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Title: Social care-related quality of life of people with dementia and their carers in England

Authors: Stacey Rand¹, Barbora Silarova¹, Ann-Marie Towers², Karen Jones¹

¹ Personal Social Services Research Unit (PSSRU), University of Kent, Canterbury, UK.

² Centre for Health Services Research (CHSS), University of Kent, Canterbury, UK.

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Conflicts of interest

The authors have no conflicts of interest to declare.

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Ethical approval

The study was approved by the Social Care Research Ethics Committee in England, Health Research Authority and Health and Care Research Wales (19/IEC08/0057). Research governance approval was also sought in local authorities where we recruited carers via publicly-funded services.

Abstract

People with dementia and their carers are a growing subgroup of people who use community-based social care. These services are designed to maintain people's quality of life, whilst living at home. The ASCOT measure of social care-related quality of life (SCRQoL), designed to evaluate quality and effectiveness of social care, has been adapted for proxy-report when someone is unable to self-report. The ASCOT-Carer has been developed to measure carer's own SCRQoL. This study sought to establish the factors related to SCRQoL of people living with dementia (proxy-reported by carers) and their carers.

Data were collected via a self-administered postal or online survey of 313 carers in England, from January 2020 to April 2021. Carers were eligible if they supported someone living with dementia at home, who was unable to self-complete questionnaires. The person living with dementia or their carer had to use at least one social care service, e.g. home care. We recruited participants via an online volunteer panel and NHS sites.

Multiple regression was applied to explore the factors significantly related to ASCOT SCRQoL by self- and proxy-report. Key influences on carers' own SCRQoL were their health, financial difficulties associated with caring, and satisfaction with social care support. Inadequate home design was significantly negatively associated with SCRQoL for people living with dementia. The latter stages of the pandemic-related restrictions (the tier system from 2nd December 2020 to study end, April 2021) were associated with significantly worse SCRQoL for PLWD, but not for carers.

The study offers insight into the factors associated with SCRQoL. In particular, the findings highlight the importance of adequate home design for people with dementia; satisfactory social care support and limiting any adverse financial impact of caring are important for carers. The findings indicate a negative effect of COVID restrictions on SCRQoL of people with dementia.

What is known about this topic?

- There are over 767,000 people living with dementia in England and Wales; two-thirds live in their own home
- Community-based social care is designed to maintain wellbeing and independence of people living with dementia and carers

What this paper adds?

- There is a high-level of unmet care-related outcome needs reported by carers of people living with dementia

- Key influences on carers' quality of life are health, financial difficulties associated with caring, and satisfaction with social care support
- Proxy-reported quality of life of people with dementia differed by proxy rating perspective; adequate home design and cognitive decline were key influences on QoL for both ratings.

Keywords: dementia; carers; Quality of Life; outcomes; social care; services

Background

There are over 767,000 people living with dementia (PLWD) in England and Wales, two thirds of whom live at home (Alzheimer's Society, 2016; Ahmadi-Abhari *et al.*, 2017). Unpaid care by family and friends is a vital source of support. It is estimated that 10% of the 5.8 million carers in England and Wales care for PLWD (NHS Digital, 2010; White, 2013). The number of carers and intensity of unpaid care are expected to increase over the next decade (Hoff, 2015). Similar trends are seen internationally (Martin Prince *et al.*, 2015), including in low-to-middle income countries (Farina *et al.*, 2020).

Alongside unpaid care, good quality and effective social care services are needed to support the care-related needs, including quality of life (QoL) and independence, of PLWD and their carers, when living at home (Department of Health and Social Care, 2019). Social care refers to non-medical services, like home care, day activities, short-term or residential breaks, assistive technology and equipment or adaptations, to support people with everyday activities. In England, these services may be fully- or partly-funded by local authorities (LAs), or purchased privately. Even if services are 'for' PLWD, there is evidence of direct and indirect impact on carers' QoL (Rand, Vadean and Forder, 2020). There are also specialist services for carers, which promote and support carers' QoL, provided by local voluntary organisations. These organisations provide peer support groups, wellbeing or social activities, professional emotional support or counselling, training for carers, and information, advice or signposting to other services.

Over the past decade in England, there has been a drive to improve the quality of social care services by focussing on the outcomes of care for people with care needs and their carers (i.e. the impact on QoL), rather than the processes or outputs of delivering care (Department of Health and Social Care, 2010b, 2010a). Social care-related QoL (SCRQoL) may be defined as those aspects of QoL that may be affected by social care services and are relevant to service users and carers. The Adult Social Care Outcomes Toolkit (Netten *et al.*, 2012) and the ASCOT-Carer (Rand *et al.*, 2015) are measures of SCRQoL for adults with support needs and their carers, respectively (see Table 1). ASCOT measures

have also been used in the evaluation of social care interventions or policy (for example, (Forder *et al.*, 2012; Whitehead *et al.*, 2016; Callaghan, Brookes and Palmer, 2017; Gridley *et al.*, 2019)), in understanding the effects of care on carers' QoL (Rand and Malley, 2014; Rand, Vadean and Forder, 2020) and in needs assessment (Johnstone and Page, 2013). They have also been translated and used internationally in evaluation, research and practice (for example, (van Leeuwen *et al.*, 2015; Nakamura-Thomas *et al.*, 2019; Yamaguchi and Rand, 2019; Trukeschitz *et al.*, 2020; Nguyen *et al.*, 2021)).

