

Valuation of informal care states: Preliminary findings from a best-worst scaling study

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ABSTRACT

Background: Informal care is an important part of the care for many patients, yet the welfare of carers is rarely considered in economic evaluations. One reason is a lack of preference-based quality of life measures for carers.

Aim: To derive preference-based utility scores for 729 (3⁶) unique informal care 'states' of the Carer Experience Scale.

Methods: Two phases of qualitative work (meta-ethnography and semi-structured interviews) were used to develop the attributes and levels of the Carer Experience Scale. A best-worst scaling exercise including 18 of the informal care states was posted to carers in 5 geographical locations in England. A weighted least squares regression was used to analyse the choice data from two centres and determine a preliminary utility tariff for the Carer Experience Scale.

Results: Utilities for the 18 attribute-level combinations were:

- Getting-on with the care recipient: rarely (0), sometimes (1.12), mostly (2.81)
- Control over aspects of care: few (1.24), some (1.60), most (2.16)
- Fulfilment from caring: rarely (0.33), sometimes (1.69), mostly (2.43)
- Assistance from organisations: little (0.78), some (1.45), a lot (2.45)
- Support from family and friends: little (0.39), some (2.1), a lot (2.94)
- Activities outside caring: few (0.2), some (2.52), most (3.14)

Discussion: Preliminary results suggest improvements on attributes of the caring experience are not equally valued. In particular, large welfare gains are likely to accrue from enabling the most confined carers to engage in more activities outside their caring role.

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BACKGROUND

In the UK alone, around 6 million people provide unpaid care to a family member or friend [1]. The intensity of care peaks in the oldest age groups, with nearly half of carers over 70 providing 50+ hours of care per week [1]. Providing care can have a substantial effect on a person's life. Evidence shows caring can have detrimental health effects [2, 3] and can limit employment opportunities [4]. However, a substantial body of research also shows that caring have positive effects [5-7]. Carers often value companionship and find aspects of caring enjoyable and rewarding [5]. A large study of carers in the Netherlands showed half would suffer a net loss in happiness if they relinquished their caring role [8].

Economic evaluations conducted from the societal perspective aim to capture all important costs and consequences [9]. Not only can informal care be an important part of the total care provided to a patient, but carers can be the target of the intervention (in the case of respite and counselling). Both situations warrant careful consideration of informal care in the economic evaluation. However, informal care is rarely considered in economic evaluation [10]. A number of methods exist to include informal care as a cost in economic evaluation [11-15]. Consideration of carers on the outcomes side may also be justified [16]. Decision-makers may, for example, want to view the impact of interventions on carers when making resource allocation decisions. QALYs offer one alternative, however these were developed for health and medical interventions [17], with patient rather than 'provider' welfare in mind. The 5 dimensions (or attributes) of the EQ-5D for example, are unlikely represent the key dimensions of the caring experience. An alternative to QALYs is to develop and use a carer-specific measure. In contrast to the literature on preference-based health measures, the literature on preference-based carer measures is sparse. To the authors' knowledge only two such measures have been developed: the Caregiver Quality of Life Instrument [18] and the CarerQol [19]. Both measures require carers to record their current caring state and complete a task to value their state.

The issues in developing a preference-based carer measure are largely the same as a preference-based health measure. The different profiles or states of the measure need to be valued. Green [20] provides a comprehensive review of health state valuation techniques, identifying time trade-offs (TTOs), standard gamble (SGs) and the visual analogue scales (VAS) as the most common approaches. Simplistically, the VAS appears to be a very feasible technique with high response rates, but doubts surround the ability of the VAS to reflect strength of preference for a given health

state. Conversely, TTOs and SGs can be difficult to complete, but have appealing theoretical foundations for health state valuations. Recently, tasks rooted in random utility theory (RUT) have been proposed for valuing health states [21, 22]. In health economics, the most well known RUT tasks are discrete choice experiments (DCEs) [23]. Best-worst scaling (BWS) is a relatively new valuation task rooted in RUT, and often embedded in a DCE [24]. BWS has been used to derive EQ5D weights [25] and more recently to value quality of life states for older people [26].

