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**Measuring carer outcomes in an economic evaluation: A content comparison of the Adult Social Care Outcomes Toolkit for Carers, Carer Experience Scale and Care-related Quality of Life using exploratory factor analysis**

Running head: Comparing carer-related preference-based measures

**Authors:**

**Lidia Engel, Doctor of Philosophy (PhD) \***

Deakin University, Geelong, Deakin Health Economics, Institute for Health Transformation, School of Health and Social Development, Faculty of Health, Victoria, Australia.

**Stacey Rand, Bachelor with Honours (BA Hons)**

Personal Social Services Research Unit (PSSRU), Cornwallis Building, University of Kent, Canterbury, United Kingdom.

**Renske Hoefman, Doctor of Philosophy (PhD)**

The Netherlands Institute for Social Research, The Hague, Netherlands.

**Jessica Bucholtz, Bachelor of Nursing (BN)**

Murdoch Children's Research Institute, Royal Children's Hospital, Victoria, Australia.

**Cathrine Mihalopoulos, Doctor of Philosophy (PhD)**

Deakin University, Geelong, Deakin Health Economics, Institute for Health Transformation, School of Health and Social Development, Faculty of Health, Victoria, Australia.

**Anne Muldowney, Master of Public Policy (MPP)**

Carers Victoria, Footscray, Victoria, Australia.

**Anna Ugalde, Doctor of Philosophy (PhD)**

Deakin University, Geelong, Institute for Health Transformation, School of Nursing and Midwifery, Faculty of Health, Victoria, Australia.

**Nikki McCaffrey, Doctor of Philosophy (PhD)**

Deakin University, Geelong, Deakin Health Economics, Institute for Health Transformation, School of Health and Social Development, Faculty of Health, Victoria, Australia.

**\* Corresponding author:**

Lidia Engel, PhD

Deakin University, Geelong, Deakin Health Economics, Institute for Health Transformation, School of Health and Social Development, Victoria, Australia

Email: [lidia.engel@deakin.edu.au](mailto:lidia.engel@deakin.edu.au)

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## **Abstract**

**Background:** To incorporate the spillover effects experienced by carers providing informal care in health policy decisions, new carer-related preference-based measures have been developed for use in economic evaluation, such as the Adult Social Care Outcomes Toolkit for Carers (ASCOT-Carer), Carer Experience Scale (CES) and Care-related Quality of Life (CarerQoL). The aim of this study was to investigate the extent to which these three instruments measure complementary or overlapping constructs.

**Methods:** Data were derived from an online survey undertaken with carers residing in Australia. An exploratory factor analysis was conducted to ascertain the underlying latent constructs of the three measures.

**Results:** Data from 351 informal carers yielded a five-factor model describing *general quality of life outside caring, problems due to caring, fulfilment from caring, social support with caring, and relationship with the care recipient*. The majority of the ASCOT-Carer and the CarerQoL items loaded onto the first and second factors, respectively. The greatest overlap was observed between CarerQoL and CES items loading onto the other three shared common factors.

**Limitations:** Online data collection resulted in inconsistent responses, which had to be removed to yield logical data. A convenience sampling approach may have compromised the generalizability of study findings.

**Conclusion:** Although some overlap was observed, the three carer-related preference-based measures seem to tap into different constructs of carer-related quality of life and caring experiences and cannot be used interchangeably.

**Key words:** Economic evaluation, informal care, outcome measurement, carer-related quality of life, preference-based measures

## 1 **Introduction**

2 The inclusion of all influential costs and benefits when conducting an economic evaluation from a  
3 societal perspective is currently the recommended approach in health policy decision-making [1]. This  
4 also implies the inclusion of the impact of health care interventions and programs on informal carers'  
5 costs and benefits, where relevant. Informal carers are usually family members, friends, or neighbours  
6 who provide regular, typically unpaid, support to a person who has a disability, mental illness, chronic  
7 condition, terminal illness or who are frail aged [2]. Although informal carers are an integral part of  
8 many health care systems, the costs and effects of informal caregiving are often neglected in  
9 economic evaluations, which can have significant impacts on cost-effectiveness inference [3]. Two  
10 previous reviews have explored the impact of including or excluding informal care on cost-  
11 effectiveness results, with studies reporting that the exclusion of informal care may alter the  
12 incremental cost-effectiveness ratio in either direction and may lead to different recommendations  
13 (i.e., the intervention became more or less cost-effective) [3, 4]. While carers' time costs have been  
14 measured and valued in some studies, carers' health and wellbeing effects have been largely ignored  
15 in many economic evaluations to date, even when adopting a societal perspective [3]. However, health  
16 and social care interventions targeting patients can also affect carers' outcomes in a number of ways  
17 [5]. For example, some interventions may reduce the physical and/or emotional demands on carers,  
18 whereas others may improve patient outcomes at the expense of carer outcomes. A previous study has  
19 shown that improving patient quality of life may reduce the need for carer time and improve carer's  
20 quality of life, suggesting that current economic evaluations that do not take carer effects into account  
21 may under-estimate (or sometimes overestimate) cost-effectiveness results [6]. Al-Janabi *et al.*  
22 recently conducted focus groups and interviews with carers to identify the mechanisms by which  
23 patients' health and social care services affect family carers' wellbeing [7]. Six mechanisms were  
24 identified that may result in positive and negative effects (also described as spillovers) on carers. Yet,  
25 when conducting cost-effectiveness analyses, spillover effects are seldom measured and there is  
26 variation in the measurement methods used [8].

1 To account for the impacts of health and social care interventions on informal care when conducting  
2 an economic evaluation, a number of carer-related preference-based measures have been developed,  
3 which include the Care-related Quality of Life (CarerQoL) [9], the Carer Experience Scale (CES) [10],  
4 and, the Adult Social Care Outcomes Toolkit for Carers (ASCOT-Carer) [11]. Compared with other  
5 measures of carer burden or quality of life that often rely on simple sum scores [12], these measures  
6 include a scoring algorithm that accounts for people's preferences, reflecting the fact that certain  
7 aspects of caring may be valued more than others. As such, a key characteristic of these measures is  
8 that they comprise a descriptive system - referring to the set of questions and response levels of the  
9 respective measure - and a valuation system (i.e. a scoring algorithm), which corresponds to the  
10 preferences attached to the different 'care states' as defined by the respective measure.

