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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

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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

## Introduction

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

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

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

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

## Methods

### *Data Source*

The data were derived from an online survey that was powered by Qualtrics® with data collection taking place between June and September 2018. Informal carers were recruited through the not-for-profit organization *Carers Victoria* (in Australia) by means of newsletters, social media postings, and direct email invitations (only those carers who had previously given permission to Carers Victoria to be contacted for research-related studies). Carers were eligible to participate in the online survey if they were older than 18 years, self-identified as a primary carer (without restricting to certain condition(s) of the care recipient), resided in Australia, and were able to read the survey in the English language. Prior to data collection, the survey was piloted with staff members at Deakin University for understanding and completion time. All participants provided implied consent by completing the survey and received a $10 gift voucher as an acknowledgment for their contribution. Ethical approval to conduct the survey was granted by the Deakin University Faculty of Health, Human Ethics Advisory Group, Burwood, Australia (reference number HEAG-H 91_2018).

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

### *Instruments*

#### *Care-related Quality of Life (CarerQol)*

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

### *Carer Experience Scale (CES)*

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

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

The ASCOT-Carer is an outcome measure aimed at assessing social care-related quality of life (SCRQoL) for informal carers across seven domains (occupation, control over daily life, self-care, personal safety, social participation, space and time to be yourself, and feeling supported and encouraged) [11]. Each domain is rated on a 0-3 scale, where zero indicates the high-level needs and three depicts the ideal state. The value set was derived using best-worst scaling, reflecting the preferences of the general population in England. Values were re-scaled on a 0-1 scale, such that high needs were given a value of 0, reflecting a measure of unmet needs [24].

### *Statistical analyses*

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

The primary analysis of this study comprised an exploratory factor analysis conducted in Mplus 8.3 [27]. The aim of the exploratory factor analysis was to ascertain the underlying latent constructs of the three measures and to assess the extent to which these three instruments measure complementary or overlapping constructs. This type of analysis is appropriate where there are no explicit assumptions regarding the underlying structure based on a-priori hypotheses. The axes of the initial factor analysis were rotated using the *geomin* oblique rotation, which permits correlations between common factors. Weighted least square means and variance adjusted model estimation was applied to account for the ordinal nature of the item-level data. To determine the appropriate number of factors to retain, the Kaiser criterion was used (based on eigenvalues greater than 1) and three model fit indices: the root mean square error of approximation (RMSEA), the Tucker-Lewis Index (TLI) and the Comparative Fit Index (CFI). RMSEA values were interpreted as indicating a close model fit (<0.05), acceptable model fit (0.05-0.08), marginal model fit (0.081-0.1) or poor model fit (>0.1) [28]. The TLI and the CFI indicated a good model fit if values were >0.9 [29]. Additionally, the selection of the number of factors was supplemented with an exploration of models with a clean factor structure i.e., item loadings are greater than 0.3 on at least one factor and no cross-factor loadings. Pearson correlation was used to examine the relationship between the factors, with coefficients interpreted as weak correlation (0-0.3), moderate (0.3-0.5), or strong (>0.5) [26]. Factor loading greater than 0.30, which are recommended for interpretative purposes, are presented only [30].

*Inconsistent and incomplete respondents*

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

## Results

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

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

CarerQol=58.550 (SD±22.014)). The use of the Australian tariff and the UK tariff for the CarerQol resulted in similar scores (Australian tariff=58.550 (SD±22.014); UK tariff=57.692 (SD±22.478)).

The distribution of responses to the three measures are presented in Figures 2-4. The correlation matrix, presented in Table 3, indicates low correlations between the items across the measures as well as within the measures. Only all ASCOT-Carer items are highly correlated with each other, except for 'personal safety'. As for the CarerQol, high correlations were only found between 'physical health problems' and 'mental health problems. The CES 'social support' showed only moderate correlations with 'institutional support' and 'activities outside caring'. Across the measures, only CarerQol 'fulfilment' and CES 'fulfilment' correlated highly, as well as the CES 'activities outside caring' with all ASCOT-Carer items, except for 'personal safety'.