This paper reports the use of best-worst scaling to value the 729 informal care states from the Carer Experience Scale (CES). In contrast to the Caregiver Quality of Life Instrument and CarerQoL these weights could be used alongside carers' self-reported caring situation, keeping the descriptive system and the valuation component separate. The paper briefly describes the development of the CES and then goes on to cover the piloting, experimental design, administration and analysis of the BWS exercise. Preliminary results from the BWS exercise are presented, based on data from 2 out of the 5 centres. The discussion highlights the implications and limitations of this study, going on to outline future work on the CES. As the full analysis remains to be conducted, we would welcome any suggestions from HESG for interesting issues to pursue.

METHODS

Identifying attributes and levels

The Carer Experience Scale (the descriptive system for the informal care states) was developed through two stages of qualitative research [27]. A meta-ethnography was used to synthesise the findings of qualitative studies on caring, and determine conceptual attributes of the caring experience. 16 semi-structured interviews with carers were then used to develop the attributes into a self-report measure. Interviews were conducted iteratively, with the findings fed into future interviews, so that each interview focussed on the most pertinent issues. Initial interviews investigated whether the attributes from the meta-ethnography covered the areas that were important to carers themselves. Later interviews were used to put the attributes into appropriate language and discuss the number and wording of the levels.

Experimental design

A best-worst scaling experiment was designed to value the caring states. BWS requires respondents to compare attributes within a scenario, and select the best attribute and the worst attribute. This task generates more information than a

traditional DCE, while not requiring respondents to undertake 'middle rankings' which often violate assumptions of the ranking model [24]. Arguably BWS is also an easier task for respondents, as they do not have to keep (at least two) scenarios in mind at a time. In this study, the BWS task was combined with a discrete choice question (outlined in figure 1). Scenarios were piloted with respondents during the interviews and findings were fed into the design of the choice task.

Figure 1—the BWS and discrete choice task

Imagine being in situation 1 below
What would be the best thing and the worst thing about it?

<i>Best thing</i>		<i>Worst thing</i>
	You can do some of the other things you want to do outside caring	
	You get little support from family and friends	✓
	You get a lot assistance from organisations and the Government	
✓	You mostly find caring fulfilling	
	You are in control of some aspects of the caring	
	You sometimes get on with the person you care for	

In situation 1 would you continue to provide care? Yes ₁ No ₂

The BWS experiment had 6 attributes and 3 levels, creating 270 unique pairs of attribute-levels. We used an Orthogonal Main Effects Plan (OMEP) design for the exercise, obtained from the following website (<http://www.research.att.com/~njas/oadir/>) suggested by Street *et al.* [28]. The design was balanced meaning that each unique pair of attributes appeared an equal number of times (in this case twice). Levels were coded in order to avoid using the bottom or the top situation in the final questionnaire (see discussion). To minimise bias, both the order of the attributes within each situation and the ordering of the situations themselves were randomised in Stata [29].

The survey

The 18 scenarios of the best-worst scaling exercise were included in a self-complete questionnaire. Also included in the questionnaire was a set of background questions

and the Care Experience Scale (shown in the appendix). The background questions focussed on the carer, the care recipient and the caring situation and were selected to assess generalisability and heterogeneity in the findings. To get robust parameter estimates and explore heterogeneity it is suggested that the BWS sample size should be at least 150 [30]. In order to achieve this sample size, we decided to post the survey to participants. Though we had reservations about posting the questionnaire, this is a common method for DCEs [23, 31] and was the most feasible approach given the resources for the study and desired sample size. The questionnaire and study protocol were reviewed by Bristol and North Somerset Ethics Committee.