11 An overview of the domains included in the three carer-related preference-based instruments and its  
12 descriptions are provided in Table 1. Different approaches were applied when deriving the descriptive  
13 systems of the three carer-related preference-based measures, which were guided by distinct  
14 theoretical frameworks. The CarerQoL was designed to measure and value the impact of providing  
15 informal care on carers and consists of two parts: a measure of subjective burden (the CarerQoL-7D)  
16 and a measure of carers' overall wellbeing (the CarerQoL-VAS) [9]. The seven dimensions of the  
17 CarerQoL-7D were selected based on existing burden measures [9]. Compared with the CarerQoL, that  
18 has a great focus on *subjective burden*, the CES captures the *caring experience* related to the process  
19 of providing care, which goes beyond the focus on strain and needs of carers, as well as beyond  
20 health-related quality of life [13]. A previous study has assessed the construct validity of the  
21 CarerQoL and the CES within the context of palliative care [14] and although both measures  
22 demonstrated good construct validity, it is currently unclear to what extent they measure similar  
23 aspects of informal care. The ASCOT-Carer four-response level questionnaire for self-completion  
24 (SCT4) or interview (INT4) measures the 'social care-related quality of life' (SCRQoL) of informal  
25 carers [11]. Adult social care refers to a range of services that aim to support a person with long-term  
26 conditions, disabilities or other needs to achieve daily activities, such as personal care, meal  
27 assistance, keeping active or socialising, or their informal carers [15]. SCRQoL refers to aspects of

1 quality of life that may be affected by adult social care services, either for the people with support  
2 needs (e.g., home care) or their carers (e.g., carer support groups). It was developed alongside the  
3 preference-weighted ASCOT instrument to measure SCRQoL of users of social care services [16].

4 Given the current paucity of head-to-head comparisons of these measures, it is currently unclear to  
5 what extent these three instruments measure complementary or overlapping constructs. This  
6 information is relevant to guide the selection of carer-related outcome measures for use in economic  
7 evaluation, where interventions may have different impacts on carers and the respective aspects of  
8 informal care, which may or may not be captured by the measures. While there appears to be some  
9 overlap between the instruments based on the content and underpinning theoretical framework,  
10 suggesting the instruments measure similar domains (see Figure 1), to date, the underlying structure  
11 of the three measures has not been explored using quantitative methods. Only recently, the ASCOT-  
12 Carer has been compared with the CES in carers in England, indicating that they capture separate  
13 constructs of SCRQoL and carer experience, with the only overlap observed in relation to *activities*  
14 *outside caring* and *social support* [17]. However, to our knowledge, no previous study has examined  
15 *all three measures* using empirical analysis, such as exploratory factor analysis. Therefore, the aim of  
16 this study was to compare the content of these three measures and investigate the conceptual (domain)  
17 overlap across the ASCOT-Carer, CES and CarerQoL using exploratory factor analysis to guide  
18 further the selection of carer-related preference-based measures for use in economic evaluation.

19

## 20 **Methods**

### 21 *Data Source*

22 The data were derived from an online survey that was powered by Qualtrics® with data collection  
23 taking place between June and September 2018. Informal carers were recruited through the not-for-  
24 profit organization *Carers Victoria* (in Australia) by means of newsletters, social media postings, and  
25 direct email invitations (only those carers who had previously given permission to Carers Victoria to  
26 be contacted for research-related studies). Carers were eligible to participate in the online survey if

1 they were older than 18 years, self-identified as a primary carer (without restricting to certain  
2 condition(s) of the care recipient), resided in Australia, and were able to read the survey in the English  
3 language. Prior to data collection, the survey was piloted with staff members at Deakin University for  
4 understanding and completion time. All participants provided implied consent by completing the  
5 survey and received a \$10 gift voucher as an acknowledgment for their contribution. Ethical approval  
6 to conduct the survey was granted by the Deakin University Faculty of Health, Human Ethics  
7 Advisory Group, Burwood, Australia (reference number HEAG-H 91\_2018).

8 The online survey contained a comprehensive set of questions and standardized instruments and was  
9 originally designed to investigate the psychometric properties of the three carer-related preference-  
10 based measures. Given the objective of this paper was to investigate the extent to which these three  
11 instruments measure complementary or overlapping constructs, only a brief summary of the overall  
12 survey is provided. The first section of the survey comprised demographic questions about the carers  
13 themselves, the care recipients and the care situation, followed by a set of standardized measures that  
14 included the CarerQoL [9, 18], the CES [10, 13], and the ASCOT-Carer [11]. The three carer-related  
15 preferences-based instruments (i.e., CarerQoL, CES, and ASCOT-Carer) were randomized in the  
16 survey to minimize potential ordering effects. The survey also contained other instruments, such as  
17 the EuroQol five dimension measure (EQ-5D-5L) [19], the Assessment of Quality of Life eight  
18 dimension (AQoL-8D) [20], the 3-item UCLA Loneliness Scale [21], and the Caregiver Reaction  
19 Assessment (CRA) [22], which were required for the psychometric validation of the three carer-  
20 related measures but were not used for the analyses reported in this paper. Respondents were also  
21 invited to complete a brief follow-up survey 2 weeks after the completion of the baseline survey to  
22 assess the test-retest reliability of the three carer-related preferences-based measures. For the current  
23 paper, only data collected at baseline were considered.

#### 24 *Instruments*

##### 25 *Care-related Quality of Life (CarerQoL)*



1 The CarerQol consists of two components, the CarerQol-7D, which is a measure of subjective burden,  
2 and the CarerQol-VAS, that measures carers' overall wellbeing [9]. The seven dimensions included in  
3 the CarerQol-7D include: fulfilment, support, relational problems, mental health problems, problems  
4 combining daily activities with care, financial problems and physical health problems, each with three  
5 response levels (*no*, *some*, and *a lot*). The CarerQol-7D forms the actual descriptive system of the  
6 measure and the 'care states' derived from this measure were valued using a discrete-choice  
7 experiment [18]. Developed in the Netherlands, the value set for the CarerQol was derived from an  
8 online survey among the general population in the Netherlands (n=992). During the discrete-choice  
9 experiment task, respondents were instructed to imagine that they provided care or support to a loved  
10 one as a result of an illness, disability or infirmity of old age. The CarerQol is available in eight  
11 languages, with value sets developed for six countries, including Australia [23]. For the current study,  
12 the Australian and the UK value sets were used to score the measure, with scores ranging from zero  
13 (the worst informal care situation) to 100 (the best informal care situation).

