the ASCOT-Carer SCRQoL expected score.

Third, the ***ASCOT-Carer SCRQoL gain*** is an estimate of the effect of social care services on QoL calculated by subtracting the ASCOT-Carer expected from the current SCRQoL score. Utility weights were applied to calculate an overall ASCOT-Carer SCRQoL gain index score (Batchelder et al, 2018). The larger the score (up to a maximum of one (1)), the larger the impact of services on the carer's quality of life – with a score of one (1) representing an impact where services improve SCRQoL from

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[1] The questionnaire is available at: www.pssru.ac.uk/ascot.

the worst possible (high-level needs) to the best possible (ideal state) for all seven ASCOT-Carer attributes.

Table 1. ASCOT-Carer attributes

Insert Table 1 here.

Box 2. ASCOT-Carer INT4 counterfactual self-estimation

Insert Box 2 here.

The carer data were linked to the service user data. In this study, we considered the service user's age, sex, primary reason for support, and severity of social care need indicated by self-report of how many of eight I/ADLs were completed alone with difficulty or were unable to be completed without help.[2] The analysis also used a variable to capture whether the care-recipient had received help to answer one or more of the questions in the ASCOT INT4 (service user version).

Intensity of service use by the care-recipient was measured as cost-weighted utilisation per week. This was calculated based on self-reported use of the following services: home care, day centres, meals services, social work support, and equipment and home adaptations. The calculation of weekly cost-weighted utilisation considered all social care services, funded publicly or privately. To estimate cost-weighted utilisation, England-mean (gross) unit cost data were used. The cost-weighted utilisation variable had the usual high degree of rightward skew. To this end, we censored cost-weighted utilisation values of greater than £1,500 per week (more than twice the gross cost of residential care) to £1,500. Even with censoring (*n*=10 (3.3%)), cost-weighted utilisation was highly skewed. We therefore used a log transformed value, which had a distribution closer to normal.

Statistical analysis

All analyses were performed using Stata version 13. Descriptive statistics are reported for the sample characteristics, the ASCOT-Carer SCRQoL gain index score (a measure of the impact of social care

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[2] This scale was calculated from the following eight I/ADLs: getting around the house; getting in/out of bed or a chair; feeding yourself; dealing with money and paperwork; washing in a bath or shower; getting un/dressed; using the toilet; and washing face and hands. Each item was rated as able to do it without help (0), with difficulty on my own (1), only with help (2) or unable to complete at all (3). The sum of the score for each of the eight items form a scale from zero (no needs) to 24 (severe needs).

services on carers' SCRQoL) and also the rating of the seven ASCOT-Carer attributes in terms of current SCRQoL and expected SCRQoL. Multiple regression analysis using ordinary least squares (OLS) was used to assess the construct validity of the ASCOT-Carer SCRQoL gain index score. Social care services are designed to address the quality of life needs of service users and carers. Therefore, the impact of services should be related to the intensity of service use. To test this hypothesis, the regression analysis included the service user's cost-weighted utilisation of social care services as an indicator of the intensity of service use. Receipt of carer-specific services were not included separately in the analysis due to the small numbers in the sample. Instead, we used an item that asked carers to self-report whether they had had a carer's assessment as an indicator of carer-specific support. Individual characteristics of the carer and care-recipient were also considered.

By contrast to ASCOT-Carer SCRQoL gain, the ASCOT-Carer current SCRQoL may additionally be associated with factors not related to social care service inputs: specifically, the individual characteristics of the carer (e.g. age, sex, health, mobility, financial situation, education or employment, social contact); the individual characteristics of the care-recipient (e.g. age, sex) and their social care needs (e.g. I/ADLs with difficulty, mental health conditions) and the caregiving context (e.g. caregiving intensity or duration, suitability of home design for caring). The mode of interview administration was also considered because it has been found that survey administration mode is related to rating of current SCRQoL (Rand et al, 2015). Although included as covariates in the estimation, all these factors were expected to be unrelated to the ASCOT-Carer SCRQoL gain.

Ethics

Ethical approval was obtained from the social care research ethics committee in England (Ref: 12/IEC08/0009, 12/IEC08/0049).

Results

Qualitative interviews

The sample characteristics are outlined in Table 2. The sample included carers of people with diverse support needs, including physical disability (44%), intellectual disability (20%), mental health problem (17%), dementia (17%) and sensory impairment (2%). The majority were female (83%) and supported a spouse/partner (41%) or an adult child (38%). All were aged 45 years or older.

Table 2. Qualitative interview sample characteristics (*n*=29)

Insert Table 2 here.

In responding to the draft ASCOT-Carer INT4 questionnaire, the carers were able to construct an internal representation of what their lives would be like without social care services and to rate their quality of life by reference to that. In 'thinking aloud' as they responded to these questions (Willis, 2005), carers articulated whether and how their experience of social care services affected their QoL in relation to each ASCOT-Carer attribute.

Positive impact of services

The carers were able to judge and describe whether or not social care support had a positive effect for all of the aspects of quality of life included in the ASCOT-Carer INT4 (see Table 3).

Table 3. Examples of how care support affect ASCOT-Carer SCRQoL attributes

Insert Table 3 here.