The questionnaire was sent to carers, rather than 'citizens', because we thought carers would be best placed to evaluate the good and bad attributes of caring. A second consideration was we wanted to test the feasibility of the CES and this had to be done with carers. It was therefore convenient to use the same questionnaire and sample for both the testing and valuation exercise. Carers for people over 65 were identified as potential participants by the Princess Royal Trust. This group of carers was sampled because of the original focus of the CES on measuring the impact of caring for an older person. People affiliated to the Princess Royal Trust for Carers have identified themselves as carers and decided to seek the support or advice of the charity, but otherwise represent a wide cross section of the caring community. The questionnaire was posted to 1,414 carers in 5 locations in England: Sandwell (West Midlands), Barnet (North London), Sunderland (North East), Lewisham (South London) and Trafford (North West). These centres represent a cross section of England in terms of: geography, affluence and ethnic make-up.

Questionnaires were posted in a pack containing: an information sheet, a translation card, a cover letter and a pre-paid envelope. To protect the carers' personal data, questionnaire packs were posted from the individual centres. Packs were posted in June and July 2007, and contact details for two study authors (HA & TF) were provided for participants should they have any questions. A single postcard reminder was sent out 1 month after the initial mail-out (again via the carers centre).

Data analysis

Data from the questionnaires was recorded in an Access Database. We recently pooled data from the first two centres (Sandwell and Barnet) and analysed it. We used a weighted least squares regression (paired method) [24] in Stata to estimate a linear additive utility model for the CES (see equation 1).

$$\begin{aligned} \ln(f) = & \text{Constant} + \beta_{11} \text{activities_few} + \beta_{12} \text{activities_some} + \beta_{13} \text{activities_most} + \\ & \beta_{21} \text{support_little} + \beta_{22} \text{support_some} + \beta_{23} \text{support_alot} + \\ & \beta_{31} \text{assistance_little} + \beta_{32} \text{assistance_some} + \beta_{33} \text{assistance_alot} + \\ & \beta_{41} \text{fulfilment_rarely} + \beta_{42} \text{fulfilment_sometimes} + \beta_{43} \text{fulfilment_mostly} + \\ & \beta_{51} \text{control_few} + \beta_{52} \text{control_some} + \beta_{53} \text{control_most} + \\ & \beta_{62} \text{getting-on_sometimes} + \beta_{63} \text{getting-on_mostly} \end{aligned}$$

(1)

Where f is the total number of times a particular best-worst pair was picked across all scenarios and across all respondents, adjusted to eliminate sampling zeros.

The natural logarithms of the 'best' frequencies are a linear function of the utilities. Assuming that the worst frequencies are inversely related to the best frequencies, then the natural logarithms of the worst frequencies are a linear function of the utilities with a sign change. This relationship between best and worst frequencies enables the 'reverse' (negative) coding of worst frequencies, which improves precision in model estimates.

RESULTS

Developing attributes and levels of Carer Experience Scale

One notable finding was the importance placed on the *process* of caring. Many people were caring for people with chronic degenerative diseases, over a long time period. 'Process' issues, such as the carer's ongoing relationship with the recipient, their ability to retain social contacts and the degree to which they felt supported were thus foremost in both the qualitative research and narratives of carers. To avoid potential double counting through including issues that were valued in their own right and influenced (health) outcomes, the attributes of the CES focus on the process of caring.

Survey

397 of the 1,414 questionnaires were returned. Reminders had only a small effect. A number of questionnaires were blank or indicated that the carer was ineligible. Adjusting the numerator (for both) and the denominator (for the ineligible carers) produced a response rate of 25%. There were 63 phone calls about the survey. The most common reasons were: (i) administration issues, such as requesting a replacement questionnaire (29 calls), eligibility questions (21 calls) and queries about the questionnaire (10 calls). Responses to the survey have only been analysed for the Barnet and Sandwell carers. Of these, approximately 71% completed the BWS

exercise fully and correctly, 4% made minor errors (a missed tick here and there), 4% gave up and 21% made major omissions, misunderstood the exercise or did not attempt it.