The results of the exploratory factor analysis are presented in Table 4. The Kaiser criterion, based on eigenvalues greater than one, suggested a five-factor model, which overall resulted in a good model fit (RMSEA=0.043 (90% CI 0.031; 0.054); CFI=0.992; TLI=0.984). These five factors broadly described *carers' general quality of life outside caring* (factor 1), *problems due to caring* (factor 2), *fulfilment from caring* (factor 3), *social support with caring* (factor 4), and *relationship with the care recipient* (factor 5). All ASCOT-Carer items, except 'personal safety', loaded onto factor one, while the CarerQol loaded mostly on factor 2. The CES loaded onto all factors apart from factor 2 (problems due to caring). Only social support with caring (factor 4) was measured by all three carer-related preference-based measures. Correlations between factors were moderate, with the highest correlation found between factor 1 and factor 2. The estimated residual variances indicated that for most items the variance was low, except for ASCOT personal safety (0.702) and CES Institutional support (0.737), where high variances remained largely unexplained by the model.

## Discussion

This study explored the content of three carer-related preferences-based measures with the aim to investigate the extent to which these three instruments measure complementary or overlapping constructs. The findings from the exploratory factor analysis indicated that despite some overlap, the measures generally assess different constructs and each measure provides some unique information. The CarerQol measures mental and physical health problems as well as financial problems, which are unique to this measure. The CES also captures information related to support from organizations and the government (i.e., formal support), which goes beyond the social support construct measured by the CarerQol and the CES item support from family and friends. The broad framing of the ASCOT-Carer 'feeling supported and encouraged' item seems to refer to both formal and social support.

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

While the ASCOT-Carer items tapped into the same factor related to carers' SCRQoL, the CarerQol focuses more on problems and burden in carers due to providing care. This confirms the theoretical underpinning of the measure, which focuses more on carer burden. The CES, a measure of caring experiences, seems more related to the *process* of providing informal care. As such, we observed a greater overlap between the CES and the CarerQol, especially across the domains fulfilment from caring, social support, and relationship with the care recipient. However, 'institutional support' and 'health and financial problems' denote unique constructs captured by the CES and the CarerQol, respectively. It is also important to note that while the developer of the CES assumed that financial problems would be captured by the assistance from organizations attribute [13], our findings suggest that this is not the case. The developers also did not measure health problems, as the qualitative interviews indicated that this was linked to other attributes included in the CES. Again, our findings do not support that statement, as none of the CES items loaded onto factor 2 in the exploratory factor analysis, describing aspects related to mental health and physical health problems.

### *Implications of findings and future research*

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

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

Compared with other preference-based measures, which include dimensions that are structurally independent to fulfil the requirement for statistical inference or multi-attribute utility theory in the design of valuation studies [36], the ASCOT-Carer has a unidimensional structure. While this may create challenges for the valuation study because the dimensions are highly correlated [36], it also raises the question on whether a carer-related preference-based measures should be chosen that is more limited in its scope but contains enough items that measure the underlying construct of interest, or whether a measure should be chosen that has a broader scope but may potentially lack sensitivity due to insufficient number of items. It is also important to keep in mind that while the ASCOT-Carer and the CarerQol asked members from the general population to value the 'care states', the CES reflects the preference of carers in the UK. While the question around whose preferences should be elicited is an ongoing debate in the literature that is not unique to carer-related preference-based measures [36], there are still some additional normative and methodological issues involved when incorporating spillover effects into an economic evaluation. This includes ethical concerns by prioritising care for those who have informal carers, and double-counting of benefits if impacts on carers' health and wellbeing are reflected by patients' utilities [8, 37, 38]. The identification of carer networks (e.g., only the primary carer or all carers involved with providing care) poses another challenge as well as general methodological challenges in incorporating spillover effects in conventional practices in economic evaluation [39, 40].