Where a positive impact of services was reported, carers sometimes spoke of how services replaced or reduced their care-related tasks. This enabled the carer to have more time or energy to meet their own needs.

> "I used to spend all my time getting him out of bed and showering him, dressing him. It took a lot of my time up. I've got that time to spare now… I can go out in the garden, deadhead the roses, and whatever I want to do."

CR19, *Occupation*

Some carers spoke of how services motivated them to self-care or to access other sources of formal support. In some cases, the support also facilitated a shift in identity and self-perception from ‘just a relative’ to a ‘carer’. This reappraisal of self-understanding gave the respondents permission to seek help. In some cases, it also changed how the carer prioritised their own needs:

> “Sometimes things happen and you forget about yourself and you end up not going to the doctor. But [Carer Support Worker] would remind me about that - say now, come on, let’s think about you because if you’re not well, how can you look after [care-recipient]. And it’s right, you’ve got to sometimes think about yourself.”

CR18, *Self-care*

Others spoke of the way in which services alleviated subjective burden in a way that improved their QoL: for example, one carer described how she was able to re-establish a better pattern of sleep after home care alleviated the physical and emotional stress of the situation:

> “I just think back to the scenario when Mum was so ill. That was just absolute hell, it really was. That was the worst month of my life. It was the pressure. It takes off your shoulders to know that somebody else is going in there and doing what she needs when they're supposed to, and you can rely on them.”

CR12, *Self-care*

No impact of services

All of the respondents reported at least one attribute where formal services did not affect their QoL. At least one carer reported ‘no impact’ of services for each of the ASCOT-Carer attributes. The rationale for the lack of impact of services was reported in some cases by carers whose SCRQoL was at the ‘ideal state’, regardless of social care services.

> "I sleep well. He sleeps well. We eat quite well – although no, I don't think it's anything to do with the support services."
>
> CR4, *Self-care*

In other cases, the carer reported 'no needs' ('it's fine') but were not motivated to proactively seek improvement. Some carers reported that they had some degree of unmet social care-related need (i.e. some needs, high-level needs) yet described how a lack of time or energy made it difficult to access support. This was even when the carer recognised that services could potentially improve QoL:

> "Some people like doing that type of thing [social events organised by carers' group]. They have a meeting once a month, but I've had to drop out of that because of doing the transport for the hospital. I do know they do have these things. It's just something that I don't have the time to join in. I'm so tired with his treatment."
>
> CR15, *Social participation*

Some carers reported a mismatch between SCRQoL needs and available interventions: for example, a carer who accessed events and day trips organised by a carer's organisation, noted that these services did not affect her ability to sleep without disturbance or anxiety (*Self-care*) [CR23]. Sometimes it was recognised that the mismatch between carer's needs and the service(s) used could be addressed by accessing a different type of service that would be more effective. This was, however, not always feasible in practice. Barriers included limited availability of other services and/or carers' preferences or attitudes towards services or the caregiving role:

> "It's very difficult. You have a week [of respite care]. Then you have another week. And then that's it. It's probably my fault, because I'm reluctant to have somebody come in and care for [care-recipient] in the home."

CR22, *Time and space to be myself*

Some reported no effect of services due to the low-intensity of the intervention or quality-related issues. For example, one carer described how the absence of proactive engagement from a carer's organisation meant that it did not affect how supported and encouraged he felt in his caring role:

> "Like I said, there's no contact with them. You get your newsletter. Unless you phone them there's no contact."

CR23, *Feeling supported and encouraged*

Negative impact of services

While the ASCOT-Carer was originally conceived as a measure of the positive effect of social care, one respondent reported that services had a negative impact on QoL:

> "Well, they come in to help [care-recipient], that's great. But it's a lot of work when they go away. They don't really clean up after them or anything like that. So actually they're all right for [care-recipient], you know, for his needs. But they actually make more work for me."

CR14, *Occupation*

As illustrated by this example, the negative effects may be conceptualised as the opposite of the positive impacts. In this case, rather than services substituting for informal care and alleviating the burden of care-related tasks, the service actually added to the carer's care-related tasks. This also contributed to the carer's sense of feeling overlooked and undervalued in her role as a carer.

Survey of carers

The sample characteristics are shown in Table 4. The sample has a lower proportion of women (54.1%), adults aged 18-64 years (53.8%) and carers in paid employment (26.9%) than the population estimate of English carers (women 60%; 18-64 years 75%; in paid employment 46%), as well as a higher proportion providing more than 35 hours of care per week (59.8%, compared to 30%

population estimate) (NHS Digital, 2010). This may reflect the study methodology of recruiting carers via adults who used publicly-funded social care services. Indeed, the older age profile and more intensive caregiving in the study sample is comparable to the 2012/13 survey sample of adult carers known to English local authority adult social services departments (≥65 years, 42.6%; ≥35 hours/week, 59.8%) (NHS Digital, 2013).