Descriptive statistics of sample

Table 1 presents the descriptive characteristics of the sample. Carers in this sample were predominantly female (72%) and mostly caring for a parent (70%). Most carers lived with the care recipient (69%) and many carried out a wide range of caring tasks. Based on the partial data, a significant number of carers provide round the clock care. Care recipients are mostly over 75 (84%) and about half have both physical and mental health problems

Table 1—Respondents providing full BWS responses (Barnet and Sandwell)

Characteristic	Respondents (n=65)	Characteristic	Respondents (n=65)
CARER		RECIPIENT	
Sex		Age	
Male	18	<75	10 [^]
Female	46	75-85	24
		>85	30
Age (years)		Relation to carer	
<60	23	Partner	11
60-70	33	Parent	45
>70	7	Other	8
Live with recipient?		Health problems	
Yes	44	None	2
No	20	Physical	21
		Mental	8
Years caring		Both physical and mental	33
<3	14		
3-10	30		
>10	18		
Tasks			
Help with daily living	59%		
Housework	84%		
Organisation	92%		
Emotional support	89%		
Hours of care per day*			
<6	8		
6-12	15		
>12	15		

*Carers who provided answer in hours/day format only

[^]Includes two care recipients who were 64 and one who was 36

Valuation of caring states

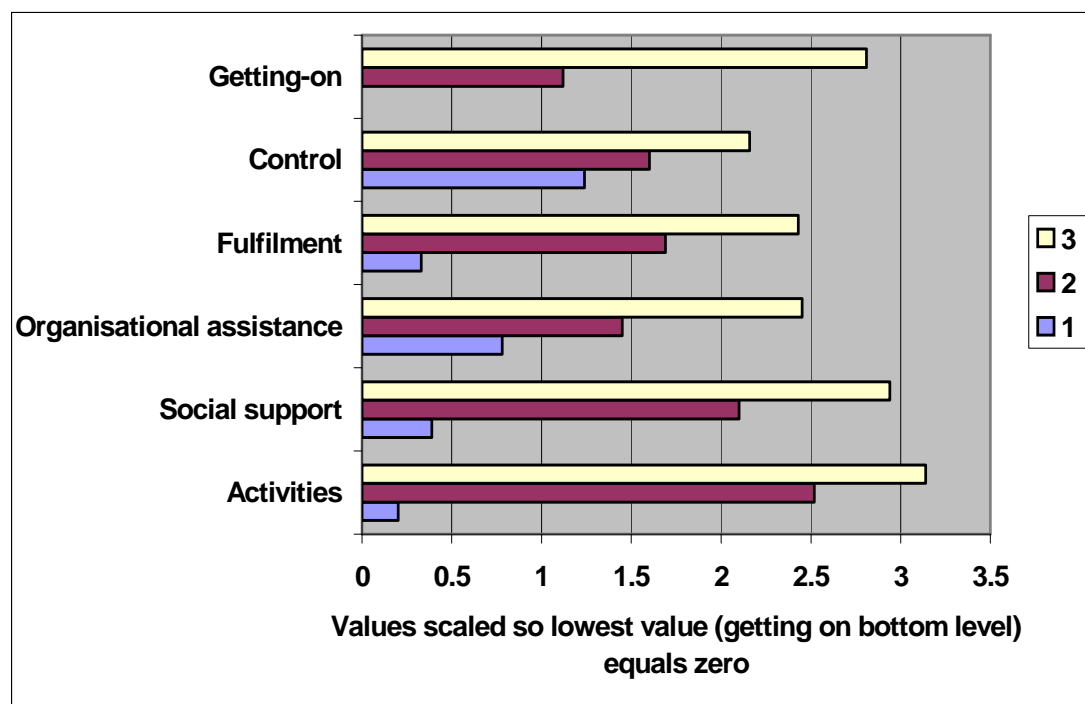
Table 2 shows the regression output for the model. The coefficients show the additional utility of each attribute level over the least valued attribute level. The attribute-level: 'Getting-on rarely' yielded the least utility and was therefore assigned a zero value. P-values, with the exception of few activities, are highly significant. This simply indicates that all the other attribute levels produce additional utility relative to 'getting-on rarely'. The confidence intervals around the attribute-levels are more informative, showing the plausible utility range for that attribute level. Five of the attributes do not have overlapping intervals, indicating a high probability that each additional level of the attribute is associated with additional utility. The exception is 'control', where the 95% confidence interval for the middle level overlaps with the intervals for the bottom and top level. This suggests the evidence is currently insufficient to reject the hypothesis that additional control yields additional utility to carers.