[Table 1]

So far, there is limited evidence of the social care outcomes of PLWD and their carers living in their own homes. Studies or routine data collections of social care outcomes may not adequately consider the views of PLWD and carers, especially those living in their own homes, due to methodological challenges, like the difficulty of establishing consent to participate and assessing individual outcomes with people with moderate-to-severe cognitive impairment (Schwarz *et al.*, 2005; Smith *et al.*, 2007; Aznar *et al.*, 2021). This may contribute to sampling bias and systematic exclusion of certain groups from research and data collections used to evaluate services and guide policy, commissioning and the allocation of limited resources (von Essen, 2004; Steel, Geller and Carr, 2005; Rand and Caiels, 2015). In some cases, self-report may be facilitated by support, adapted formats or communication aids (e.g. Talking Mats, Easy-Read) (Murphy, Gray and Cox, 2007; Turnpenny *et al.*, 2018). Even with adapted methods, there are individuals who are not able to self-report (van Baalen *et al.*, 2011). To address these issues, a proxy-report version of ASCOT (ASCOT-Proxy) has been developed (Rand and Caiels, 2015; Rand, Caiels, *et al.*, 2017a; Caiels *et al.*, 2019).

In the *Measuring the social care Outcomes of PLWD and their carers* (MOPED) study, carers of PLWD in England were surveyed using the ASCOT-Proxy and ASCOT-Carer, to establish their feasibility and psychometric properties (reported elsewhere (Silarova *et al.*, no date)). The study focussed on carers of PLWD, who were living at home, using community-based social care and where the PLWD was unable to self-report. The rationale was that this subgroup is at risk of being excluded from research and national data collections, like the Adult Social Care Survey in England (NHS Digital, 2019). The secondary aims of the MOPED study are considered in this paper, as follows: (1) what is the profile of unmet social care needs, as defined using QoL outcomes, of PLWD living in their own homes and their carers, who are in contact with some form of community-based social care; and (2) what are the factors associated with the outcomes of PLWD and their carers.

Methods

A self-completion survey of 313 carers of PLWD in England was conducted between January 2020 and March 2021. Survey data were collected using an online (Qualtrics) or postal questionnaire. Written informed consent was obtained from all participants.

Sampling

Participants were recruited through NHS sites (memory clinics) and an online opt-in volunteer panel. A letter, email or telephone call of invitation and study information sheet were shared with potential participants. If someone wished to participate in the study, s/he was asked to complete a brief self-completion questionnaire to confirm eligibility. The inclusion criteria were: carers in England, aged over 18 years, providing help or support to someone living with dementia, who uses community-based social care, and does not live in residential or nursing care and is unable to self-complete a structured questionnaire, even with help. The latter reflects the MOPED study's primary aim, i.e. to validate the ASCOT-Proxy measure in a sample where the individual is not able to self-report.

A total of 271 carers who responded to the invitation letter were not eligible for the study, based on their responses to the self-completion questionnaire against the study inclusion criteria. Of those who were found to be eligible ($n=637$), 345 carers began to complete the questionnaire. Of these, a total of 313 carers (91.3%) completed the survey and confirmed consent by either clicking submit (online) or returning the completed survey by post.

Questionnaire

The same content was presented in the online and postal questionnaires. Self- or proxy-reported data were collected on the characteristics of the carer (age, sex, ethnicity, overall health) and the care-recipient (age, overall health, cognitive status), caregiving situation (hours of care per week, co-residence, and self-reported financial impact of caring) and the type and intensity of community-based social care services.

The ASCOT-Carer and ASCOT-Proxy measures were administered (see Table 1). Both are measures of social care-related QoL. The ASCOT-Carer is a measure for unpaid carers, which has been developed and psychometrically tested in a diverse sample of carers in England (Rand *et al.*, 2015). The ASCOT-Proxy is an adapted version of ASCOT, designed to measure proxy-reported SCRQoL for people who cannot self-report (Rand, Caiels, *et al.*, 2017a). The psychometric properties of the ASCOT-Proxy and

ASCOT-Carer using this study sample are reported in Silarova *et al.*, 2021. Further detail of these instruments are available at www.pssru.ac.uk/ascot.

For the ASCOT-Proxy, the proxy respondent (i.e. the carer) is asked to rate the person's QoL from a *proxy-person* and *proxy-proxy* perspective. There is evidence that proxy report systematically differs by perspective (Pickard and Knight, 2005; Rand and Caiels, 2015), so they are reported separately. Neither proxy perspective is equivalent to self-report. They are both proxy-report measures estimated using different strategies by the proxy respondent – specifically, the proxy's judgement based on their own views, attitudes and beliefs (*proxy-proxy*) and the proxy's judgement based on their internal construction of the person's views, attitudes and beliefs (*proxy-person*).

Utility weights were applied for both the ASCOT-Carer and ASCOT-Proxy to calculate index scores, whereby 1 (maximum value) represents full SCRQoL (Netten *et al.*, 2012; Batchelder *et al.*, 2019). Preference weights applied for the ASCOT-Proxy were those developed for ASCOT (Netten *et al.*, 2012); a separate set of weights has not yet developed for the ASCOT-Proxy.

Ethical approval

The study was approved by the Social Care Research Ethics Committee in England, Health Research Authority and Health and Care Research Wales (Reference: XX/XXXX/XXXX). Research governance approval was also sought in local authorities where we recruited carers via publicly-funded services.