Table 4. Descriptive statistics (*n*=316)

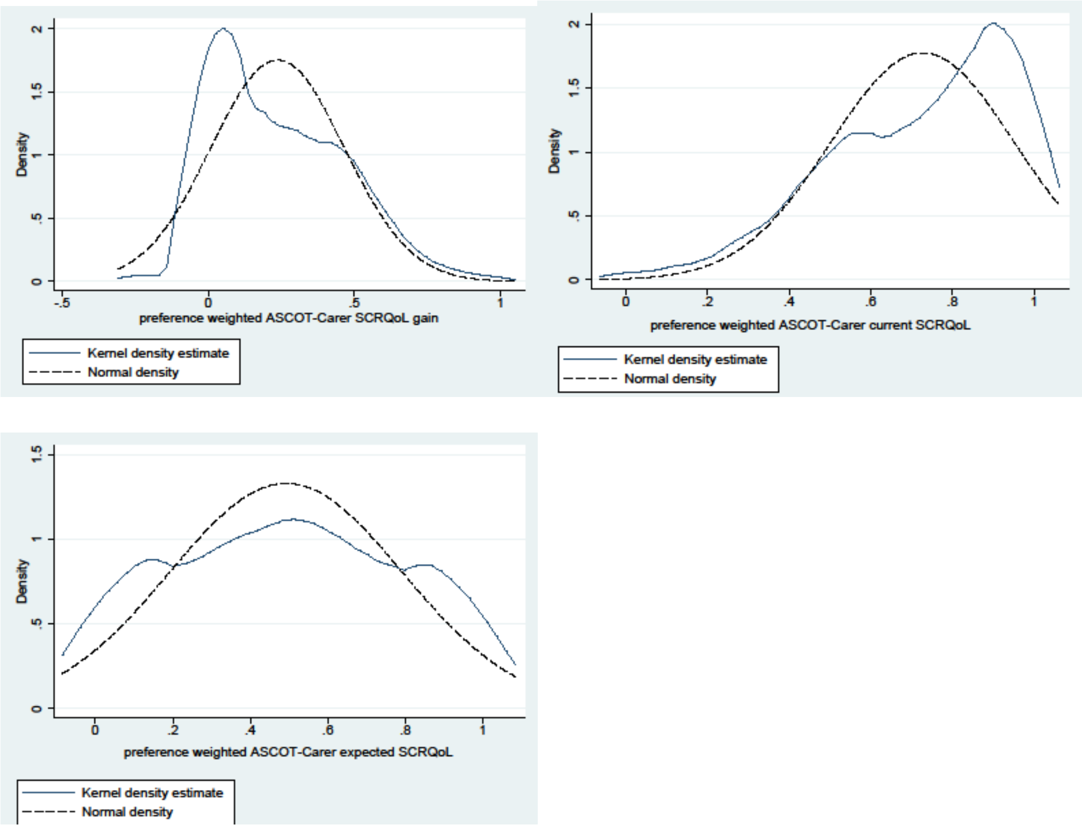
Insert Table 4 here.

Of the study sample, 67.4% reported that they did not receive any carer-specific support, of which just over 10% (*n*=35) received only information and advice. This is considerably lower than the estimate of carers in England who have not had a carers' assessment (94%) or have been assessed but did not receive any services as a result (2%) (NHS Digital, 2010). Again, this is likely to be due to the study methodology and focus on carers of people who were using publicly-funded services. The most commonly reported type of support were carers support group (*n*=48, 15.2%) and counselling (*n*=26, 8.3%) with only a small number of carers who had received training (*n*=4) or support to stay in employment (*n*=2). Just under a third of the sample (*n*=102, 32.5%) reported that they had accessed a short-term break in the past 12 months. With regard to social care service use by the care-recipient, there were 11 cases (3.5%) where the only service by the care-recipient used at the time of interview was home adaptations or equipment. Other services accessed included: domiciliary care (*n*=193, 61.1%); day centre (*n*=74, 23.4%); social worker support (*n*=66, 20.9%); support from a voluntary helper (*n*=10, 3.2%); and meals services (*n*=7, 9.7%).

The distribution of the ASCOT-Carer SCRQoL scores for current, expected (without services) and gain (effect of services) are shown in Figure 1. These represent the preference-weighted scores, whereby each outcome state is converted into a score that reflects its relative value, based on the views of the general population (Batchelder et al, 2018). For current and expected SCRQoL, the scores range from zero (worst possible) to one (best possible) quality of life. The distribution of the ASCOT-Carer

SCRQoL current scores were negatively skewed (mean 0.73, std. dev. 0.23) with a ceiling effect at the upper end of the scale. The ASCOT-Carer expected scores were leptokurtic with a tri-modal distribution with peaks at the upper and lower end of the scale as well as around the mean (0.49, std. dev. 0.30). The ASCOT-Carer SCRQoL gain score may be negative, which reflects instances where services have a negative impact on QoL, up to a total of one, which represents cases where services improve QoL from the worst to best possible QoL. In this study, the ASCOT-Carer gain scores were positively skewed with a floor effect (mean 0.24, std. dev. 0.23, range -.24 to .99).