#### 14 *Carer Experience Scale (CES)*

15 The CES was developed in the UK for measuring the caring experience of carers for use in economic  
16 evaluation. The care states described by the six attributes (activities, support from family and friends,  
17 assistance from organisations, fulfilment, control, and getting-on with the care recipient) and three  
18 levels were valued using the best-worst scaling technique [10]. In the valuation task, carers of older  
19 people were asked to pick the best and worst attribute level from different profiles presented. The  
20 hypothetical choice task was completed by 162 carers of older people in a postal questionnaire. The  
21 scores derived were re-scaled on a 0-to-100 scale, where a score of 100 indicates full attainment on  
22 the CES. There is currently only an English version available of the CES with a value set derived  
23 from the UK only.

#### 24 *Adult Social Care Outcomes Toolkit for Carers (ASCOT-Carer)*

25 The ASCOT-Carer is an outcome measure aimed at assessing social care-related quality of life  
26 (SCRQoL) for informal carers across seven domains (occupation, control over daily life, self-care,

1 personal safety, social participation, space and time to be yourself, and feeling supported and  
2 encouraged) [11]. Each domain is rated on a 0-3 scale, where zero indicates the high-level needs and  
3 three depicts the ideal state. The value set was derived using best-worst scaling, reflecting the  
4 preferences of the general population in England. Values were re-scaled on a 0-1 scale, such that high  
5 needs were given a value of 0, reflecting a measure of unmet needs [24].

## 6 *Statistical analyses*

7 Data analyses included descriptive analysis of the carer and care recipient characteristics, as well as  
8 descriptive analysis of the response data of the three preference-based measures using STATA 15  
9 [25]. A correlation matrix was generated for the individual items of the ASCOT-Carer, CarerQoL, and  
10 CES. The spearman correlation coefficients were interpreted as weak correlations (0-0.3), moderate  
11 (0.3-0.5), or strong correlations (>0.5) [26].

12 The primary analysis of this study comprised an exploratory factor analysis conducted in Mplus 8.3  
13 [27]. The aim of the exploratory factor analysis was to ascertain the underlying latent constructs of the  
14 three measures and to assess the extent to which these three instruments measure complementary or  
15 overlapping constructs. This type of analysis is appropriate where there are no explicit assumptions  
16 regarding the underlying structure based on a-priori hypotheses. The axes of the initial factor analysis  
17 were rotated using the *geomin* oblique rotation, which permits correlations between common factors.  
18 Weighted least square means and variance adjusted model estimation was applied to account for the  
19 ordinal nature of the item-level data. To determine the appropriate number of factors to retain, the  
20 Kaiser criterion was used (based on eigenvalues greater than 1) and three model fit indices: the root  
21 mean square error of approximation (RMSEA), the Tucker-Lewis Index (TLI) and the Comparative  
22 Fit Index (CFI). RMSEA values were interpreted as indicating a close model fit (<0.05), acceptable  
23 model fit (0.05-0.08), marginal model fit (0.081-0.1) or poor model fit (>0.1) [28]. The TLI and the  
24 CFI indicated a good model fit if values were >0.9 [29]. Additionally, the selection of the number of  
25 factors was supplemented with an exploration of models with a clean factor structure i.e., item  
26 loadings are greater than 0.3 on at least one factor and no cross-factor loadings. Pearson correlation

1 was used to examine the relationship between the factors, with coefficients interpreted as weak  
2 correlation (0-0.3), moderate (0.3-0.5), or strong (>0.5) [26]. Factor loading greater than 0.30, which  
3 are recommended for interpretative purposes, are presented only [30].

#### 4 *Inconsistent and incomplete respondents*

5 Prior to running the analyses, the survey data were cleaned, including the removal of suspected  
6 fraudulent responses from participants who completed the survey with registered IP addresses outside  
7 of Australia (n=266). Additionally, inconsistent responses were removed by applying two consistency  
8 tests. First, responses were removed if they reported the lowest level score on the CES ‘fulfilment  
9 from caring’ and the highest level score on the CarerQol ‘fulfilment from caring’, and *vice versa*  
10 (n=19). The second consistency test was based on the CES ‘support from family and friends’ and the  
11 CarerQol ‘support with carrying out my care tasks (e.g., from family, friends, neighbours,  
12 acquaintances)’ question (n=21). After removing inconsistent responses, the final sample comprised  
13 500 respondents. However, due to a randomization error in the online survey, some participants were  
14 not provided with the three carer-related measures (140, 141 and 143 participants missed the ASCOT-  
15 Carer, the CarerQol and CES respectively). For all analyses undertaken in this study, only responses  
16 with complete data across the three measures were used.

17

## 18 **Results**

19 In total, 351 completed all questions across the ASCOT-Carer, CES and Carer-QoL, which were  
20 included in the analyses. Table 1 provides the characteristics of the 351 carers, including  
21 characteristics of the care recipient and information on the informal care situation.

22 Table 2 provides descriptive statistics for the three carer-related preference-based measures. While  
23 possible range of scores vary across the three preference-based measures, all measures indicate  
24 quality of life decrements (ASCOT-Carer=0.626 (SD±0.241); CES=60.562 (SD±20.297); and

1 CarerQol=58.550 (SD±22.014)). The use of the Australian tariff and the UK tariff for the CarerQol  
2 resulted in similar scores (Australian tariff=58.550 (SD±22.014); UK tariff=57.692 (SD±22.478)).  
3 The distribution of responses to the three measures are presented in Figures 2-4. The correlation  
4 matrix, presented in Table 3, indicates low correlations between the items across the measures as well  
5 as within the measures. Only all ASCOT-Carer items are highly correlated with each other, except for  
6 'personal safety'. As for the CarerQol, high correlations were only found between 'physical health  
7 problems' and 'mental health problems. The CES 'social support' showed only moderate correlations  
8 with 'institutional support' and 'activities outside caring'. Across the measures, only CarerQol  
9 'fulfilment' and CES 'fulfilment' correlated highly, as well as the CES 'activities outside caring' with  
10 all ASCOT-Carer items, except for 'personal safety'.  
11 The results of the exploratory factor analysis are presented in Table 4. The Kaiser criterion, based on  
12 eigenvalues greater than one, suggested a five-factor model, which overall resulted in a good model fit  
13 (RMSEA=0.043 (90% CI 0.031; 0.054); CFI=0.992; TLI=0.984). These five factors broadly  
14 described *carers' general quality of life outside caring* (factor 1), *problems due to caring* (factor 2),  
15 *fulfilment from caring* (factor 3), *social support with caring* (factor 4), and *relationship with the care*  
16 *recipient* (factor 5). All ASCOT-Carer items, except 'personal safety', loaded onto factor one, while  
17 the CarerQol loaded mostly on factor 2. The CES loaded onto all factors apart from factor 2  
18 (problems due to caring). Only social support with caring (factor 4) was measured by all three carer-  
19 related preference-based measures. Correlations between factors were moderate, with the highest  
20 correlation found between factor 1 and factor 2. The estimated residual variances indicated that for  
21 most items the variance was low, except for ASCOT personal safety (0.702) and CES Institutional  
22 support (0.737), where high variances remained largely unexplained by the model.

