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ORIGINAL RESEARCH ARTICLE

Measuring Care-Related Quality of Life of Caregivers for Use in Economic Evaluations: CarerQol Tariffs for Australia, Germany, Sweden, UK, and US

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Abstract

Background Informal care is often not included in economic evaluations in healthcare, while the impact of caregiving can be relevant for cost-effectiveness recommendations from a societal perspective. The impact of informal care can be measured and valued with the CarerQol instrument, which measures the impact of informal care on seven important burden dimensions (CarerQol-7D) and values this in terms of general quality of life (CarerQol-VAS). The CarerQol can be included at the effect side of multi-criteria analyses of patient interventions or in cost-effectiveness or utility analysis of interventions targeted at caregivers.

Objective At present, utility scores based on relative utility weights for the CarerQol-7D are only available for the Netherlands. This study calculates CarerQol-7D tariffs for Australia, Germany, Sweden, UK, and US.

Methods Data were collected among the general population in Australia, Germany, Sweden, UK, and US by an Internet survey. Utility weights were collected with a discrete choice experiment with two unlabeled alternatives described in terms of the seven CarerQol-7D dimensions. An efficient experimental design with priors obtained from the Netherlands was used to create the choice sets. Data was analyzed with a panel mixed multinomial logit model with random parameters.

Results In all five countries, the CarerQol-7D dimensions were significantly associated with the utility of informal care situations. Physical health problems were most strongly associated with the utility for informal care situations. The tariff was constructed by adding up the relative utility weights per category of all CarerQol-7D dimensions for each country separately.

Conclusion The CarerQol tariffs for Australia, Germany, Sweden, UK, and US facilitate the inclusion of informal care in economic evaluations.

Key Points for Decision Makers

The impact of providing informal care to family or friends is often overlooked when evaluating the costs and effects of interventions in healthcare. This article discusses the CarerQol instrument, which makes it possible to include the impact of caregiving on caregivers at the effect side of economic evaluations of healthcare interventions.

This article reports tariffs for the CarerQol instrument for five countries: Australia, Germany, Sweden, UK, and US.

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1 Introduction

Economic evaluations of healthcare interventions increasingly support public decision making in healthcare, especially on new pharmaceuticals. Economic evaluations provide cost-effectiveness information of healthcare by comparing the

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costs and effects of an intervention with its best alternative. Important in these evaluations is that all relevant costs and effects of interventions are considered. Which costs and effects are deemed relevant depends on the perspective of the economic evaluation [1–3]. It is often advocated that researchers conducting economic evaluations should apply a broad scope in their evaluations and consequently use the societal perspective [3, 4]. This often implies that not only effects on patients and costs of formal healthcare use are relevant, but that economic evaluations should also consider the impact of the evaluated interventions on family and friends of patients [5–9]. In practice, most economic evaluations ignore (important aspects of) informal care, including those claiming to provide cost-effectiveness recommendations from a societal perspective [10, 11]. Informal care constitutes a large part of the total care provided to patients and the elderly in many countries [12, 13]. Although providing informal care can be fulfilling for caregivers, lending care can also be both mentally and physically straining [14–18]. Without consideration of the impact of informal care, the results of economic evaluations may be biased with the risk of leading to sub-optimal policy recommendations.

The impact of caregiving on informal caregivers can be included in economic evaluations by measuring and valuing the effects on caregivers in terms of their 'care-related quality of life' [19, 20]. Tariffs can be applied to calculate care-related quality-of-life scores of caregivers for use in economic evaluations. This may be useful when evaluating interventions for patients requiring informal care (e.g., because of their chronic conditions or age-related health problems). In these situations where patient interventions are evaluated, care-related quality of life cannot be directly added to patient effects in a cost-effectiveness analysis (CEA) or cost-utility analysis (CUA). However, care-related quality of life can be included next to and separate from patient effects in a cost-consequence or multi-criteria analysis. In other situations, the focus may be on evaluating interventions for informal carers (e.g., respite care programs). Caregiver utilities are central here. Care-related quality of life can then serve as the primary outcome measure and be included at the effect side of a CEA or CUA [20, 21]. The CarerQol-7D instrument produces such care-related quality-of-life scores of caregivers with the use of 'tariffs'. The resulting care-related quality-of-life scores take differences in the importance of problems that caregivers can face into account. The CarerQol-7D measures two positive dimensions of caregiving (fulfilment and support) and five problem dimensions (relational problems, mental health, physical health, financial problems, and problems combining daily activities with caring), each with three response categories ('no', 'some', 'a lot') (see Fig. 1).

At this moment, a tariff for calculating standard (care-related) utility scores for all CarerQol-7D states is only available for the Netherlands [22]. This tariff is based on

the preferences of the general public of the Netherlands for the 2187 (3^7) caregiving states described by the CarerQol-7D instrument. The practical application of the CarerQol instrument in scientific studies could be facilitated by population-specific tariffs for other countries than the Netherlands, as is common in health state valuations [23–25]. This study provides tariffs for the CarerQol instrument for five countries: Australia, Germany, Sweden, UK, and US.