### *Strengths and limitations*

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

## Conclusion

The results of this study suggest that despite some overlap, the three carer-related preference-based measures tap into different constructs of carer-related quality of life and caring experiences and should not be treated interchangeably. While the CarerQol and the CES showed more overlap, especially with respect to fulfilment from caring, social support and relationship problems with the care recipient, the ASCOT-Carer is a measure of carers' SCRQoL that had little overlap with the other measures. Further validation studies of the three measures in different caregiving scenarios are required to guide the selection of carer-related outcome measures for use in economic evaluation.

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

| **Instrument** | **Domain** | **Description of the domain** |
|---|---|---|
| **ASCOT-Carer** [11] | 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 |
| **CarerQol** [9] | 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 |
| **CES** [13] | 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 [a]**

| | asc1 | asc2 | asc3 | asc4 | asc5 | asc6 | asc7 | car1 | car2 | car3 | car4 | car5 | car6 | car7 | ces1 | ces2 | ces3 | ces4 | ces5 | ces6 |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| asc1 | 1 | | | | | | | | | | | | | | | | | | | |
| asc2 | **0.67** | 1 | | | | | | | | | | | | | | | | | | |
| asc3 | **0.64** | **0.64** | 1 | | | | | | | | | | | | | | | | | |
| asc4 | 0.15 | 0.25 | 0.22 | 1 | | | | | | | | | | | | | | | | |
| asc5 | **0.68** | **0.64** | **0.63** | 0.22 | 1 | | | | | | | | | | | | | | | |
| asc6 | **0.75** | **0.71** | **0.63** | 0.19 | **0.67** | 1 | | | | | | | | | | | | | | |
| asc7 | **0.61** | **0.52** | **0.59** | 0.16 | **0.59** | **0.60** | 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 | **0.50** | 0.42 | 0.43 | 0.11 | 1 | | | | | | |
| ces1 | **0.64** | **0.63** | **0.59** | 0.16 | **0.59** | **0.64** | **0.51** | -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 | **0.58** | -0.11 | 0.04 | -0.21 | -0.11 | -0.15 | **-0.62** | -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 | **-0.60** | -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.

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

| | **Correlations among factors** | | | | |
|---|---|---|---|---|---|
| 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

[a] For each item, the highest loading on the corresponding factor is presented in bold text.

[b] These are the variances of the items after accounting for all of the variance in the exploratory factor analysis model.