Analysis

Descriptive statistics were calculated for the study sample of completed questionnaire ($n=313$). The frequency (%) of unmet social care outcome need was reported for each ASCOT-Carer and ASCOT-Proxy attribute. Each attribute of the ASCOT-Carer and ASCOT-Proxy was rated by respondents as the ideal state (highest QoL), no needs, some needs, or high level needs (lowest QoL). Rating of either some or high level needs was taken as an indicator of unmet social care need.

To explore the factors related to SCRQoL, regression models were estimated using Ordinary Least Squares (OLS) with the ASCOT-Carer and ASCOT-Proxy (*proxy-proxy*, *proxy-person*) as the dependent variables. Analyses were conducted on complete cases only.

In the ASCOT-Carer model, the independent variables considered were the individual characteristics of the carer (sex, aged ≥ 65 years, self-rated health) and care-recipient (Minimum Dataset Cognitive Performance Scale (MDS CPS) (Morris *et al.*, 1994)), and caregiving situation (carer co-residence with the care-recipient, ≥ 50 hours care per week, and financial difficulties due to caring). The carer's

satisfaction with social care support was also considered. These factors were selected on the basis of their conceptualised relationship to social care-related QoL as *primary stressors* (cognitive status of care recipient, hours of informal care per week), *secondary stressors* (financial difficulties) or *moderators* that exacerbate or ameliorate the impact of stressors (carer's health, experienced satisfaction with care) (Sörensen *et al.*, 2006). Individual characteristics (age, sex, ethnicity) may influence their experience of stressors, their moderation or appraisal, or have a direct influence of subjective QoL (Sörensen *et al.*, 2006). We also considered whether the survey was completed online or by postal survey, to establish whether there was an effect for mode of administration.

In the ASCOT-Proxy models, the independent variables were selected based on previous research on factors related to SCRQoL in other populations, including older adults (van Leeuwen *et al.*, 2014) and adults with intellectual disabilities (Rand and Malley, 2017). These, and also this study, are informed by an adapted production of welfare model (Forder *et al.*, 2018), which proposes that SCRQoL is related to care recipient characteristics (age), informal support availability and intensity (co-residence with carer, hours of care per week), care-related needs (cognitive impairment), environmental factors (suitability of home for care needs) and social care support (day service use, hours of home care). Like for the ASCOT-Carer model, the mode of survey administration was also considered.

Although the study was planned and funded before the COVID-19 pandemic, the data collection coincided with phases of COVID-related legal restrictions in England, which affected everyday life (e.g. ability to socialise). Therefore, we also considered the survey completion date, to control and account for these wider contextual shifts. Dummy variables were created for the following phases of COVID-related policy in England (Brown and Kirk-Wade, 2021), against a baseline pre-first national lockdown in England (up to 25th March 2020): first national lockdown (26th March 2020 until 3rd July 2020); minimal restrictions (4th July 2020 to 13th September 2020); reintroduction of restrictions by regional tier system (14th September 2020 to 4th November 2020); second national lockdown (5th November until 1st December 2020); reintroducing the regional tier system (2nd to 29th December 2020); third national lockdown (30th December until 7th March 2021); easing restrictions (8th March to study end, April 2021).

Goodness of fit statistics were calculated and reported, including the overall F-test and adjusted R-squared. The Ramsey RESET statistic (Ramsey, 1969) was calculated to test for omitted variable bias or misspecification error. The D'Agostino-Pearson K² test (D'Agostino, Belanger and D'Agostino, 1990) was applied to test the normality of residuals. The Breusch-Pagan test of heteroscedasticity was also calculated (Breusch and Pagan, 1979).

All analyses were performed in Stata version 16.

Results

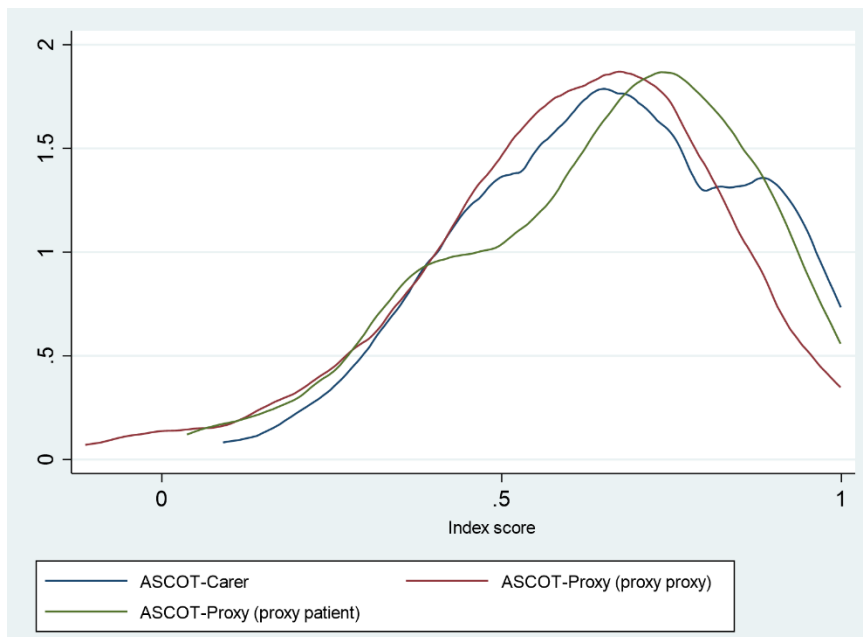
The sample descriptive statistics are shown in Table 2. Most of the respondents were caring for a parent (48.9%) or spouse/partner (41.5%). The majority were women (75.7%). The age range of respondents was from 24 to 90 years. Over half of the sample (56.2%) were aged under 65 years, with the majority of carers aged either 55-64 years (34.5%) or 65-74 years (29.1%). The sample comprised 5.4% carers from ethnic minorities, which is slightly lower than the estimated 8% of all carers in England (NHS Digital, 2010). Over half (57.8%) of the sample were carers who live with the person they support.