23

## 24 **Discussion**

25 This study explored the content of three carer-related preferences-based measures with the aim to  
26 investigate the extent to which these three instruments measure complementary or overlapping

1 constructs. The findings from the exploratory factor analysis indicated that despite some overlap, the  
2 measures generally assess different constructs and each measure provides some unique information.  
3 The CarerQol measures mental and physical health problems as well as financial problems, which are  
4 unique to this measure. The CES also captures information related to support from organizations and  
5 the government (i.e., formal support), which goes beyond the social support construct measured by  
6 the CarerQol and the CES item support from family and friends. The broad framing of the ASCOT-  
7 Carer ‘feeling supported and encouraged’ item seems to refer to both formal and social support.

8 We were able to confirm the unidimensional structure of the ASCOT-Carer that was previously  
9 reported by Rand et al. [11]. Similar to that study, we also found that the ‘personal safety’ item of the  
10 ASCOT-Carer does not fit the unidimensional structure well, which could be, however, due to the  
11 uneven distribution of response levels, as most carers reported an ideal state on this item. It seems that  
12 while all ASCOT-Carer items relate to aspects of carers’ general quality of life outside caring, the  
13 ‘personal safety’ item measures aspects related to the relationship with the care recipient and control  
14 over the caring situation, which may affect carers’ safety. It is, generally, important to note that  
15 although the ASCOT-Carer assesses the aspects of quality of life important to carers that may be  
16 supported by adult social care interventions, none of the questions (except for feeling supported and  
17 encouraged) directly refer to carers’ caring role or responsibilities. One of the drivers for the  
18 development of the ASCOT-Carer was the policy aim to support carers in their caregiving role by  
19 enabling them to sustain important aspects of everyday life and their own health [31]. Therefore, the  
20 quality of life attributes in the measure are deliberately broad, even if there are also aspects of quality  
21 of life that may be improved by formal care services [32]. This has important implications, as items  
22 that appear to be similar across the measures, such as ‘control’, measure different underlying  
23 constructs. The CES measures ‘control over the caring’, while the ASCOT-Carer is concerned with  
24 ‘control over daily life’, which may or may not be related to the caring situation. Our exploratory  
25 factor analysis results confirmed that these two control questions do not measure the same construct.  
26 While the ASCOT-Carer items tapped into the same factor related to carers’ SCRQoL, the CarerQol  
27 focuses more on problems and burden in carers due to providing care. This confirms the theoretical

1 underpinning of the measure, which focuses more on carer burden. The CES, a measure of caring  
2 experiences, seems more related to the *process* of providing informal care. As such, we observed a  
3 greater overlap between the CES and the CarerQoI, especially across the domains fulfilment from  
4 caring, social support, and relationship with the care recipient. However, ‘institutional support’ and  
5 ‘health and financial problems’ denote unique constructs captured by the CES and the CarerQoI,  
6 respectively. It is also important to note that while the developer of the CES assumed that financial  
7 problems would be captured by the assistance from organizations attribute [13], our findings suggest  
8 that this is not the case. The developers also did not measure health problems, as the qualitative  
9 interviews indicated that this was linked to other attributes included in the CES. Again, our findings  
10 do not support that statement, as none of the CES items loaded onto factor 2 in the exploratory factor  
11 analysis, describing aspects related to mental health and physical health problems.

#### 12 *Implications of findings and future research*

13 Economic evaluations to date have been mainly concerned with the affected individual and spillover  
14 effects have been largely ignored. Although this focus is changing, a recent review indicated that  
15 studies that assessed spillover effects used the EQ-5D to measure caregiver/family member utility,  
16 followed by other generic preference-based measures, such as the Short Form Six Dimension (SF-6D)  
17 or the Health Utilities Index (HUI) [8]. With the development of carer-related preference-based  
18 measures, it is anticipated that the use of these measures will increase in future economic evaluations  
19 but the choice of measure is context dependent and requires careful considerations. Our findings have  
20 demonstrated that they measure different constructs and, as such, cannot be used interchangeably.  
21 Given that interventions and programs may have different impacts on carers and their caring situation,  
22 it is crucial to understand which dimensions of the respective measure are likely to be impacted when  
23 determining the appropriate measure. The choice of carer-related preference-based measures will also  
24 be driven by the scope of the intervention and whether it aims to improve the health and wellbeing of  
25 carers or their care recipients, which may result in spillover effects. While the CES and the CarerQoI  
26 seem to be more appropriate for examining the changes related to the caring situation directly (e.g.,  
27 changes related to the relationship with the care recipient or fulfilment from caring), the ASCOT-

1 Carer measures carers' broader quality of life outside caring. This raises some important consideration  
2 around the use of the ASCOT-Carer alongside other generic preference-based health-related quality of  
3 life measures. Although in a previous study, the ASCOT-Carer showed little overlap with the EQ-5D-  
4 3L [17], some degree of overlap is expected with broader measures of quality of life, such as the  
5 ICEpop CAPability measure for Adults (ICECAP-A) or Older Adults (ICECAP-O) [33-35] that  
6 requires further investigation. The inclusion of physical and mental health in the CarerQol also creates  
7 some challenges around the use of the CarerQol alongside generic measures of health due to the  
8 potential risk of double counting. Generally, to guide further the selection of carer-related preference-  
9 based measure, more validation studies are needed that examine the measures' practicality, reliability,  
10 validity and responsiveness to change in different caregiving contexts and their relationship with other  
11 preference-based health-related quality of life measures. While our study findings have shown that the  
12 three carer-related preference-based measures capture different constructs, it remains to be tested  
13 which of those measures are more appropriate and psychometrically sound in informal carers. Future  
14 research should also examine the implications of the choice of carer-related preference-based measure  
15 in an economic evaluation on the cost-effectiveness inference.