Figure 1. Kernel density estimate



The ratings of current and expected SCRQoL for each ASCOT-Carer attribute are shown in Table 5. Wilcoxon signed-rank tests indicated that expected SCRQoL was significantly lower than the current SCRQoL for the seven attributes (p<0.001), which indicates that services had an effect on all SCRQoL attributes. Between 45% (*Occupation*) and 65% (*Personal safety*) of the sample reported that services had no impact on QoL for each ASCOT-Carer attribute. Of those who reported no effect, carers who reported high-level needs are disproportionately represented: for example, 22 of the 24 carers who reported high-level needs for *Occupation* reported no effect of services on their quality of life. By contrast, fewer than half of the 68 carers who reported the ideal state of *Occupation* reported services had no effect on SCRQoL. In all cases where carers reported high-level need and also that services affected SCRQoL, expected SCRQoL was rated at a higher QoL state than the current SCRQoL state. This results in a negative ASCOT-Carer SCRQoL gain score (i.e. services have a negative effect on QoL).

Table 5. ASCOT-Carer SCRQoL rating by attribute (*n*=316)

Insert Table 5 here.

The majority of the sample (75.9%) had an overall positive preference weighted ASCOT-Carer SCRQoL gain index score. This indicates that services improved SCRQoL to some degree. Of the remaining carers, most reported no impact of services on quality of life (21.9%). A small number of carers reported that services had an overall negative effect on quality of life (2.2%).

The results of the regression analysis are shown in Table 6. After controlling for various factors related to QoL, including carer and care-related characteristics, care-recipient characteristics, and mode of interview administration, there was a significant positive relationship between cost-weighted utilisation of social care services by the care-recipient and ASCOT-Carer SCRQoL gain (β=.023, p=0.02). There was also a significant negative association between household financial difficulties and the estimated impact of services on SCRQoL (β=-.085, p=0.01). Since the INT4 counterfactual self-estimation method in this study asked carers to consider the combined effect of publicly funded *and* privately purchased social care services, this negative relationship may reflect the reduced ability of households with fewer financial resources to purchase additional services to address QoL deficits that are not addressed by publicly-funded support. Otherwise, as expected, none of the other control variables considered in these analyses were significantly associated with an effect of services on carers’ SCRQoL gain at the 5% level.

Table 6. Multiple regression of the ASCOT-Carer SCRQoL gain index score

Insert Table 6 here.

Discussion

This study has identified the ways in which community-based social care services may affect carers' SCRQoL through a novel counterfactual self-estimation method using the ASCOT-Carer INT4 (Rand et al, 2012). Social care-related QoL is a key outcome of adult social care services. The ASCOT-Carer INT4 is an extended and modified version of the carer SCRQoL measure, which is included as an overarching outcome indicator in the Adult Social Care Outcomes Framework (ASCOF) (Department of Health and Social Care, 2017).[3] In a qualitative analysis, it was found that carers were able to describe whether and how community-based services affected each of the ASCOT-Carer SCRQoL attributes. This was confirmed by quantitative analysis of a survey of carers in England, in which expected SCRQoL was significantly lower than current SCRQoL for all seven ASCOT-Carer attributes. Social care services were found to promote carers' SCRQoL through substitution for care-related tasks, by supporting carers in self-care or access to other support, and to reappraise their role as a 'carer'. Negative impacts of services were reported when services increased care-related tasks, undermined the carer in the caregiving role, and contributed to subjective burden. For many carers, however, there was no self-reported effect of services on QoL for one or more the ASCOT-Carer attributes.

The combined qualitative and quantitative findings are consistent with other qualitative studies of the barriers to accessing support and the benefit of community-based social care services in terms of carers' strain, burden or quality of life outcomes (for example, Brimblecombe et al, 2018; Greenwood et al, 2015; Winslow, 2003). The barriers identified in these studies include attitudes towards services, lack of information to enable carers to access services, actual or perceived

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[3] The ASCOT-Carer was developed based on the Carer SCRQoL (Rand et al, 2012). The two measures have six overlapping SCRQoL domains; however, the ASCOT-Carer INT4 includes an additional domain. It also has four levels of response, by comparison to the Carer SCRQoL's three-levels of response, and is also a preference-weighted measure (Rand et al, 2015, Batchelder et al, 2018). The Carer SCRQoL only provides the current QoL score. By contrast, the ASCOT-Carer allows the calculation of current, expected (without services) and gain (impact of service) scores.

unavailability of services (e.g. due to eligibility criteria), and/or issues related to the quality or cost of services (Brimblecombe, et al, 2018; Rand and Malley, 2014; Winslow, 2003). Most of these barriers are potentially relevant to all carers; however, the additional barriers of language and concerns of religious or cultural appropriateness of services may be experienced by carers from minority ethnic groups (Greenwood et al, 2015). There is also some evidence that male carers are less likely to seek help, which may be related to the attitude of commitment to the role informed by a sense of duty or responsibility and lack of information (Greenwood and Smith, 2015).

There has been less focus on the mechanisms by which carers may benefit from services. This may be due to the focus in the literature on the evaluation of specific social care interventions or policy. An exception is a qualitative study of family carers in the USA by Winslow (2003), which found that carers benefited from services, including carer support groups, through gaining knowledge, practical skills or care-related information, community and social/emotional support and personal renewal. The study presented here adds to the social care evidence base to show how community-based support may affect carers' SCRQoL. It was found that carers were able to weigh-up and rate whether social care services had an effect on the ASCOT-Carer SCRQoL attributes (see Box 1). Respondents were also able to identify whether or how social care services (or other support) could improve their QoL. While ASCOT-Carer has not been used in England as a tool for the assessment of carers' needs, it has the potential to be used in this way. Preliminary studies in Japan and Finland have shown promising results of the tool's acceptability and feasibility for use as an assessment tool, despite the cultural and contextual differences (Kettunen, 2018; Yamaguchi and Rand, 2019).