[Table 2]

Two thirds of participants reported that they had used home care services in the past week. Half had accessed carer support groups (49.5%) in last 12 months. Around a third of the sample had accessed day services or activities (30.0%) and/or breaks from caring (31.0%) in last 12 months, including short-term or emergency breaks or residential respite care. While further detailed data on the type and mode of delivery of support was not collected in the survey, the delivery of community-based social care services were affected by the COVID-19 pandemic. Many services were delivered instead online or by telephone, or with adaptations (e.g. use of PPE, social distancing) to reduce the risk of COVID-19 transmission, or were temporarily suspended.

The SCRQoL index score distribution for the ASCOT-Carer and two proxy perspectives for the ASCOT-Proxy are shown in Figure 1. The ASCOT-Carer, which is scored from 0 (worst SCRQoL) to 1 (best SCRQoL), was positively skewed with an average index score of .65 (std. dev.=.21; range .09 to 1.00; $n=312$). Likewise, the ASCOT-Proxy index scores, which are scored from -.17 (worst SCRQoL) to 1 (best SCRQoL), are also positively skewed. The proxy-person index score (mean=.64, std. dev.=.22, range .04 to 1.00; $n=278$) was significantly higher than the proxy-proxy index score (mean=.60, std. dev.=.22, range -.11 to 1.00; $n=284$) ($t(274) = -3.45, p<.001$).

Figure 1. ASCOT-Carer and ASCOT-Proxy index score



The frequency (%) of unmet need by ASCOT-Carer and ASCOT-Proxy attribute are shown in Table 3. Across all ASCOT-Carer domains, except feeling safe (*Personal safety*, 3.2%) and being able to look after themselves by eating well, exercise and attending medical appointments (*Self-care*, 32.1%), over 50% of carers reported that they had unmet needs. The highest % unmet need were reported by carers with regard to being able to do things they value and enjoy (*Occupation*), having time and space to themselves (*Time and space*) and being able to sustain social relationships with friends and family (*Social participation*).

The % unmet need for ASCOT-Proxy was higher for the proxy-proxy than the proxy-person rating for all domains, except feeling safe (*Personal safety*) and effect of how care is delivered on a person's sense of self (*Dignity*). Relatively low unmet needs (5% to 16%) were reported for the four ASCOT attributes that relate to basic care-related needs (*Accommodation*, *Personal comfort and cleanliness*, *Food and drink*, and *Personal safety*) (see Table 1). Over half of the sample proxy-reported unmet care-related outcome needs for aspects of care-related quality of life, beyond basic care needs (i.e. *Occupation*, *Control over daily life* and *Social participation*). Unmet need was rated by 21.1% (proxy-proxy) or 35.1% (proxy-person) for *Dignity*. This relates to *how* paid care is delivered. Unmet needs indicate that the way in which care or support workers delivery care either sometimes (some needs) or completely (high-level needs) makes the person feel undermined. This is notably higher than surveys of adult social care service users in England (2019/20 adult social care survey in England, 9.3% of surveyed service users rated *Dignity* as some or high-level needs (NHS Digital, 2021)).

[Table 3]

The results of the multivariate regression analysis for ASCOT-Carer are shown in Table 4. Goodness of fit statistics were acceptable. The residuals were normally distributed (D'Agnostino-Pearson $K^2 = 1.85$, $p = .40$) and the variance of the residuals was homogenous (Breusch-Pagan test $X^2(1) = 2.21$, $p = .14$). There is no evidence for omitted variable bias (Ramsey-RESET, $F(3,279) = 1.41$, $p = .24$). The adjusted R^2 indicates that the model explains 43.9% of the variance.

The ASCOT-Carer SCRQoL index score was significantly positively associated with good or very good self-rated health and satisfaction with care services ($p < .001$), and negatively associated with high intensity caregiving (≥ 50 hours per week), financial difficulties related to caring, co-residence with the person they support, and care-recipient severe cognitive impairment ($p < .05$). None of the variables of the phase of COVID-related restrictions in England were significantly associated with SCRQoL, after controlling for other variables in the model. Questionnaire administration online, rather than by postal survey, also did not reach significance ($B = -.021$, $p = .44$).

[Table 4]

The results of the OLS analysis for the ASCOT-Proxy SCRQoL index score rated by the proxy's own view (proxy-proxy) or the proxy's view of the person's view (proxy-person) are shown in Table 5. Both models had no evidence of omitted variable bias (Ramsey RESET $p > .05$). However, the variance of the residuals was heterogenous for both models (Breusch-Pagan $p < .01$). The residuals were also not normally distributed in the proxy-proxy model (D'Agnostino-Pearson $K^2 = 6.29$, $p = .04$), so we applied robust estimates of variance (Huber-White).