2 Methods

2.1 Data

Data were collected in August 2014 in Australia, Germany, Sweden, UK, and US. A web-based questionnaire was distributed by an Internet survey company to respondents representative of the adult population in each of these five countries in terms of age, sex, and educational level. Per country at least 500 respondents were recruited for the study. This number was motivated by efficiency measures of the design used in this choice experiment [26]. The number of respondents included in the data analysis was: 551 (Australia), 562 (Germany), 548 (Sweden), 552 (UK), and 550 (US). Descriptive statistics of the study samples can be found in Table 1.

2.2 Discrete Choice Experiment

Discrete choice experiments were conducted to develop tariff sets for the CarerQol-7D for Australia, Germany, Sweden, UK, and US. The methodology applied here is based on the estimation of the CarerQol tariff for The Netherlands [22]. Respondents were instructed to imagine that while completing the survey they provided care or support to a loved one as a result of an illness, disability, or infirmity of old age. They were also asked to keep the same care recipient in mind during the whole experiment. After completing the choice tasks, respondents were asked for the level of difficulty of the choice tasks and their familiarity with informal care giving, or with caregivers in their own circles of family and friends.

Choice sets were constructed with an efficient experimental design with priors from the CarerQol-7D tariff set for the Netherlands [22] to calculate standards errors of the parameters as statistically efficient as possible to increase reliability of the results with smaller sample sizes [27–29]. The efficient experimental design contained 40 choice sets,[1]

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[1] Minimum number of independent choice probabilities: $S \times (J - 1) \geq K$, where S is the number of choice sets, J is the number of alternatives, and K is the degrees of freedom of parameters.

Table 1 Background information of respondents in mean (standard deviation) or percentages

Characteristics		Australia (n = 551) Mean (SD) or %	Germany (n = 562) Mean (SD) or %	Sweden (n = 548) Mean (SD) or %	UK (n = 552) Mean (SD) or %	US (n = 550) Mean (SD) or %
Age (years)		45.5 (16.4)	46.7 (16.3)	47.3 (17.5)	46.6 (16.7)	45.8 (16.9)
	18–24	12.3	11.2	12.4	12.1	13.3
	25–34	18.0	15.3	15.7	17.0	17.5
	35–44	19.6	20.6	16.8	17.8	17.5
	45–54	18.3	17.1	17.0	17.6	19.3
	55–64	14.7	14.4	16.2	15.0	15.6
	65+	17.1	21.4	21.9	20.3	16.9
Sex	Female	51.2	51.6	50.9	51.6	51.5
	Male	48.8	48.4	49.1	48.4	48.6
Educational level	Low	1.1	21.2	17.9	20.7	13.3
	Middle	67.7	55.7	49.6	23.0	28.2
	High	31.2	23.1	32.5	56.3	58.6
Paid work	Full time	35.0	42.0	39.4	43.7	37.3
	Part time	19.8	14.2	10.0	14.7	13.1
	No	45.2	43.8	50.6	41.7	49.6
Partner	Yes	54.1	61.7	56.8	62.0	55.1
	No	44.8	37.5	40.5	37.1	44.2
	Did not state	1.1	0.7	2.7	0.9	0.7

SD standard deviation

which were blocked over four groups of respondents, i.e., in the survey, ten choice sets were presented to each respondent. The utility functions consisted of two dummy variables per attribute (reference level: no for the two positive attributes of the CarerQol-7D, a lot for the five negative attributes), interaction terms for all attribute combinations, and a constant term for the first alternative in the choice set. The dummy variables were treated as Bayesian priors with a normal distribution using mean and standard error of the multinomial logit (MNL) model of the tariff for the CarerQol-7D in the Netherlands, allowing parameter values to be both negative and positive (see "Appendix", Table 5). The efficient experimental design was optimized for D-efficiency in the basic multinomial logit model [28] calculating mean values using 1000 Halton draws [30]. The efficient experimental design was constructed in Ngene (ChoiceMetrics, Australia).

In this discrete choice experiment, respondents were asked to choose between two unlabeled hypothetical informal care situations (see Fig. 2 for an example). These hypothetical informal care situations were described by a combination of the seven attributes and three levels of the CarerQol-7D: (1) fulfilment with carrying out your care tasks, (2) relational problems with the care receiver, (3) problems with your own mental health, (4) problems combining your care tasks with your daily activities, (5) financial problems because of your care tasks, (6) support with carrying out your care tasks, and (7) problems with your own physical health. The levels of these attributes were 'no',

'some', and 'a lot'. Color coding was used to aid visual representation of the information: positive attribute levels were displayed in green text, the negative levels in red text, and the intermediate levels in orange text [31]. The choice sets were presented in random order to the respondents.