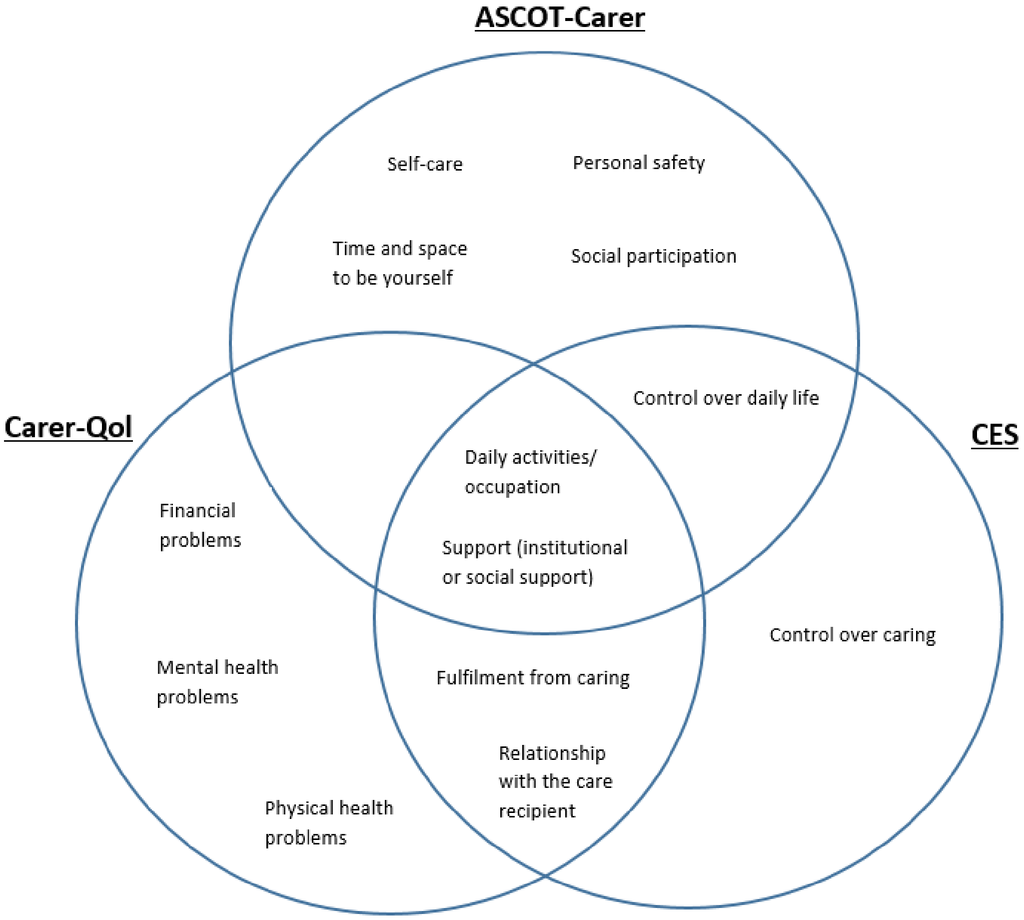

**Figure 1**: Conceptual mapping of domains in the ASCOT-Carer, CarerQol and CES