[Table 5]

In both models, the severity of the person's cognitive impairment was negatively related to QoL ($p < .01$) and suitability of the home for caregiving had a significant positive association with SCRQoL ($p < .05$). The administration of the questionnaire as an online survey, rather than postal survey, was not significantly associated with SCRQoL ($p > .05$). The other factors related to ASCOT-Proxy index score differed by the proxy perspective of rating. For rating by the proxy of their view of the person's perspective (proxy-person), there was a significant negative association with care-recipient's age of 65 years or older, and also increased number of I/ADLs with difficulty ($p < .01$); however, there was no significant association for care-recipient age or difficulty with I/ADLs, where the carer was asked to rate their view of the person with dementia's quality of life (proxy-proxy). Conversely, SCRQoL rated by the proxy-proxy perspective was significantly positively associated with the availability and intensity of both informal (co-residence and hours of care per week) and formal support (home care hours per week, day activities) ($p < .05$); there were no significant associations between these variables and proxy-person perspective rated SCRQoL.

When controlling for the other variables considered in the model, the effect of the COVID-related restriction phase variables were not significantly associated with proxy-proxy rating of SCRQoL, except for the phase of reintroducing restrictions from 14th September 2020 to 4th November 2020 in England, which was associated with lower SCRQoL ratings against the baseline of pre-COVID (B=-.130, $p=.01$). For the model with proxy-person rated SCRQoL, the three later stages of the pandemic covered by the data collection period for this study (i.e. reintroducing the tier system, third national lockdown and steps out of lockdown, from December 2020 to study end in April 2021) were all negatively associated with SCRQoL ($p<.05$).

Discussion

In this study, we identified the pattern of unmet social care need, as defined using QoL outcomes, of a sample of community-dwelling PLWD and their carers in England. This is a group that is at risk of exclusion from social care research. The study applied the recently-developed proxy-report version of the ASCOT, designed to address this issue (Silarova *et al.*, no date; Rand, Caiels, *et al.*, 2017a; Caiels *et al.*, 2019). Despite sampling carers who already had contact with social care, over half self-reported unmet need in five of the seven carers' SCRQoL domains (all except *Self-care* and *Personal safety*), as well as proxy-reported unmet need for the care-recipient in three of eight SCRQoL domains (*Occupation*, *Control over daily life* and *Social participation*). Despite the Care Act (2014) definition of social care need in terms of social care QoL outcomes, for both adults with support needs and carers (Social Care Institute of Excellence, 2020), outcome needs are remaining unaddressed, especially for carers, even when in contact with social care services. This indicates that there is a need for better ways of identifying, establishing unmet social care-related QoL needs and effectively supporting PLWD and their carers to address these unmet needs.

The profile of social care outcome need of the surveyed carers aligns with other evidence, which indicates that the current provision of community-based support in England is not adequately meeting the needs of PLWD and their carers. The fragmentary nature of the social care system, the transience of the care workforce and chronic underfunding have been highlighted as challenges to providing high-quality person-centred care that is able to improve and sustain QoL for PLWD and their carers (Department of Health and Social Care, 2019). With regard to home care, for example, the use of 15-minute visits, zero-hour shift rotas, and frequent changes in care workers all contribute to difficulty in delivering high-quality personalised care; it precludes the development of meaningful working relationships between carer and care staff, which improve social care outcomes and facilitate care transitions (Dalgarno *et al.*, 2021). More could be done to adequately fund and promote innovation in the community-based care sector to meet the needs of PLWD and their

carers, especially in light of the COVID-19 pandemic and trend away from institutionalised care (Bennett, Honeyman and Bottery, 2018; Alders and Schut, 2019; Szcześniak *et al.*, 2021).

This study also sought to understand the factors related to SCRQoL, either self- or proxy-reported by carers. The findings of this study for the factors related to carers' SCRQoL are consistent with those from a study of a heterogeneous sample of carers in England (Rand *et al.*, 2015). Key influences on carers' SCRQoL are self-rated health, intensity of caregiving, financial difficulties related to caring and satisfaction with social care support (Rand *et al.*, 2015). Interestingly, the previous study (Rand *et al.*, 2015) did not find any effect of co-residence, whereas it was found to be negatively associated with QoL here. In this study, we also collected and considered data on the severity of cognitive impairment; it was also found to be significantly related to lower QoL outcomes. Taken together, these findings offer a view of the risk factors for poor QoL outcomes for carers of PLWD. Those living with the person they support, with poor self-rated health, providing ≥ 50 hours per week, experiencing financial difficulties due to caring, and supporting someone with severe cognitive impairment are more likely to experience lower SCRQoL. Although the Care Act (2014) removed the criteria of 'substantial and regular care' for access to assessment and support to address carers' own social care needs in England, these findings indicate that risks to SCRQoL are related to both intensity (as indicated by hours of care) and proximity (as indicated by co-residence) in caregiving. Therefore, an understanding of caregiving context, as well as carers' own health and financial situation, is important to needs assessments, care planning and delivery. These may also be important data to collect and consider in datasets to guide policy, service planning and delivery at local, regional and national levels.

The significant association with service satisfaction highlights how social care support, even when services may be provided 'for' the person with dementia, rather than for carers, is important for carers' SCRQoL. In a study of carers in England, the way in which services have either positive, neutral or negative effects on carers' SCRQoL has been described, with positive impacts related to a reduction of time spent on caregiving tasks, by encouraging carers to focus on self-care, access support or reappraise their role or priorities, and by alleviating subjective burden. Poor quality or inadequate care may lead to negative effects on carers' QoL: for example, brief 15-minute home care visits, especially where care workers are rushed and do not have time to tidy away afterwards, may mean the carer has to provide additional support to compensate (Rand, Vadean and Forder, 2020). This highlights the ideal practice of partnership working with formal carers to support the person with dementia (i.e. carers as co-workers (Twigg and Atkins, 1994)) and benefit of care workers having a view of the carer's (joint) needs alongside the person they support (i.e. carers as co-clients (Twigg and Atkins, 1994)). However, such an approach of proactive planning,

communication and collaboration between formal and informal carers, even if valued by carers and recognised by policy as beneficial in supporting carers and the person with dementia, and has been shown to be effective in other contexts (e.g. in Sweden (Lethin *et al.*, 2016)), is challenging to achieve within the current budgetary constraints of social care commissioning in England (Dalgarno *et al.*, 2021).