Table 2—Utility values for the attribute-levels of the CES (Dummy variable model)

Attribute	Utility	95% confidence interval	p-value
Activities			
Few	0.20	0.0 – 0.41	0.055
Some	2.52	2.28 – 2.76	<0.001
Most	3.14	2.91 – 3.37	<0.001
Support from family and friends			
A little	0.39	0.17 – 0.61	0.001
Some	2.10	1.79 – 2.41	<0.001
A lot	2.94	2.70 – 3.17	<0.001
Assistance from organisations			
A little	0.78	0.55 – 1.02	<0.001
Some	1.45	1.17 – 1.73	<0.001
A lot	2.45	2.19 – 2.72	<0.001
Fulfilment			
Rarely	0.33	0.12 – 0.54	0.002
Sometimes	1.69	1.36 – 2.02	<0.001
Mostly	2.43	2.15 – 2.72	<0.001
Control			
Few	1.24	0.95 – 1.52	<0.001
Some	1.60	1.29 – 1.91	<0.001
Most	2.16	1.86 – 2.47	<0.001
Getting-on			
Rarely	0.00		
Sometimes	1.12	0.86 – 1.38	<0.001
Mostly	2.81	2.54 – 3.07	<0.001

Figure 2 shows the results graphically. Improvements on all attributes do not appear to be valued equally. Carers appear to indicate that they would gain more benefit from improvements in their relationship (getting-on) with the care recipient and ability to engage in activities outside caring, than improvements in control over caring. In fact an improvement of one level (few (1) to some (2)) in activities is valued more highly than an improvement in two levels of control (few aspects (1) to most aspects (3)). Increases in the levels on the *same* attribute do not appear to be valued to equally, nor is there a systematic tendency to value increases at the higher or lower end more highly. In 'activities' movement from the bottom to middle level is valued most, while for 'getting on' movement from the middle to top level is valued most.

Figure 2—Preliminary weights for the Carer Experience Scale (unscaled)



In table 3 the weights are rescaled so that the worst caring state (333333) is assigned a score of zero and the best caring state (111111) is assigned a score of 1. The 0-1 weights are derived from the regression output by subtracting one-sixth of the utility of the bottom state from each coefficient and then dividing through by the resulting utility of the top state. Apart from the simplicity of a 0 to 1 scale, this allows the percentage utility contribution of each attribute-level to be viewed. There are 12 attribute-level increments between the bottom caring state and the top caring state (2

each for the 6 attributes). Three increments alone: few activities to some activities (0.178), little social support to some social support (0.134) and sometimes getting-on to mostly getting-on (0.130) contribute 44% of the total utility difference between the bottom and top state.

Table 3—Preliminary weights for the Carer Experience Scale (0-1 scale)

	Bottom state	Middle state	Top state
	111111	222222	333333
Getting-on	-0.038	0.048	0.178
Control	0.058	0.085	0.129
Fulfilment	-0.012	0.092	0.150
Organisational Assistance	0.022	0.074	0.151
Support (family and friends)	-0.009	0.125	0.188
Activities	-0.022	0.156	0.204
TOTAL	0	0.580	1

DISCUSSION

This study presents preliminary utility weights for informal care states. These weights can be used alongside the CES descriptive system, to create a preference-based carer measure for use in economic evaluation. We found that certain aspects of the caring experience had more potential than others to contribute to (dis)utility from caring. Carers on average appear to be willing to sacrifice large amounts of control for (qualitatively) smaller gains in activities outside caring (especially if they are already confined). These findings are consistent with other recent work demonstrating that people attach different values to gains on different aspects of caring [19, 32]. Although this may be obvious, sum-score measures, which predominate in caring literature, typically assume each item, and incremental improvements on a given item, are equally valued. Our preliminary findings indicate on the contrary, that each incremental improvement on an attribute is unlikely to be valued equally.