16 Compared with other preference-based measures, which include dimensions that are structurally  
17 independent to fulfil the requirement for statistical inference or multi-attribute utility theory in the  
18 design of valuation studies [36], the ASCOT-Carer has a unidimensional structure. While this may  
19 create challenges for the valuation study because the dimensions are highly correlated [36], it also  
20 raises the question on whether a carer-related preference-based measures should be chosen that is  
21 more limited in its scope but contains enough items that measure the underlying construct of interest,  
22 or whether a measure should be chosen that has a broader scope but may potentially lack sensitivity  
23 due to insufficient number of items. It is also important to keep in mind that while the ASCOT-Carer  
24 and the CarerQol asked members from the general population to value the 'care states', the CES  
25 reflects the preference of carers in the UK. While the question around whose preferences should be  
26 elicited is an ongoing debate in the literature that is not unique to carer-related preference-based  
27 measures [36], there are still some additional normative and methodological issues involved when

1 incorporating spillover effects into an economic evaluation. This includes ethical concerns by  
2 prioritising care for those who have informal carers, and double-counting of benefits if impacts on  
3 carers' health and wellbeing are reflected by patients' utilities [8, 37, 38]. The identification of carer  
4 networks (e.g., only the primary carer or all carers involved with providing care) poses another  
5 challenge as well as general methodological challenges in incorporating spillover effects in  
6 conventional practices in economic evaluation [39, 40].

### 7 *Strengths and limitations*

8 While previous studies have only examined one or two of the three carer-related preference-based  
9 measures within the same study [14, 17], a strength of our study is the exploration of all three  
10 measures, offering further guidance on the use of the measures in future economic evaluation studies.  
11 The inclusion of carers in the online survey, regardless of their age or the condition(s) of the care  
12 recipient, represents another strength of our study, making the findings more generalizable to all  
13 carers providing informal care. However, since recruitment was mainly facilitated through Carers  
14 Victoria, participants included in our study are not necessarily representative of all carers in Australia  
15 and the demographic characteristics of the carers also indicates a less diverse sample. A further  
16 limitation of the study relates to the collection of data via an online survey, which included an  
17 incentive in form of a gift card for survey completion. The gift card may have encouraged fraudulent  
18 responses, which we were able to identify and exclude from the analyses reported in this paper.  
19 Through the application of the two consistency checks, we aimed to diminish further the number of  
20 inconsistent responses.

21

### 22 **Conclusion**

23 The results of this study suggest that despite some overlap, the three carer-related preference-based  
24 measures tap into different constructs of carer-related quality of life and caring experiences and  
25 should not be treated interchangeably. While the CarerQol and the CES showed more overlap,  
26 especially with respect to fulfilment from caring, social support and relationship problems with the



1 care recipient, the ASCOT-Carer is a measure of carers' SCRQoL that had little overlap with the other  
2 measures. Further validation studies of the three measures in different caregiving scenarios are  
3 required to guide the selection of carer-related outcome measures for use in economic evaluation.

4

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**Table 1:** Overview of the domains included in the three carer-related preference-based instruments

<b>Instrument</b>	<b>Domain</b>	<b>Description of the domain</b>
<b>ASCOT-Carer [11]</b>	Occupation	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
<b>CarerQol [9]</b>	Fulfilment from caring	Positive feelings arising from informal care on the part of the caregiver
	Relational problems	Negative feelings of the caregiver in relation to the receiver of care
	Mental health problems	Mental health problems experienced by the informal caregiver
	Problems with daily activities	Dealing with problems confronted by the informal caregiver while carrying out his or her daily activities
	Financial problems	Care-related financial problems
	Support with care tasks	Support from family and friends with care tasks
	Physical health problems	Feelings of chronic fatigue on the part of the caregiver and damage to physical health
<b>CES [13]</b>	Activities outside caring	Being able to do a range of things outside of caring (e.g., socialising, physical activity and spending time on hobbies, leisure or study)
	Support from family and friends	Personal help in caring and/or emotional support from family, friends, neighbours or work colleagues
	Assistance from organisations and the Government	Help from public, private or voluntary groups in terms of benefits, respite and practical information
	Fulfilment from caring	Positive feelings from providing care, which may come from: making the person you care for happy, maintaining their dignity, being appreciated, fulfilling your responsibility, gaining new skills or contributing to the care of the person you look after
	Control over the caring	Being able to influence the overall care of the person you look after
	Getting on with the person you care for	Being able to talk with the person you look after, and discuss things without arguing

**Table 2: Characteristics of carers, care recipients and informal care situation (n=351)**

	N (%)
Gender, Female	279 (80)
Mean age (min; max)	53 (21; 88)
Country of birth, Australia	281 (80)
Language spoken at home, English	333 (95)
Education	
Year 11 or below	62 (18)
Year 12	27 (8)
Certificate/Diploma	95 (27)
Undergraduate	127 (36)
Postgraduate	35 (10)
Other	5 (1)
Marital status	
Single	24 (7)
Married/ de-facto	266 (76)
Divorced/Separated/Widowed	57 (16)
Not answered	4 (1)
Occupation	
Employed (full-time, part-time, casual, self-employed)	169 (48)
Student	4 (1)
Unemployed	4 (1)
Retired, housework duties including carer tasks	172 (49)
Other/ Not answered	2 (1)
Household income	
Less than \$52,000 per year	143 (41)
\$52,000 - \$129,999 per year	119 (34)
\$130,000 or more per year	41 (12)
Other/ Not answered	48 (14)
Living arrangement	
Living alone	13 (4)
Spouse/partner	122 (35)
Living with (a) family member(s)	209 (60)
Living with (a) non family member(s)	3 (1)
Other/Not answered	4 (1)
Gender of care recipient, Female	213 (61)
Mean age care recipient (min; max)	47 (2; 98)
Relationship to the care recipient	
Partner	90 (26)
Daughter/Son	118 (34)
Mother/Father	109 (31)
Another family member, friend, neighbour	31 (9)
Not answered	3 (1)
Sharing household with the care recipient, Yes	285 (81)
Condition(s) of care recipient	
Temporary disease or disability	19 (5)
Chronic disease or disability	50 (14)
Dementia or memory problems	29 (8)
Mental health problems	63 (18)
Intellectual or developmental disability	93 (27)
Problems due to aging	61 (17)
Terminal illness	16 (5)
Neurological	14 (4)

Not answered/ missing	6 (2)
Duration of care	
Less than 24 months	88 (25)
24 months or more	262 (75)
Not answered	1 (0)
Hours of care per week	
Less than 40 hours	192 (55)
40 hours or more	153 (44)
Not answered	6 (2)

---



**Table 3: Descriptive statistics for instruments used in the analyses**

	N	Mean	SD	Min.	Max.	Possible range
ASCOT-Carer	351	0.63	0.24	0.022	0.99	0-1
CES	351	60.56	20.30	10.14	100	0-100
CarerQol (AUS tariff)	351	58.55	22.01	0	100	0-100
CarerQol (UK tariff)	351	57.69	22.48	0	98.8	0-100

ASCOT-Carer= Adult Social Care Outcomes Toolkit for Carers; CES=Carer Experience Scale;  
CarerQol= Care-related Quality of Life.