One of the aims of this study was to demonstrate and test the approach of collecting QoL outcomes for PLWD who cannot self-report, by proxy report. The psychometric testing of the ASCOT-Proxy is reported elsewhere (Silarova *et al.*, no date). In this paper, we have identified the factors related to proxy-reported SCRQoL from both perspectives (proxy-proxy and proxy-person). Some variables were significantly associated with SCRQoL rated by proxy-proxy and proxy-person perspectives, notably cognitive impairment and design of the home. Home design that is adequate for care needs has been found to be related to SCRQoL in studies of adults with physical disability or mental health conditions in England (van Leeuwen *et al.*, 2014; Rand, Malley, *et al.*, 2017), adults with intellectual disabilities in England (Rand and Malley, 2017) and older home care service users in Finland (Nguyen *et al.*, 2021). Good quality housing with adequate space, layout and design to flexibly adapt around changing individual needs has been found to be important for maintaining the overall quality of life, independence and dignity or privacy of PLWD and their carers (Soilemezi *et al.*, 2019). In this study, we demonstrate also the association with social care outcomes and importance of considering housing and care, together, in supporting PLWD at home.

The rating of QoL differs systematically by the proxy perspective adopted by the respondent, with proxy-proxy rating typically lower than proxy-person rating and less aligned to self-report (where it is possible to collect these data) (Pickard and Knight, 2005). In this study, we, likewise, found that proxy-proxy report was significantly lower than proxy-person report. In the multivariate regression, the factors related to QoL outcomes also varied, which would be expected due to the differences in how each perspective is understood and rated by the respondent. Importantly, the variables related to the availability, type and intensity of both informal (hours of care, co-residence) and formal (hours of home care, day care) care were significantly positively related to QoL. The proxy respondent is correctly understanding and rating the ASCOT-Proxy as a measure of the impact of care on SCRQoL. However, these significant relationships are not found with the proxy-person ratings. This is consistent with qualitative evidence from the development of the ASCOT-Proxy, whereby some proxy respondents would describe how the person was ambivalent, unaware or even antagonistic towards care and support, even if (in the proxy respondent's view) it promoted QoL outcomes (Rand, Caiels, *et al.*, 2017b; Caiels *et al.*, 2019). This is important when considering which of the ratings to apply or use in different contexts. Arguably, the proxy-person view has value if the

aim is to gain insight into the person's perspective of their situation; however, the proxy-proxy perspective may offer a measure of the impact of care on QoL that may not be possible with the proxy-person report.

The impact of the different phases of COVID-related restrictions were also considered on carers' self-reported and proxy-reported SCRQoL. Longitudinal studies have shown that there were shifting patterns of access to community-based social care for older people, including PLWD, and their carers, as well as corresponding effects on anxiety, depression and QoL (Giebel *et al.*, 2020, 2021). In this study, we did not find any significant effect of COVID restriction phase on carer SCRQoL.

However, this may be due to the existing high-level needs of the subgroup of carers – i.e. supporting someone with moderate-to-severe dementia living at home – and also, that the model controls for satisfaction with social care support, which may control for instances where support had been either completely withdrawn or adapted. By contrast, there were significant effects in the ASCOT-Proxy models. The reintroduced restriction phase (autumn 2020) was significantly negatively associated with SCRQoL (proxy-proxy), and the phases after the second national lockdown were negatively associated with SCRQoL (proxy-person). These findings indicate that there were negative QoL impacts, whilst controlling for social care support, of the pandemic-related restrictions for PLWD in their own homes. From the person's own perspective, there appears to be a sustained cumulative effect towards the latter stages of restriction covered by the study period. By contrast, the proxy-proxy report perspective identified a significant negative effect after the transition to reintroduce restrictions after the first easing.

Finally, the mode of administration, either online or postal survey, was considered in the models with ASCOT-Carer and ASCOT-Proxy. In a previous study, it was found that carers reported lower ASCOT-Carer SCRQoL when it was completed by telephone compared to face-to-face interview (Rand *et al.*, 2015). However, in this study, there was no significant difference between self-report postal compared to self-report online survey for the ASCOT-Carer. This finding also applied to the ASCOT-Proxy scores. This finding is potentially important in guiding whether and how the measures are used in social care evaluation and research. Currently, for example, adult social care outcomes data are routinely collected in England by postal survey (NHS Digital, no date), although there is interest in shifting towards an online or hybrid (i.e. postal and online) approach to data collection. This finding provides tentative evidence that there is not a systematic bias by mode when using the questionnaires as self-report instruments.

The study has some limitations. First, the sample size is modest and the number of cases for some categories are low. Especially with the dummy variables for the phases of restrictions, variables may

not have reached significance due to the small numbers. Second, it is not possible to be confident in the representativeness of the sample to the population of study (i.e. PLWD in their own homes, who have informal care and use social care support). This is because of the lack of robust population estimates for this group. By comparing to the 2009/10 population estimate of English carers (NHS Digital, 2010), however, the sample likely underrepresents carers from ethnic minorities and male carers.