Any conclusions drawn from the limited sample are tentative and will be subject to revision when the entire dataset is analysed. The findings about activities and control are however worthy of further discussion. The large utility difference between few and some activities outside caring, was unexpected, as some carers indicated that outside activities were low down on their list of priorities during the qualitative phase

to develop the attributes. However research shows that maintaining outside interests can often be a vital coping strategy for heavily burdened carers. One study of coping strategies for stress in caring found: free time, distractions and outside interests were the three most helpful strategies to carers [6, p.75]. Changes in control, while important, appear to have less impact on utility than improvements on other attributes. Indeed the results show insufficient evidence to reject the hypothesis that there is no difference in utility between the bottom and middle level of control and the middle and top level of control. One hypothesis is that control is important to carers but contributes less to their utility than other attributes and this is reflected in the small incremental increases in utility. An alternative hypothesis, which emerged through the qualitative phase of developing the CES, is that control is valued highly by a small group of carers and very little, even negatively by others. The use of 'population' averages for the weights masks this heterogeneity. Our qualitative work and previous research [33] suggested that males, particularly those that had control earlier in life, are more comfortable and may value control more highly than females when providing care. A key advantage of BWS, when utilised alongside statistically efficient designs, is that it will provide insights into this heterogeneity for relatively modest sample sizes. This allows hypotheses such as: "do males value improvements in control more highly than females?" to be explored.

Qualitative work played an important role in both the selection of attributes and in the design of the questionnaire. Although this sort of qualitative work is recommended for developing outcome measures and discrete choice experiments [34], it is frequently omitted or poorly reported [35]. As a result the reasons for the choice of attributes and methods of attribute selection are often opaque. In our study we discussed the language of the attributes and levels with participants. Integrating their feedback prevented us from using potentially inappropriate terminology, which may have reduced response, created distress and led to misleading responses. A second finding through piloting of the survey, revealed the difficulties that respondents had with selecting a best attribute from the bottom scenario and a worst attribute from the top scenario. There is no rule regarding the coding of attributes (in other words how the attribute levels are linked to the numbers on the design website). To avoid the presence of a bottom scenario we therefore coded 4 of the attributes in the following way: top level =1 middle level =2 and bottom level =3 and two of them top = 3, middle =1 and bottom =2. Using this method we were still able to use a statistically efficient design, with every attribute pair appearing twice.

Best-worst scaling is relatively new to healthcare research, and this study represents the first use of the technique to value informal care states. As a result there are some limitations of the work, notably in response rate and task comprehension. Although we exceeded our target sample size of 150, response to the questionnaire was around 25% and a sizeable proportion of these respondents did not fully complete the BWS exercise. This study was however exploratory, and further work will be conducted to assess the characteristics of the sample population and how these relate to the general population of carers. Findings from other studies suggest carers are a hard group to survey and previous postal preference elicitation work with carers has resulted in response rates in the region of 18%-40% [8, 13, 14, 19]. Common reasons are that carers are often very busy, strained, or has given up providing informal care due to death or institutionalisation. Furthermore, DCE response rates of <35% are not uncommon [36]. A second limitation of our work relates to the cognitive ease of the task. While best worst scaling is arguably an easier task than TTO or SG and indeed a traditional DCE, it can still be confusing. Feedback on the questionnaires and by phone suggested some carers had problems: identifying how the scenarios (situations) differed, imagining themselves in a hypothetical caring situation and selecting a worst attribute. Inevitably completion rates would have been higher had the exercise been interview administered, but this was not possible within the budget and time constraint. Although a number of carers did not understand the exercise, very few who completed it, appear to have done so 'irrationally'. Bottom level attributes were very rarely ticked as 'best', and top level attributes very rarely ticked as 'worst'. Further, as an unintended consequence of exercise, the large number of partially completed questionnaires will allow us to investigate whether certain subgroups of people (for example the older carers) found completing the BWS difficult.