The findings also contribute to an understanding of how to estimate the *effect* of services on carers' social care-related QoL. The counterfactual self-estimation method developed for the ASCOT to measure the impact of social care services on services users' care-related quality of life (Netten et al, 2012) has been adapted for use with family and friend carers (Rand et al, 2012). The ASCOT counterfactual self-estimation method was developed independently from a similar method for the evaluation of the impact of a climate educational programme on individual’s attitudes and behaviour (Mueller and Gaus, 2015; Mueller et al, 2014). These methods share a conceptual basis in that they seek to estimate the impact of an intervention by using respondents’ own self-estimation of the counter-factual situation (i.e. without the treatment or intervention). The difference between the factual and the self-estimated counter-factual provide an estimate of impact of the intervention on outcomes. This method is especially useful in situations where the use of control or comparison groups is limited due to constraints on budget, time or inability to collect data.

The ASCOT-Carer INT4 counterfactual self-estimation method is based on an application of the same method applied to service users with the ASCOT (Malley et al, 2019). There is evidence that carers are able to construct their own counterfactual and estimate their QoL in an imagined situation that social care services were no longer available and no other help stepped in (Rand et al, 2012). Imagining the counterfactual situation, however, may evoke negative emotions, especially if the carer relies on services to maintain their wellbeing and has experienced a situation without them and/or is concerned over potential cuts to social care services (Rand et al, 2012). Furthermore, it was difficult to distinguish between services ‘for’ services users and ‘for’ carers especially due to the indirect (‘spillover’) effects of social care interventions (Rand and Malley, 2014). Despite these challenges, the counterfactual self-estimation method was acceptable and feasible if respondents had sufficiently detailed information about the nature of the interview, the interviewer proceeded with sensitivity to the potential emotional impact of the interview, and carers were asked to either consider all social care services regardless of who they were ‘for’ (Rand et al, 2012).

This survey of carers in England provides an insight into the (self-)estimated impact of social care on carers’ SCRQoL. The key finding was that the majority of carers (75.9%) reported a positive effect of social care services on SCRQoL. As would be expected since carer-specific services are typically low intensity and the impact of social care on carers’ lives is usually indirect, that positive effect is relatively modest. Just over one in five carers reported no impact of services, whilst a small minority

(2.2%) reported negative effects. Even if the effects of services were modest, these results support the argument that social care interventions have some effect on carers' QoL; however, they do not in all cases. Negative impact also needs to be considered. Regression analysis to assess the construct validity of the ASCOT-Carer INT4 gain index score as a measure of the impact of services found that (as hypothesised) the self-estimated impact of services (ASCOT-Carer SCRQoL gain) was related to the intensity of service use by care-recipients. An unexpected significant negative association between ASCOT-Carer SCRQoL gain and household financial difficulties may be associated with the reduced ability of these households to top up support with privately-funded services.

This study has a number of limitations. First, the study sample is limited to those carers known to local authority social services departments. The profile of this subgroup of carers is different from the wider population of carers in England. Therefore, further research is needed to explore the potential impact of social care support for carers not currently identified by services and/or with unmet needs. This is especially important given the policy context. Since the survey was conducted before the implementation of the Care Act (2014), which places responsibility on local authorities to identify and meet carers' eligible unmet outcome needs, further data collection may be useful to identify trends in the pattern of unmet need and carers' outcomes since then.

Second, a potential issue with counterfactual self-estimation is bias, i.e. over- or underestimation of the counterfactual by self-estimation (Malley et al, 2019; Mueller & Gaus, 2015; Mueller et al, 2014). This self-estimation bias may be influenced by, for example, cognitive biases that may be linked to depression or cognitive impairment. As such, the systematic under- or over-estimation of impact may vary by the characteristics of the respondent. Indeed, a preliminary study of the self-estimation using ASCOT found statistically significant underestimation by comparison with another estimation method (the production function approach (Forder et al, 2018)) that varied by individual characteristics, for example, level of social care need (Malley et al, 2019). In this study, the sample size is limited, so we were unable to replicate this comparison between counterfactual self-estimation (ASCOT-Carer INT4) and the production function method applied to carers (Forder et al, 2018). Therefore, further research is needed to establish the extent of self-estimation bias with the ASCOT-Carer INT4 method by comparing carers' self-estimate of impact against estimates from other study designs or methods (e.g. the production function approach).

Conclusion

This study has identified ways in which carers' experience the effects of social care on their QoL. This is important if social care is to achieve its stated aim of improving the QoL of service users *and their carers*, which forms the basis of English carers' policy strategy and the Care Act (2014) (Department of Health and Social Care, 2017, 2018). In reality, this is challenging. Despite greater rights and entitlements under the Care Act (2014), there has been a reduction in uptake of carers' assessments and access to services (National Audit Office, 2015). This ought to be a concern if – as has been shown in this study – social care support has the potential to improve QoL. That said, the findings also indicate that there are issues related to whether interventions are accessible, of adequate quality and intensity, and tailored to the needs of carers – especially for those in 'at risk' subgroups (e.g. working carers). The ASCOT-Carer INT4 offers a method by which interventions and policies may be evaluated, as well as potentially a way of assessing need in a way that could identify the right services and support for individual needs. All of this depends, however, on having accessible, effective and reliable, high-quality support available to carers with support needs.