Conclusion

This study adds to what is known about social care outcomes in England by its focus on PLWD, who live at home and are unable to self-report, and their carers. This is a subgroup, who are at risk of exclusion from social care research and national data collections. The study has shown that there is a high-level of unmet need, defined by QoL outcomes. This indicates that the social care system has not aligned to the policy direction and legislative framework of the Care Act (2014), which set out a focus both on individual QoL, rather than addressing deficits or tasks. If the aim of promoting QoL outcomes, both of PLWD and their carers, is to be realised, the chronic issues in the English social care system need to be addressed, especially in planning and delivering services to work creatively, collaboratively and meaningfully with PLWD and their carers. The study also identified factors related to QoL outcomes, including the impact of the COVID-related restrictions in England. Whilst the focus of the pandemic has primarily been on its impacts in residential and nursing care, this study identifies the impact also for people living at home, which warrants further interest and investigation in the recovery phase from the pandemic.

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Tables

Table 1. ASCOT and ASCOT-Carerer domains (Adapted from (Netten *et al.*, 2012; Rand *et al.*, 2015))

Domain	ASCOT definition	ASCOT-Carerer definition
Occupation	Being occupied in a range of meaningful and enjoyable activities, including paid employment, unpaid work, caring for others or leisure activities.	<i>See definition for ASCOT</i>
Control over daily life	Choosing what to do and when to do it; having control over their daily life and activities.	<i>See definition for ASCOT</i>
Social participation	Being content with their social situation, including meaningful relationships with friends and family, as well as feeling involved and part of their community.	<i>See definition for ASCOT</i>
Personal safety	Feeling safe and secure, where concerns about safety can include fear of abuse or other physical harm or accidents.	<i>See definition for ASCOT, with the addition of: '..., which may arise as a result of caring'.</i>
Food and drink	Having a varied, nutritious and culturally appropriate diet with enough food and drink that the person enjoys, at regular and timely intervals.	n/a
Accommodation comfort and cleanliness	Feeling that the home environment (all rooms) is clean and comfortable.	n/a
Personal comfort and cleanliness	Feeling personally clean and comfortable, and looks presentable or, at best, is dressed and groomed in a way that reflects the person's personal preferences.	n/a
Dignity	A positive sense of self and personal significance, due to the way the person is helped and supported.	n/a
Self-care	n/a	Feeling able to look after oneself, in terms of eating well, getting enough sleep and attending medical appointments.
Space and time to be yourself	n/a	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	n/a	Feeling encouraged and supported by care workers, social care professionals, and others, in their role as a carer.

Table 2. Sample characteristics (n=313)

	Frequency N (%), or Mean, Std. Dev., Range
Carer characteristics	
Male	76 (24.3%)
Aged ≥ 65 years	137 (43.8%)
Ethnicity: Black, Asian, multiple or mixed, or other †	17 (5.4%)
Self-rated health: good or very good †, ††	229 (73.1%)
Care recipient characteristics	
Aged ≥ 65 years	291 (93.0%)
Care-recipient: <i>partner/spouse</i>	130 (41.5%)
<i>parent</i>	153 (48.9%)
<i>other (sibling, child, friend, in-law)</i>	30 (9.6%)
Number of ADLs with difficulty or unable to complete ††, §	5.2, 2.5, 1 to 8
MDS CPS: severe or very severe impairment †, ††	185 (59.1%)
Caring situation/impact	
Home design meets care needs very well †	101 (32.3%)
Co-resident with care-recipient	181 (57.8%)
≥ 50 hrs care per week ††	147 (47.0%)
Caring has caused financial difficulty ††	128 (40.9%)
Social care	
Home care support (<i>in past week</i>)	212 (67.7%)
Hours (<i>in past week</i>) ††	14.4, 31.9, 0 to 168
Day services or activities ††	94 (30.0%)
Information & advice for the carer	207 (66.1%)
Carers support group	155 (49.5%)
Breaks from caring (emergency, short-term or >24 hrs)	97 (31.0%)
Satisfied with services †, ††	183 (58.5%)
Survey completion date by COVID-19 restriction phase (Brown and Kirk-Wade, 2021)	
Before 1 st national lockdown	40 (12.8%)
First national lockdown	74 (23.6%)
Minimal lockdown	7 (2.2%)
Reintroducing restrictions	16 (5.1%)
2 nd national lockdown	25 (8.0%)
Reintroducing the tier system	19 (6.1%)
3 rd national lockdown	85 (27.2%)
Steps out of lockdown	47 (15.0%)
Survey	
Completed online †	250 (79.9%)

† Base category: Ethnicity (white or white British); Self-rated health (fair, bad or very bad); MDS CPS (borderline, mild, moderate or moderate-severe); Home design (meets most, some or no needs); Satisfied with services (neither satisfied nor dissatisfied, quite, very or extremely dissatisfied); Completed online (by post)

†† Missing data: Self-rated health (Carer) (n=1); ADLs (n=3); MDS CPS (n=5); ≥ 50 hrs care per week (n=3); Day services or activities (n=1); Caring has caused financial difficulty (n=2); Home care hours (n=10); Day services or activities (n=1); Satisfied with services (n=4)

§ I/ADLs: getting around indoors; get in/out of bed; feed self; finances and paperwork; wash all over by self; get dressed and undressed; use the toilet; wash hands and face.