The CES could potentially be used for economic evaluation in a number of ways. First it could be used as the outcome measure in cost-effectiveness analysis to assist priority setting where the goal is boost the quality of life of carers. Second it could be used in a cost-consequence analysis alongside cost/QALY [37] as an indication of the 'spill-over' effects on carers. Such an approach is already recommended for NICE public health guidance when relevant costs are not captured in the cost/QALY calculation [38]. Third, it may be possible to develop ways of synthesising carer benefits and health benefits into a single welfare unit. These welfare units could be used in a cost-utility analysis or cost benefit analysis of an intervention that impacts on both patient and carer. In deciding on whether to include informal care, what

instrument to use and what approach to take for the economic evaluation, a number of questions are likely to be relevant. What is the decision problem, and how important is informal care likely to be? What perspective is appropriate for the intervention? Whose values are appropriate in assessing the relative value of caring states (internally)? What are the information requirements of the decision-maker? Often, informal care throws up awkward questions, which are left unanswered, resulting in the issue being sidelined in the majority of economic evaluations [10, 39].

The findings of this study are only preliminary. Further work is being conducted to pool the data from all 5 centres to provide a complete dataset for the CES weights. Different methods of regression [24] will be used in the modelling of valuations for the CES. The results will be contrasted. Work will be conducted to explore preference heterogeneity. This is particularly pertinent to this group where the relationship, reasons for caring, condition and time input vary so much. The analysis of the accept-reject question will allow us to establish the proportion of carers that were able to identify situations where they would want to pass care over to someone else. We should be able to get some insights into these carers' characteristics and also the characteristics of situations where carers were to relinquish the care. The discret-choice question was worded in a way to try to identify the point at which utility from caring equals 0. As data synthesis techniques advance in RUT choice experiments [40], this could provide a meaningful lower anchor for the scale. Further investigation will also explore the feasibility and validity of the CES. One advantage in feasibility terms of the CES is that it does not require carers to undertake a valuation exercise, just report their own caring situation. Should the CES show further promise in terms of feasibility and validity, this study outlines preliminary weights (albeit with caveats) that the CES could be combined with. This provides one way for economists to take the potentially important impacts on unpaid carers into account in economic evaluations.

We would particularly welcome discussion on the following topics:

- Whose values should be used to derive weights for the Carer Experience Scale?
- Alternative ways of anchoring the CES
- Intervention studies where the CES could be used

Acknowledgements

The authors would like to thank: the Medical Research Council for funding the work, the Princess Royal Trust for Carers for providing access to their members and all the carers who gave up their time to complete the questionnaire.

APPENDIX: THE CARER EXPERIENCE SCALE

PLEASE TICK ONE BOX FOR EACH GROUP to indicate which statement best describes your current caring situation.

1. Activities outside caring (*Socialising, physical activity and spending time on hobbies, leisure or study*)

- You can do most of the other things you want to do outside caring 1
You can do some of the other things you want to do outside caring 2
You can do few of the other things you want to do outside caring 3

2. Support from family and friends (*Personal help in caring and/or emotional support from family, friends, neighbours or work colleagues*)

- You get a lot of support from family and friends 1
You get some support from family and friends 2
You get little support from family and friends 3

3. Assistance from organisations and the Government (*Help from public, private or voluntary groups in terms of benefits, respite and practical information*)

- You get a lot of assistance from organisations and the Government 1
You get some assistance from organisations and the Government 2
You get little assistance from organisations and the Government 3

4. 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*)

- You mostly find caring fulfilling 1
You sometimes find caring fulfilling 2
You rarely find caring fulfilling 3

5. Control over the caring (*Your ability to influence the overall care of the person you look after*)

- You are in control of most aspects of the caring 1
You are in control of some aspects of the caring 2
You are in control of few aspects of the caring 3

6. Getting on with the person you care for (*Being able to talk with the person you look after, and discuss things without arguing*)

- You mostly get on with the person you care for 1
You sometimes get on with the person you care for 2
You rarely get on with the person you care for 3

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