Funding details: This article is based on independent research commissioned and funded by the NIHR Policy Research Programme, the Quality and Outcomes of person-centred care policy Research Unit (QORU). The views expressed in the publication are those of the authors, and not necessarily those of the NHS, the NIHR, the Department of Health and Social Care, or its arm's length bodies, or other government departments.

Conflict of interest statement: The authors declare that there is no conflict of interest.

Acknowledgments: We would like to acknowledge and thank Dr Juliette Malley and Professor Ann Netten for their advice and involvement in the data collection, Sarah Godfrey for proof-reading and editing the manuscript, and the participating organisations and participants for their support of the study.

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Tables

Box 1. Analytical framework

Positive impact of services on carer social care-related QoL

- By reducing the time spent on care-related tasks
- By motivation and encouragement to focus on self-care, access support and reappraise their role/priorities
- By alleviating subjective burden

No impact of services on carer social care-related QoL

- No underlying social care need (i.e. at the ‘ideal state’ due to factors other than social care)
- Mismatch between carer’s need(s) and the social care intervention
- Lack of time, motivation or energy to engage with services *
- Limited formal social care support – insufficient amount or quality

Negative impact of services on carer social care-related QoL

- By increasing the time spent on care-related tasks *
- By overlooking the carer’s own needs and/or undermining their role *
- By contributing to subjective burden *

* Identified through the analysis. (The other concepts were specified *a priori*).

Box 2. ASCOT-Carer INT4 counterfactual self-estimation

Occupation (‘doing things I value and enjoy’)

Q. Does the support that you and your husband, John get from the day centre affect how you spend your time?

- Yes
- No
- Don’t know

Q. Imagine that you and your husband, John did not have the support from the day centre that you do now, and no other help stepped in. In that situation, which of the following would best describe how you would spend your time?

- I would be able to spend my time as I want, doing things I value or enjoy (*Ideal state*)
- I would be able to do enough of the things I value or enjoy with my time (*No needs*)
- I would do some of the things I value or enjoy with my time, but not enough (*Some needs*)
- I wouldn’t do anything I value or enjoy with my time (*High-level needs*)

Table 1. ASCOT-Carer attributes

Attribute	**Description**
Occupation (*doing things I value and enjoy*)	Being sufficiently occupied in a range of meaningful, enjoyable activities whether it be formal employment, unpaid work, caring for others or leisure activities
Control over daily life	Choosing what to do and when to do it, and having control over their daily life and activities
Self-care	Feeling able to look after oneself, in terms of eating well and getting enough sleep
Personal safety	Feeling safe and secure, where concerns about safety can include fear of abuse or other physical harm or accidents, which may arise as a result of caring
Social participation	Being content with their social situation, where social situation includes the sustenance of meaningful relationships with friends and family, as well as feeling involved and part of their community
Space and time to be yourself	Having space and time in everyday life. Enough time away from caring to have a life of their own outside of the caring role
Feeling supported and encouraged	Feeling encouraged and supported by professionals, care workers and others, in their role as a carer

Table 2. Qualitative interview sample characteristics (*n*=29)

	Frequency
Gender of carer	
Male	5
Female	24
Age of carer	
45-54 years	6
55-64 years	8
65-74 years	9
75 years or over	6
Relationship of care-recipient to carer	
Spouse/partner	12
Child	11
Parent or grandparent	4
Sibling	2
Co-resident with care-recipient	
Lives with care-recipient	22
Lives somewhere else	7
Primary support reason for care-recipient	
Physical disability or impairment	13
Intellectual disability (autism spectrum disorder)	6 (3)
Dementia	5
Mental health problem	5
Sensory impairment	1
Services used by the carer in the past 12 months	
Carers' organisation or group	26
Information and advice	21
Training for carers	5
Counselling or someone to talk to in confidence	2
Support to stay in employment	1
Services used by the care-recipient in the past 12 months	
Home care/personal assistant	16
Day centres/activities	14
Equipment or home adaptations	13
Residential replacement care or breaks	8
Lifeline alarm	5
Supported living (housing with support worker on-site)	2
Meals services	2