**Table 4: Correlation matrix between the items of the three carer-related preference-based measures <sup>a</sup>**

	asc1	asc2	asc3	asc4	asc5	asc6	asc7	car1	car2	car3	car4	car5	car6	car7	ces1	ces2	ces3	ces4	ces5	ces6
asc1	1																			
asc2	<b>0.67</b>	1																		
asc3	<b>0.64</b>	<b>0.64</b>	1																	
asc4	0.15	0.25	0.22	1																
asc5	<b>0.68</b>	<b>0.64</b>	<b>0.63</b>	0.22	1															
asc6	<b>0.75</b>	<b>0.71</b>	<b>0.63</b>	0.19	<b>0.67</b>	1														
asc7	<b>0.61</b>	<b>0.52</b>	<b>0.59</b>	0.16	<b>0.59</b>	<b>0.60</b>	1													
car1	-0.12	-0.12	-0.18	-0.12	-0.16	-0.11	-0.21	1												
car2	-0.12	-0.13	-0.15	-0.27	-0.17	-0.09	-0.16	0.22	1											
car3	-0.32	-0.29	-0.41	-0.18	-0.33	-0.24	-0.36	0.14	0.32	1										
car4	-0.26	-0.38	-0.37	-0.30	-0.32	-0.31	-0.20	0.02	0.32	0.39	1									
car5	-0.24	-0.26	-0.41	-0.28	-0.27	-0.20	-0.26	0.01	0.25	0.36	0.33	1								
car6	-0.29	-0.24	-0.28	-0.13	-0.32	-0.28	-0.48	0.15	-0.05	0.15	0.05	0.12	1							
car7	-0.27	-0.33	-0.46	-0.18	-0.33	-0.31	-0.32	0.11	0.25	<b>0.50</b>	0.42	0.43	0.11	1						
ces1	<b>0.64</b>	<b>0.63</b>	<b>0.59</b>	0.16	<b>0.59</b>	<b>0.64</b>	<b>0.51</b>	-0.08	-0.11	-0.32	-0.38	-0.26	-0.29	-0.30	1					
ces2	0.44	0.40	0.44	0.10	0.47	0.42	<b>0.58</b>	-0.11	0.04	-0.21	-0.11	-0.15	<b>-0.62</b>	-0.18	0.41	1				
ces3	0.30	0.23	0.32	-0.03	0.29	0.32	0.39	0.06	0.03	-0.11	-0.05	-0.03	-0.14	-0.10	0.22	0.30	1			
ces4	0.29	0.28	0.31	0.19	0.25	0.26	0.33	<b>-0.60</b>	-0.29	-0.19	-0.15	-0.04	-0.20	-0.13	0.32	0.23	0.13	1		
ces5	0.09	0.02	0.06	0.17	0.02	0.01	0.11	-0.20	-0.26	-0.06	-0.06	-0.10	0.02	0.02	0.00	0.04	0.10	0.21	1	
ces6	0.14	0.14	0.17	0.24	0.16	0.08	0.22	-0.33	-0.35	-0.21	-0.14	-0.11	-0.12	-0.14	0.09	0.09	0.01	0.38	0.29	1

asc=ASCOT-Carer; car=CarerQol; ces=CES.

<sup>a</sup> Across all three measures, higher scores indicate a more impaired state of quality of life, except for CarerQol item 1 (car1) and item 6 (car6), where higher scores indicate greater fulfilment from caring and greater support with carrying out care tasks, respectively.

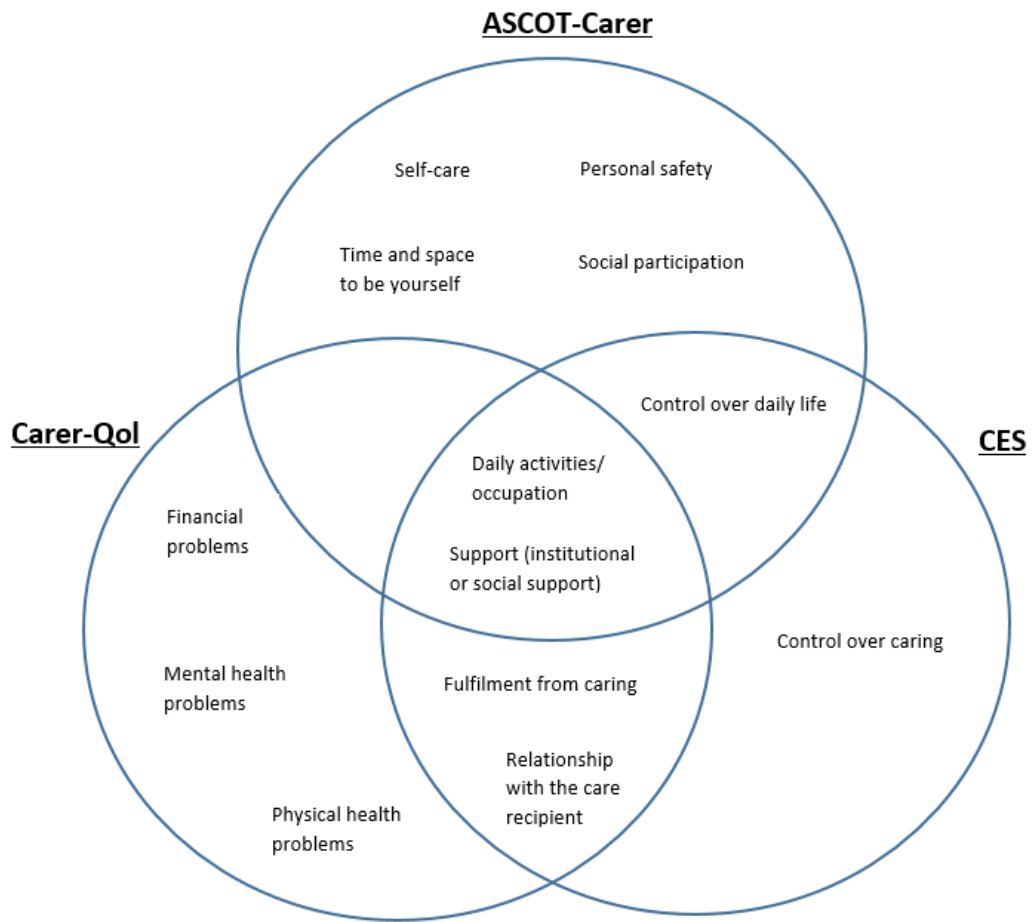
**Table 5: Results from the exploratory factor analysis (5-Factor model)**