In addition, at the start of the questionnaire, information was gathered on the respondents' age, sex, highest attained educational level, marital status, and current employment status.

The questionnaire was translated in Swedish by native speakers involved in research among informal caregivers and in German by Mapi values. The original English version of the CarerQol instrument [19] was translated into Swedish and German using forward–backward translation. The English translation was performed by the authors and checked for accuracy by native speakers and informal care researchers from Australia, UK, and US. This resulted in separate questionnaires for each of the three countries, which were largely identical but contained some country-specific adaptations to spelling and wording (e.g., 'neighbours' or 'neighbors' in the examples provided with the seven dimensions of the CarerQol).

2.3 Analyses

The data were analyzed with a panel mixed multinomial logit (MMNL) model, allowing for the presence of unobservable preference heterogeneity in the population

Fig. 1 The CarerQol instrument

We would like to form an impression of your caregiving situation.
Please tick a box to indicate which description best fits your caregiving situation at the moment.

Please tick only one box per description: 'no', 'some' or 'a lot of'.

I have ☐ ☐ ☐ fulfilment from carrying out my care tasks.

I have ☐ ☐ ☐ relational problems with the care receiver *(e.g., he/she is very demanding or behaves differently; we have communication problems).*

I have ☐ ☐ ☐ problems with my own mental health *(e.g., stress, fear, gloominess, depression, concern about the future).*

I have ☐ ☐ ☐ problems combining my care tasks with my own daily activities *(e.g. household activities, work, study, family, leisure activities).*

I have ☐ ☐ ☐ financial problems because of my care tasks.

I have ☐ ☐ ☐ support with carrying out my care tasks, when I need it *(e.g., from family, friends, neighbours, acquaintances).*

I have ☐ ☐ ☐ problems with my own physical health *(e.g., more often sick, tiredness, physical stress).*

How happy do you feel at the moment?
Please place a mark on the scale below that indicates how happy you feel at the moment.

completely unhappy   *completely happy*

0 1 2 3 4 5 6 7 8 9 10

(random parameters) and the correlation of responses across observations (panel structure) [26, 32]. Likelihood ratio tests were used to construct the model specification, in particular considering whether the model should include: (1) an alternative specific constant, (2) random or fixed parameters, (3) interaction effects of the attributes, and (4) collapsed attribute levels. These tests were performed for each country separately.

2.4 CarerQol Tariff

The tariff for the CarerQol-7D was based on individual-specific parameters. These parameters were calculated by randomly assigning the unconditional distribution of the panel MMNL model (population level estimates of the panel MMNL model) over a hypothetical sample of 10,000 individuals with bootstrap sampling [26]. Next, the individual-specific parameter estimates from the bootstrap sampling were averaged. The mean parameter values were rescaled to represent the CarerQol-7D tariff ranging from 0 (worst informal care situation) to 100 (best informal care situation). The standard errors of the tariff were calculated by dividing the standard errors of the MMNL parameters by the same total score. Analyses were performed in Nlogit 5.0 (Econometric Software Inc., Plainview, New York, US). Finally, for the purpose of illustration, CarerQol-7D utility scores were calculated for six caregiving situations described by the CarerQol-7D using the tariffs of Australia, Germany, Sweden, UK, and US. These caregiving states were selected given their prevalence in a large dataset of

Fig. 2 Example of choice set.
Note: in the choice-sets, the
levels were color coded: the best
level per attribute (i.e., 'no' for
the negative attributes and 'a lot
of' for the positive attributes)
was printed in *green*, the middle
level in *orange*, and the worst
level in *red*

Which caregiving situation do you prefer?

Caregiving situation A	Caregiving situation B
You have **no fulfilment** from carrying out your care tasks	You have **a lot of fulfilment** from carrying out your care tasks
You have **a lot of relational problems** with the care receiver	You have **a lot of relational problems** with the care receiver
You have **some problems** with your own **mental health**	You have **a lot of problems** with your own **mental health**
You have **some problems** combining your care tasks with your own **daily activities**	You have **a lot of problems** combining your care tasks with your own **daily activities**
You have **a lot of financial problems** because of your care tasks	You have **some financial problems** because of your care tasks
You receive **a lot of support** with carrying out your care tasks, when you need it	You receive **no support** with carrying out your care tasks, when you need it
You have **some problems** with your own **physical health**	You have **a lot of problems** with your own **physical health**

informal caregivers in the Netherlands [17]. The six CarerQol-7D states ranged from less to more desirable caregiving situations (see Table 4). The CarerQol-7D utility scores of the five countries of this study and of the Netherlands, computed using the tariffs presented in Hoefman et al. [22], are presented in a radar plot created in Microsoft Excel (US).