Table 3. Examples of how care support affect ASCOT-Carer SCRQoL attributes

Attribute	Examples of how social care services were perceived to have an effect on QoL	
Occupation	"Yes they do because without [services] I would be quite tired. I can go off on a Thursday knowing he's cared for. I have my mobile on in case of any emergencies obviously. And I go out and have lunch and do just what I want to do."	**CR17**, female carer for her spouse / partner, day centre and home care
Control over daily life	"Well if I didn't have some respite care, for example, I would have a lot less control over what I was able to do beyond here. If my parents didn't get any [personal budget] payments at all then I would be tied very much to being here and looking after them. So that would also give me less control, wouldn't it?"	**CR2**, female carer for her parents, personal budget, respite care, home care
Self-care	"If he wasn't away those couple of days each week it would put extra pressure on me and I probably then wouldn't want to even deal with myself [because of depression]. So yes… I just wouldn't have the time to do the other little bits and pieces that allow me to do what I do for myself then."	**CR28**, female carer for her spouse / partner, personal budget, day centre
Personal safety	"I suppose one of the most important things is probably the carers going in. The other things I suppose are the apparatus that she's got in place because she is heavy and when she falls over, and she has had a lot of falls, my sister and I can't even lift her. We have to get the ambulances out … 'cause she's a dead weight, so I suppose having the right apparatus and the people [around help me feel safe], yeah."	**CR12**, female carer for her mother, home care and equipment / adaptations
Social participation	"I'd have very little social contact at all if I didn't have the [carer group] and the girls [home care] and all that…. I've met other carers that go to [carer group] once a month. If I walk down the town one of them will recognise me and say hello and I can have a little chat and it's nice."	**CR21**, female carer for her spouse/partner, home care and carers' support group
Space and time to be yourself	"You're always thinking, yeah. At the weekends, he's got a lot of energy. He has to be out every day, so I've got to find all the time things for him to do. If he's in the respite, which is absolutely marvellous, I don't have to --, Then he has to have his meals at 12 o'clock, five o'clock, ten o'clock and set things to eat, so I've always to be certain I've got the right things in. When he's not here, it's a relief to me."	**CR4**, female carer for her adult son, respite care
Feeling supported and encouraged	"Well I have to say that the carers were very kind to me. They could see sometimes that I was, you know, struggling and upset. And some of them were very good and maybe put an arm round me."	**CR10**, female carer for her sister, home care

Table 4. Descriptive statistics (*n*=316)

	Mean † **(Std. Dev., min. to max.)**
ASCOT-Carer SCRQoL	.727 (.225, 0 to .999)
ASCOT-Carer SCRQoL expected	.492 (.300, 0 to .999)
ASCOT-Carer SCRQoL gain	.238 (.227, -.243 to .987)
Cost-weighted service utilisation (censored ††, log transform)	4.420 (1.603, 0 to 7.314)
Log of scale of care-recipient I/ADLs	2.256 (.720, 0 to 3.219)
	Frequency (%)†
Carer characteristics	
Aged ≥65 years	146 (46.2%)
Male	145 (45.9%)
Higher education (university or professional qualification)	86 (27.2%)
Household claims means-tested benefits	107 (33.9%)
In paid employment	85 (26.9%)
Financial situation: manage very well	36 (11.5%)
Financial situation: manage well	79 (25.2%)
Financial situation: no difficulty	137 (43.6%)
Financial situation: some difficulty	44 (14.0%)
Financial situation: severe difficulty	18 (5.7%)
Social contact (telephone): most days	153 (48.4%)
Social contact (telephone): once or twice a week	114 (36.1%)
Social contact (telephone): monthly or less	49 (15.5%)
Social contact (meet up): most days	53 (16.8%)
Social contact (meet up): once or twice a week	143 (45.2%)
Social contact (meet up): monthly or less	120 (38.0%)
Involved in social groups	143 (45.3%)
Had a carers’ assessment	80 (25.4%)
Care duration: less than five years	94 (29.8%)
Care duration: 5 to 20 years	160 (50.6%)
Care duration: >20 years	62 (19.6%)
Hours of care per week: <10 hours	49 (15.5%)
Hours of care per week: 10 to 34 hours	78 (24.7%)
Hours of care per week: 35 to 49 hours	47 (14.9%)
Hours of care per week: 50 hours or more	142 (44.9%)
Home design: meets most, some or no needs †††	110 (34.9%)
Mobility: no problems	206 (65.2%)
Health: good or very good	145 (45.9%)
Health: fair	116 (36.7%)
Health: bad or very bad	55 (17.4%)
Care-recipient characteristics	
Aged ≥65 years	184 (58.2%)
Male	132 (41.8%)
Help to complete one or more ASCOT-Carer question	77 24.4%)
Primary support reason: mental health	75 (23.7%)
Interview administration	
Interview by telephone	51 (16.1%)

† **Missing values**: Carer SCRQoL (*n*=3); Carer SCRQoL expected (*n*=4); Carer SCRQoL gain (*n*=5); Cost-weighted utilisation (*n*=14); spatial lag (*n*=15); Log scale of care-recipient I/ADLs (*n*=1); Household finances (*n*=2); Had a carers’ assessment (*n*=1); Home design (*n*=1).

†† With an upper limit of £1,500.