	Factor Loadings <sup>a</sup>					Estimated residual variances <sup>b</sup>
	Factor 1	Factor 2	Factor 3	Factor 4	Factor 5	
ASCOT-Carer Occupation	<b>.921</b>					.153
ASCOT-Carer Control over daily-life	<b>.870</b>					.239
ASCOT-Carer Self-care	<b>.628</b>					.265
ASCOT-Carer Personal safety		<b>-.350</b>				.702
ASCOT-Carer Social participation	<b>.711</b>					.300
ASCOT-Carer Space and time to be yourself	<b>.979</b>					.141
ASCOT-Carer Feeling supported and encouraged	<b>.479</b>			.450		.277
CarerQoI Fulfilment from care tasks			<b>.931</b>			.111
CarerQoI Relational problems		.445			<b>-.480</b>	.438
CarerQoI Mental health problems		<b>.714</b>				.440
CarerQoI Problems with daily activities		<b>.591</b>				.479
CarerQoI Financial problems		<b>.655</b>				.550
CarerQoI Support with care tasks				<b>-.799</b>		.316
CarerQoI Physical health problems		<b>.846</b>				.300
CES Activities outside caring	<b>.782</b>					.282
CES Support from family and friends				<b>.780</b>		.161
CES Institutional support	<b>.417</b>					.737
CES Fulfilment from caring			<b>-.694</b>			.253
CES Control over the caring					<b>.637</b>	.596
CES Getting on with the person					<b>.569</b>	.414
<b>Correlations among factors</b>						
Factor 1	1					
Factor 2	-.477	1				
Factor 3	-.152	.188	1			
Factor 4	.434	-.191	-.190	1		
Factor 5	.115	-.246	-.360	.051	1	

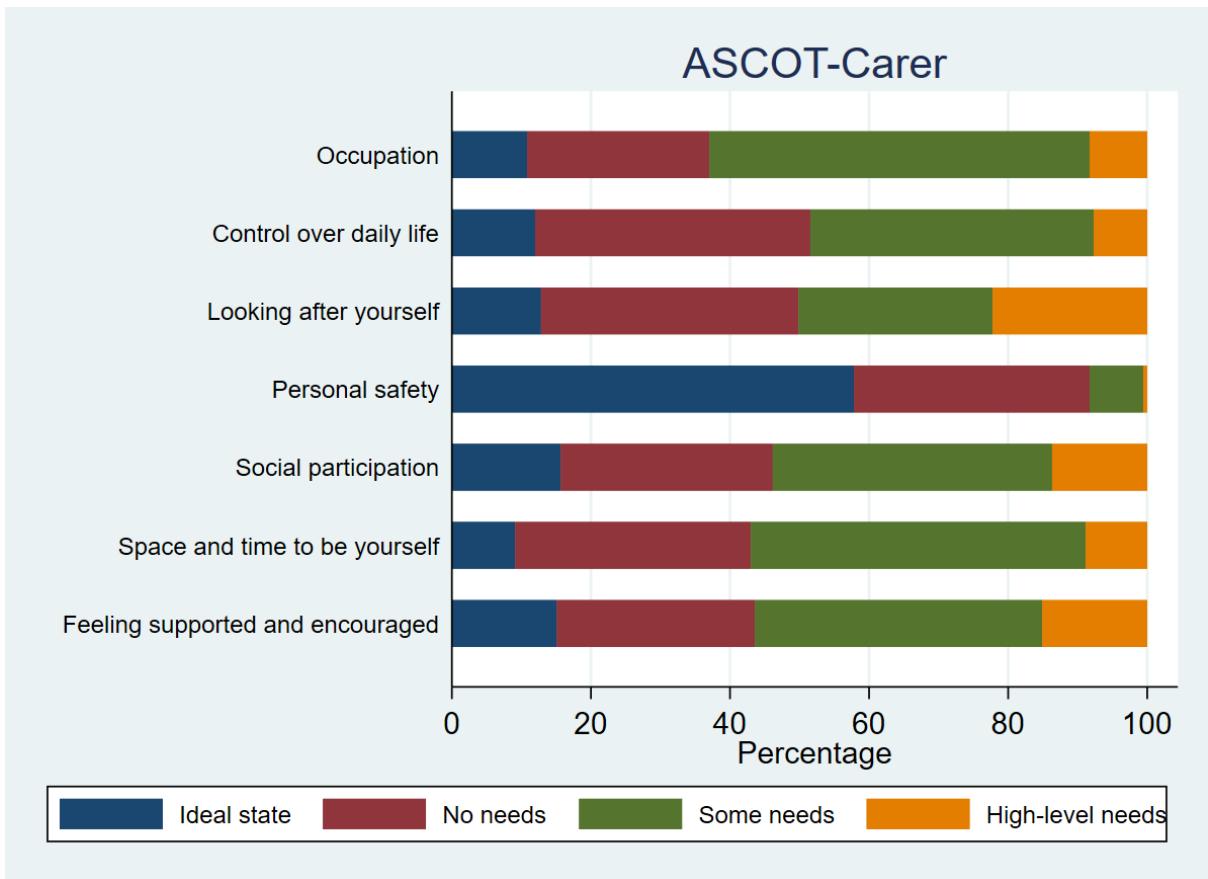
RMSEA=0.043 (90% CI 0.031; 0.054); CFI=0.992; TLI=0.984

<sup>a</sup> For each item, the highest loading on the corresponding factor is presented in bold text.