Table 3. Unmet need

	ASCOT-Carer [†]	ASCOT-Proxy proxy proxy ++	ASCOT-Proxy proxy person +++
	N (%)	N (%)	N (%)
Accommodation cleanliness and comfort		34 (10.9%)	14 (4.5%)
Personal cleanliness and comfort		45 (14.4%)	14 (4.5%)
Food and drink		49 (15.7%)	32 (10.2%)
Dignity		66 (21.1%)	110 (35.1%)
Control over daily life	162 (51.8%)	173 (55.3%)	165 (52.7%)
Occupation (<i>doing things I value and enjoy</i>)	224 (71.6%)	234 (74.8%)	188 (60.1%)
Social participation	184 (58.8%)	197 (62.9%)	155 (49.5%)
Personal safety	10 (3.2%)	37 (11.8%)	50 (16.0%)
Self-care	100 (32.1%)		
Time and space	196 (62.6%)		
Feeling supported and encouraged	157 (50.2%)		

[†] **Missing data:** Personal safety (n=1)

⁺⁺ **Missing data:** Food and drink (n=3), Dignity (n=21), Control (n=3), Occupation (n=1), Social (n=1), Personal safety (n=2)

⁺⁺⁺ **Missing data:** Accommodation (n=4), Personal comfort and cleanliness (n=2), Food and drink (n=6), Dignity (n=22), Control (n=5), Occupation (n=3), Social (n=3), Personal safety (n=5)

Table 4. OLS ASCOT-Carer

	B	95% CI	p value
Male	.039	-.005 to .083	.082
Aged ≥ 65 years	.019	-.025 to .063	.403
Ethnicity: Black, Asian, multiple or mixed, or other	-.072	-.155 to .011	.088
Self-rated health: good or very good	.124***	.082 to .166	<.001
MDS CPS: severe or very severe impairment	-.057**	-.094 to -.019	.003
Co-resident with care-recipient	-.059*	-.117 to -.001	.044
≥ 50 hrs care per week	-.069*	-.124 to -.013	.015
Financial difficulty due to caring	-.094***	-.132 to -.056	<.001
Satisfied with services	.142***	.105 to .178	<.001
Survey completion by COVID-19 phase:			
<i>First national lockdown</i>	-.054	-.115 to .007	.081
<i>Minimal lockdown</i>	.027	-.100 to .154	.674
<i>Reintroducing restrictions</i>	-.047	-.139 to .045	.314
<i>2nd national lockdown</i>	-.008	-.090 to .074	.850
<i>Reintroducing the tier system</i>	-.016	-.104 to .071	.712
<i>3rd national lockdown</i>	-.043	-.105 to .019	.173
<i>Steps out of lockdown</i>	-.031	-.104 to .042	.407
Survey online	-.021	-.073 to .032	.443
Constant	.651***	.562 to .739	<.001
N	300		
Anova F-text	14.74***		
Adjusted R ²	.439		
Ramsey RESET	1.41		
D'Agnostino-Pearson K ²	1.85		
Breusch-Pagan	2.21		

* <.05, ; ** <.01 *** <.001

Table 5. OLS ASCOT-Proxy

	Proxy-proxy perspective			Proxy-person perspective		
	B	95% CI	p value	B	95% CI	p value
Care recipient is aged \geq 65 years	-.076	-.171 to .018	.113	-.136**	-.213 to -.059	.001
Home design meets care needs very well	.079**	.027 to .131	.003	.051*	<.001 to .102	.050
I/ADLs with difficulty	-.008	-.019 to .003	.139	-.021**	-.034 to -.009	.001
MDS CPS: severe or very severe impairment	-.121***	-.176 to -.067	<.001	-.088**	-.152 to -.024	.007
Co-resident with care-recipient	.088**	.023 to .153	.009	.013	-.064 to .090	.739
\geq 50 hrs care per week	.072*	.012 to .133	.019	.030	-.045 to .105	.433
Home care hours (in past week)	.001*	<.001 to .002	.012	<.001	-.001 to .001	.743
Day services or activities	.056*	<.001 to .113	.050	.006	-.053 to .064	.849
Survey completion by COVID-19 phase:						
<i>First national lockdown</i>	-.017	-.110 to .075	.716	-.050	-.129 to .030	.219
<i>Minimal lockdown</i>	-.085	-.283 to .114	.402	-.066	-.207 to .075	.357
<i>Reintroducing restrictions</i>	-.130*	-.234 to -.027	.014	-.125	-.264 to .015	.081
<i>2nd national lockdown</i>	<.001	-.104 to .105	.996	-.084	-.181 to .012	.087
<i>Reintroducing the tier system</i>	-.060	-.182 to .063	.340	-.160*	-.311 to -.008	.039
<i>3rd national lockdown</i>	-.075	-.175 to .026	.145	-.094*	-.184 to -.004	.041
<i>Steps out of lockdown</i>	-.064	-.173 to .044	.245	-.170**	-.269 to -.072	.001
Survey online	.005	-.059 to .069	.882	-.025	-.097 to .047	.497
Constant	.688***	.528 to .847	<.001	1.007***	.861 to 1.152	<.001
N	269			263		
Anova F-text	5.26***			4.05***		
Adjusted R ²	.203			.157		
Ramsey RESET	1.68			1.71		
D'Agostino-Pearson K ²	6.29*			4.88		
Breusch-Pagan	10.44**			15.85***		

* <.05, ; ** <.01 *** <.001