††† Reference categories:

Home design: meets all needs of the carer
Mobility: some or severe problems

Table 5. ASCOT-Carer SCRQoL rating by attribute (*n*=316)

ASCOT-Carer attribute	**ASCOT-Carer INT4 SCRQoL Current *N* (%) †**	**ASCOT-Carer INT4 SCRQoL Expected *N* (%) ††**	**Wilcoxon signed rank test z (p value)**	**No self-estimated impact of services *N* (%)**	**No self-estimated impact of services, Current SCRQoL**
Occupation ('doing things I value and enjoy')			12.43 (<0.001)	142 (45.1%)	
Ideal state	68 (21.5%)	30 (9.5%)			29 (20.4%)
No needs	93 (29.4%)	49 (15.5%)			38 (26.8%)
Some needs	131 (41.5%)	106 (33.7%)			53 (37.3%)
High-level needs	24 (7.6%)	130 (41.3%)			22 (15.5%)
Control over daily life			11.95 (<0.001)	144 (45.7%)	
Ideal state	80 (25.3%)	41 (13.0%)			39 (27.1%)
No needs	119 (37.7%)	58 (18.4%)			46 (31.9%)
Some needs	107 (33.9%)	124 (39.4%)			51 (35.4%)
High-level needs	10 (3.1%)	92 (29.2%)			8 (5.6%)
Self-care			10.57 (<0.001)	177 (56.2%)	
Ideal state	127 (40.2%)	71 (22.5%)			70 (39.6%)
No needs	113 (35.8%)	89 (28.3%)			57 (32.1%)
Some needs	51 (16.1%)	90 (28.6%)			29 (16.4%)
High-level needs	25 (7.9%)	65 (20.6%)			21 (11.9%)
Personal safety			9.71 (<0.001)	205 (65.1%)	
Ideal state	228 (72.2%)	163 (51.8%)			162 (79.0%)
No needs	69 (21.8%)	59 (18.7%)			30 (14.6%)
Some needs	12 (3.8%)	59 (18.7%)			9 (4.4%)
High-level needs	7 (2.2%)	34 (10.8%)			4 (2.0%)
Social participation			10.20 (<0.001)	190 (60.5%)	
Ideal state	113 (35.9%)	71 (22.6%)			70 (36.8%)
No needs	96 (30.5%)	68 (21.7%)			47 (24.7%)
Some needs	80 (25.4%)	97 (30.9%)			49 (25.8%)
High-level needs	26 (8.2%)	78 (24.8%)			24 (12.7%)
Time and space to be myself			11.11 (<0.001)	168 (53.3%)	
Ideal state	67 (21.2%)	41 (13.0%)			40 (23.8%)
No needs	114 (36.1%)	61 (19.4%)			48 (28.6%)
Some needs	110 (34.8%)	117 (37.1%)			56 (33.3%)
High-level needs	25 (7.9%)	96 (30.5%)			24 (14.3%)
Feeling supported and encouraged			10.49 (<0.001)	175 (56.1%)	
Ideal state	66 (21.0%)	40 (12.8%)			37 (21.1%)
No needs	113 (36.0%)	64 (20.4%)			57 (32.6%)
Some needs	86 (27.4%)	80 (25.6%)			35 (20.0%)
High-level needs	49 (15.6%)	129 (41.2%)			46 (26.3%)

† **Missing values**: Social participation (*n*=1); Feeling supported and encouraged (*n*=2).

†† **Missing values**: Occupation (*n*=1); Control (*n*=1); Self-care (*n*=1); Safety (*n*=1); Social participation (*n*=2); Time and space to be myself (*n*=1); Feeling supported and encouraged (*n*=3).

Table 6. Multiple regression of the ASCOT-Carer SCRQoL gain index score

	Coefficient (B)	Robust Std. Error
Utilisation		
Cost-weighted utilisation (censored, log)	0.023*	0.010
Had a carers' assessment	0.043	0.033
Control factors: carer characteristics		
Aged ≥65 years	-0.055	0.039
Male	0.017	0.031
Higher education (university or professional qualification)	-0.026	0.030
In paid employment	<0.001	0.038
Financial situation: some or severe difficulties †	-0.084*	0.033
Social contact (telephone): once or twice a week †	-0.009	0.029
Social contact (telephone): monthly or less	-0.037	0.040
Social contact (meet up): once or twice a week †	-0.004	0.042
Social contact (meet up): monthly or less	-0.018	0.044
Involved in social groups	0.047	0.029
Care duration: 5 to 20 years †	0.008	0.030
Care duration: >20 years	0.033	0.041
Hours of care per week: 10 to 34 hours †	-0.008	0.042
Hours of care per week: 35 to 49 hours	0.004	0.050
Hours of care per week: 50 hours or more	0.027	0.045
Home design: meets most, some or no needs †	-0.019	0.029
Mobility: no problems †	-0.059	0.033
Health: fair †	-0.043	0.031
Health: bad or very bad	-0.076	0.041
Control factors: care-recipient characteristics		
Aged ≥65 years	-0.026	0.031
Male	0.033	0.032
Log scale of care-recipient I/ADLs	0.045	0.023
Help to complete one or more ASCOT-Carer question	-0.053	0.032
Primary support reason: mental health	-0.035	0.036
Interview administration		
Interview by telephone	-0.012	0.037
Constant	0.137	0.084
n	292	
R²	0.18	
F value / LR Chi²	2.56**	
Ramsey RESET test (misspecification)	1.06	
White's test (heteroscedasticity)	292.0	

*p<0.05, **p<0.01

† Reference categories:

Financial situation: manage very well, well or with no difficulty
Social contact (telephone or meet up): most days
Care duration: less than five years
Hours of care per week: <10 hours
Home design meets all needs of the carer
Mobility: some or severe problems
Health: good or very good