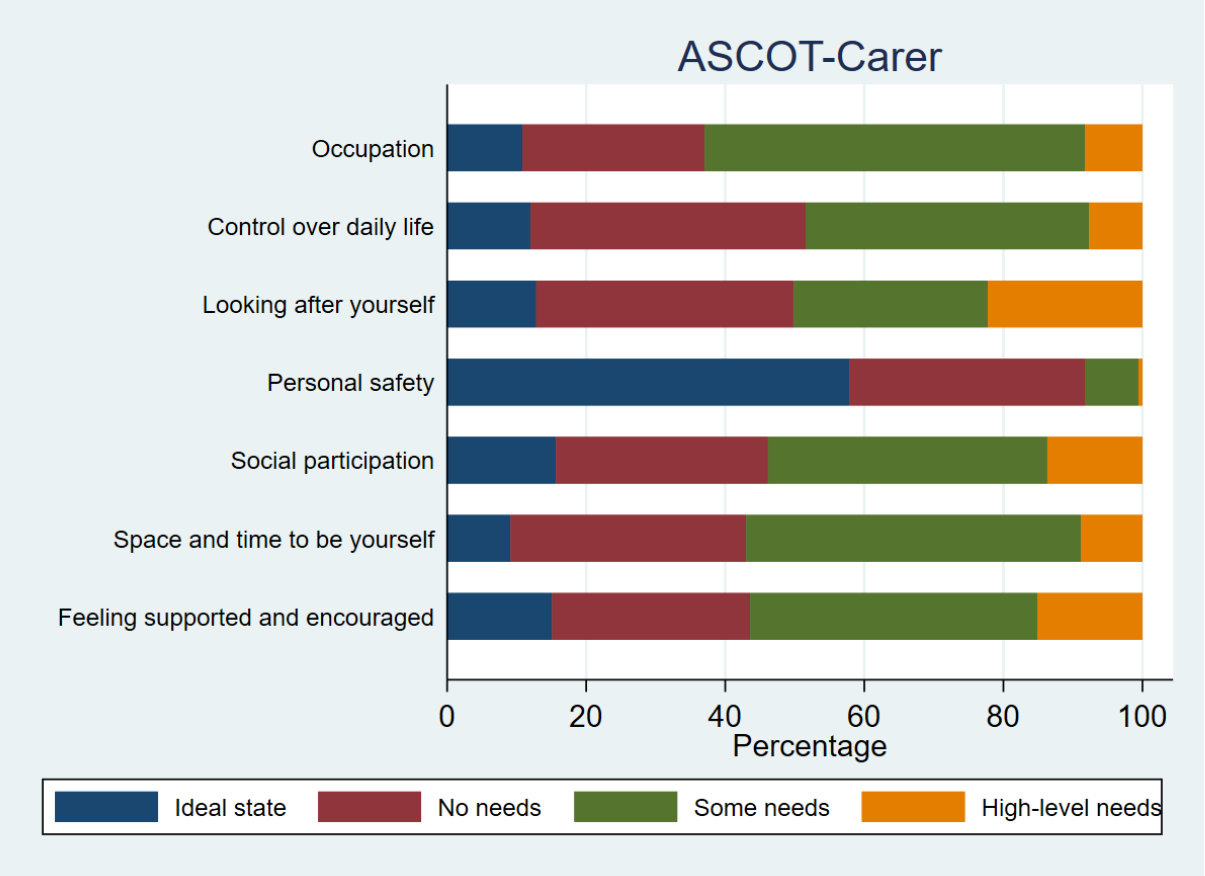

**Figure 2:** Distribution of responses to the ASCOT-Carer.

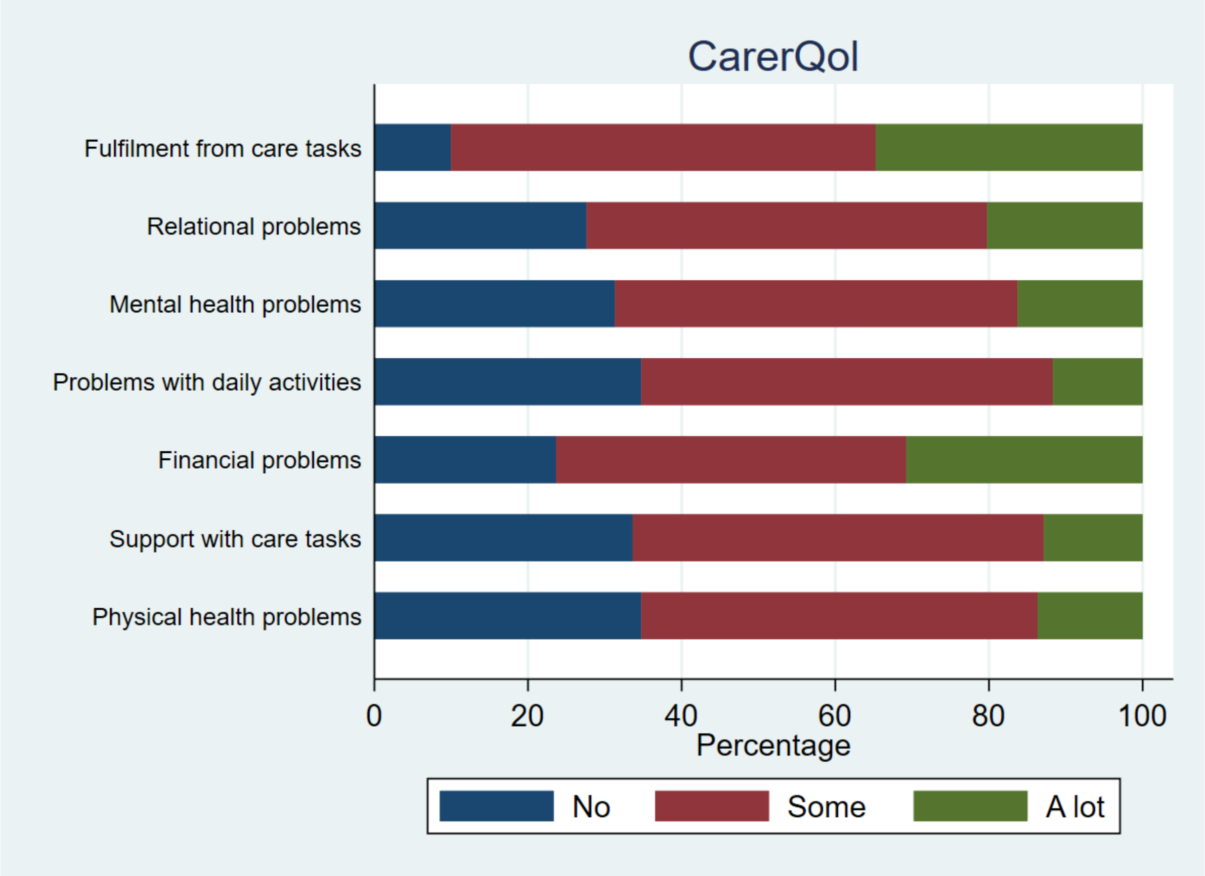