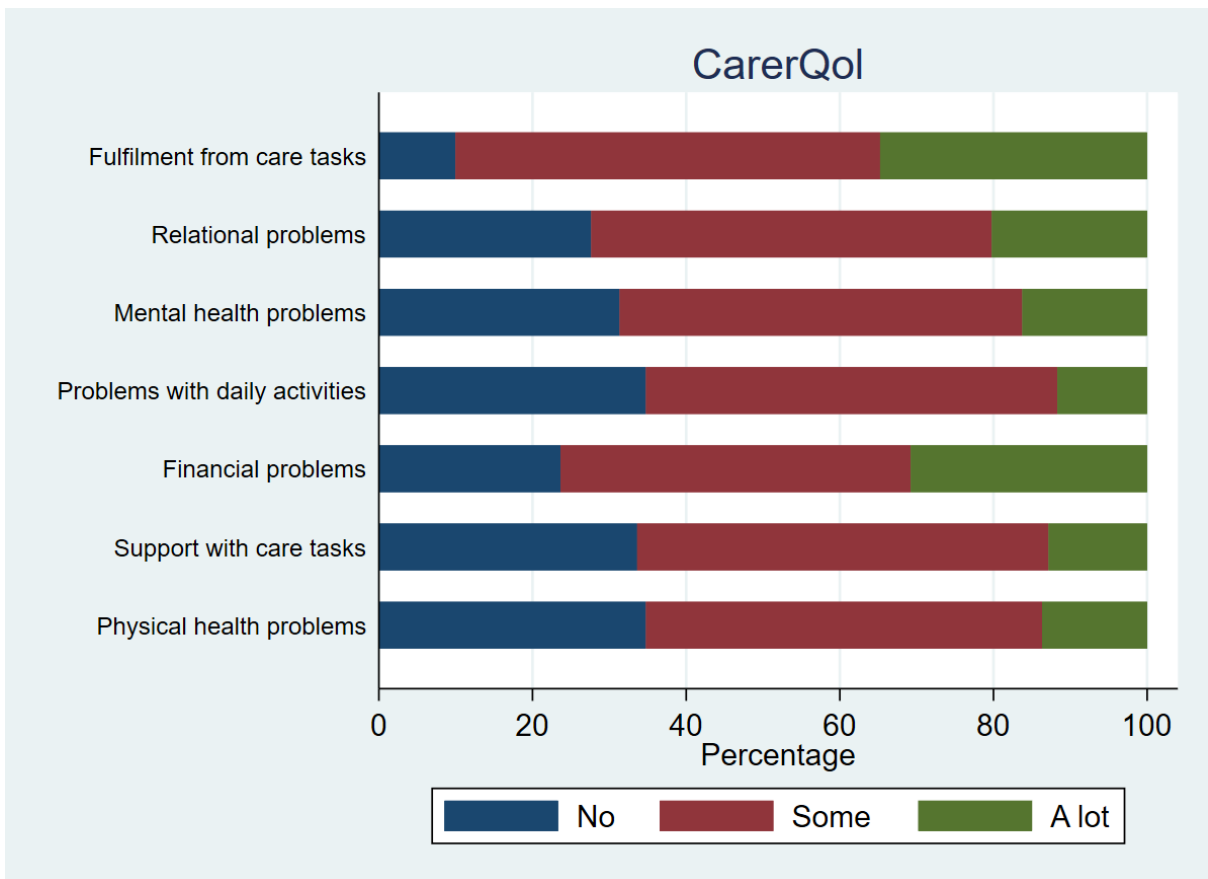
<sup>b</sup> These are the variances of the items after accounting for all of the variance in the exploratory factor analysis model.



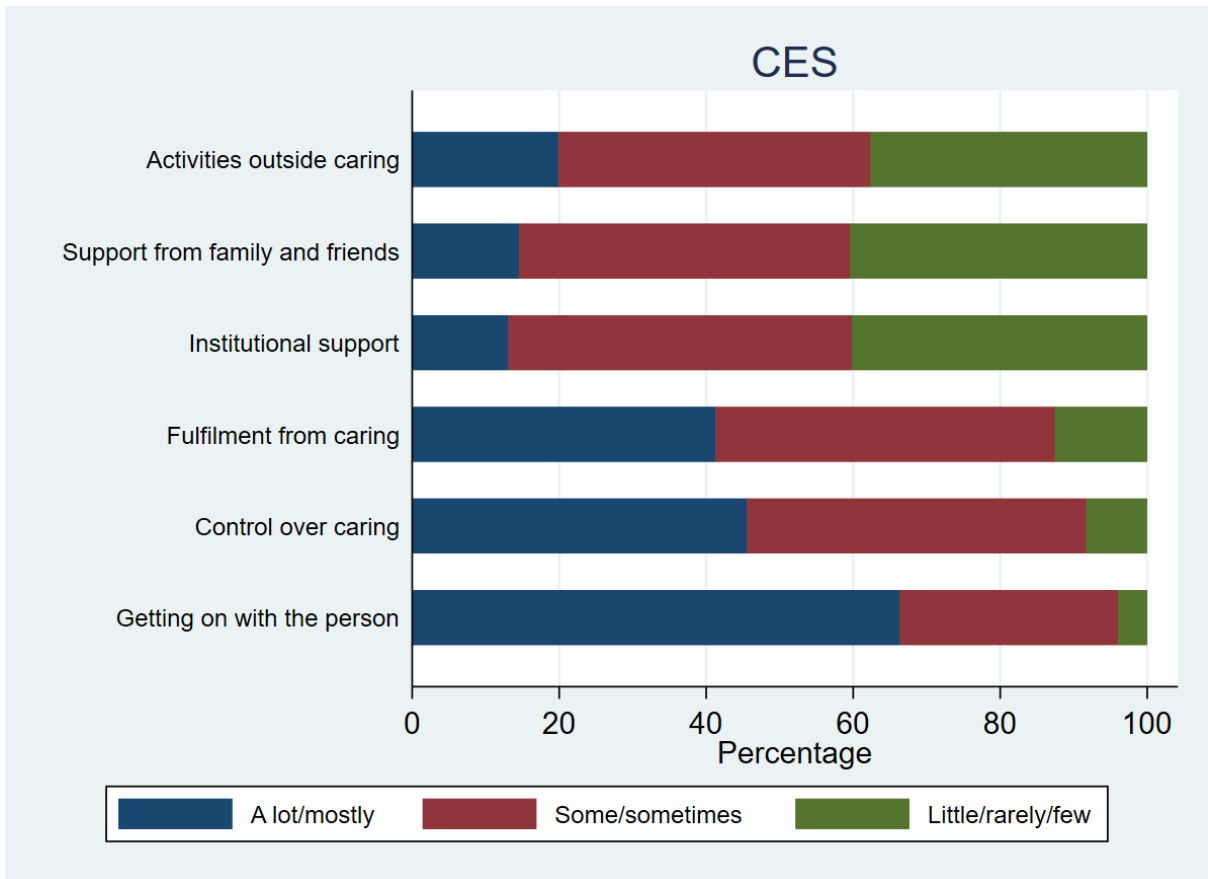
**Figure 1:** Conceptual mapping of domains in the ASCOT-Carer, CarerQol and CES



**Figure 2:** Distribution of responses to the ASCOT-Carer.



**Figure 3:** Distribution of responses to the CarerQol.



**Figure 4:** Distribution of responses to the CES.