**Figure 3:** Distribution of responses to the CarerQol.

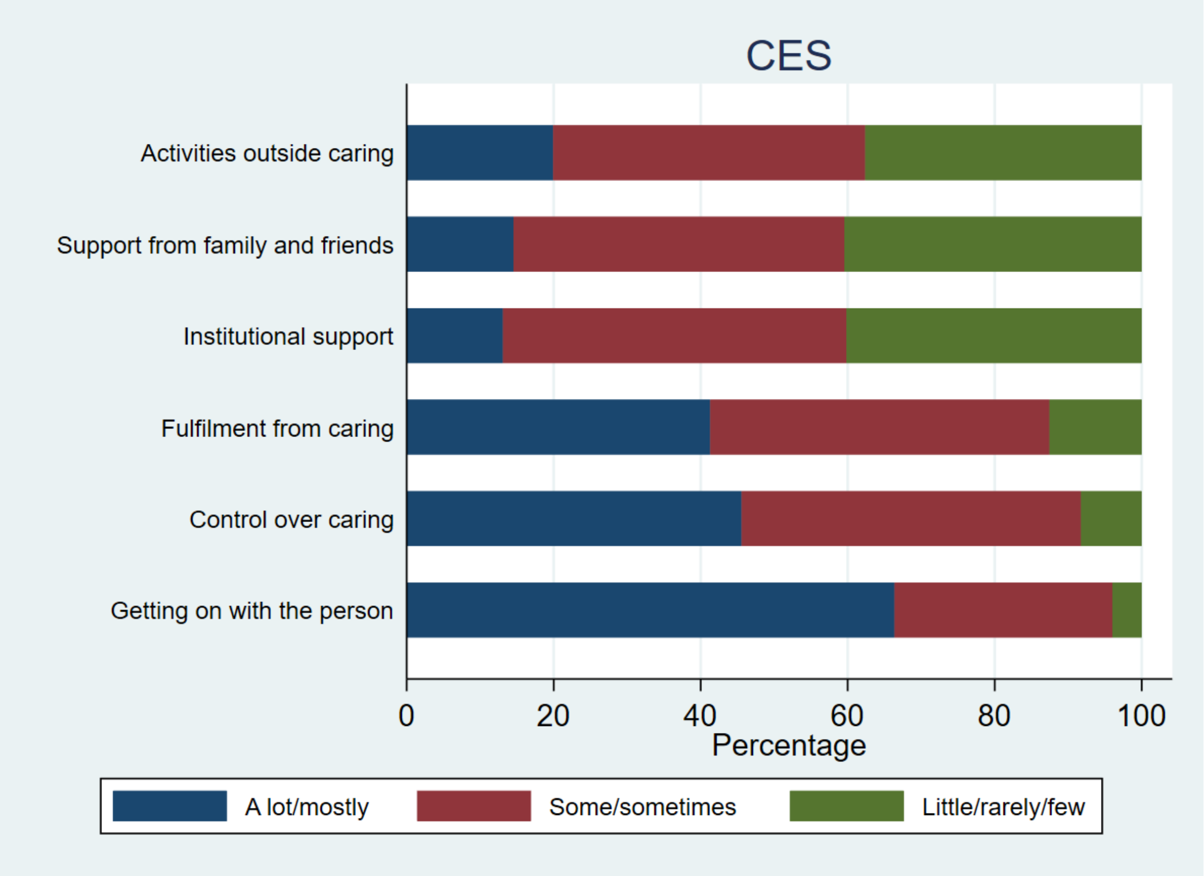

**Figure 4:** Distribution of responses to the CES.