3 Results

3.1 Utility of Informal Care Situations

The relative weights of the seven dimensions of the CarerQol-7D for the five countries are presented in Table 2. For all countries, all the seven CarerQol-7D dimensions were significantly associated with the utility of informal care situations. In each of the five countries, the utility of informal care situations was significantly higher when this situation was more attractive in terms of more fulfilment and support and no or less caregiving problems.

In all five countries, informal care-related utility was relatively strongly influenced by the presence of physical health problems. In the majority of countries, mental health problem and financial problems also had a relatively strong influence on care-related utility. In general, two CarerQol-7D dimensions (problems with daily activities and support) were relatively weakly associated with the utility of informal care situations.

3.2 CarerQol Tariff

Table 3 presents the CarerQol tariffs for Australia, Germany, Sweden, UK, and US. Total utility scores for

CarerQol states can be calculated by adding up the tariff per category of the seven CarerQol-7D dimensions. For example, an informal care situation in which the caregiver has "no fulfilment, some relational problems, a lot of mental health problems, some problems combining daily activities, no financial problems, some support and a lot of physical health problems" (CarerQol-7D state 2 in Table 4) represents utility scores of 35.6, 43.5, 40.3, 35.9, and 36.0 in Australia, Germany, Sweden, UK, and US, respectively.

For the purpose of illustration, the radar plot (Fig. 3) presents the CarerQol-7D scores of six caregiving situations of Australia, Germany, Sweden, UK, US, and the Netherlands. In general, the CarerQol-7D scores of all countries resemble each other fairly well. The ranking of the six states according to their utility value is identical across countries, and the range of utility values per state does not overlap with the following better state.

4 Discussion

This study derived preference weights for the seven dimensions of the CarerQol-7D instrument in Australia, Germany, Sweden, UK, and US to calculate country-specific tariffs for the CarerQol for use in economic evaluations. In line with the results of the study conducted in the Netherlands [22], all seven dimensions of the CarerQol-7D were important for the utility value of informal care situations in the general population in the five countries. As expected, people prefer caregiving situations characterized by more positive experiences from caring (more fulfilment and social support) and fewer relational, health, and financial problems or fewer problems combining care with

Table 2 Panel MMNL model per country

CarerQol-7D dimension	Australia			Germany			Sweden			UK			US		
	Coef.	SD[a]	p value	Coef.	SD[a]	p value	Coef.	SD[a]	p value	Coef.	SD[a]	p value	Coef.	SD[a]	p value
Fulfilment (ref. no)															
Some	1.17	0.73	0.000	0.95	[d]	0.000	1.37	1.74	0.000	1.11	2.25	0.000	0.57	1.25	0.000
A lot	1.45	1.23	0.000	1.20	[d]	0.000	1.53	1.97	0.000	1.45	2.84	0.000	0.85	1.32	0.000
Relational problems (ref. a lot)															
No	1.13	0.65	0.000	1.38	1.37	0.000	1.96	2.25	0.000	1.39	2.04	0.000	0.82	1.31	0.000
Some	0.78	0.60	0.000	0.87	1.17	0.000	1.45	1.88	0.000	0.98	1.49	0.000	0.52	1.24	0.000
Mental health problems (ref. a lot)															
No	1.82	1.31	0.000	1.07	1.41	0.000	2.16	2.11	0.000	2.68	2.48	0.000	1.72	1.58	0.000
Some	1.20	1.11	0.000	1.00	0.79	0.000	1.71	1.81	0.000	1.86	1.71	0.000	1.22	1.06	0.000
Problems with daily activities (ref. a lot)															
No	0.84	0.81	0.000	0.73	1.01	0.000	0.98	1.83	0.000	0.83	1.77	0.000	0.41	1.00	0.000
Some	0.42	0.60	0.000	0.48	0.81	0.000	0.69	1.44	0.000	0.36	1.74	0.035	[b]		
Financial problems (ref. a lot)															
No	1.49	1.49	0.000	1.64	1.72	0.000	1.88	2.15	0.000	1.96	2.62	0.000	1.27	1.55	0.000
Some	1.05	0.92	0.000	1.06	1.28	0.000	1.24	1.43	0.000	1.33	1.81	0.000	0.89	1.16	0.000
Support (ref. no)															
Some	0.50	[d]	0.000	0.51	1.03	0.000	0.52	1.09	0.000	0.77	1.21	0.000	0.39	0.79	0.000
A lot	[c]		0.000	0.73	1.08	0.000	0.63	1.39	0.000	0.92	1.25	0.000	0.44	0.84	0.000
Physical health problems (ref. a lot)															
No	1.79	1.84	0.000	1.21	1.93	0.000	2.21	2.25	0.000	2.05	2.68	0.000	1.65	1.83	0.000
Some	1.44	1.39	0.000	1.07	1.58	0.000	1.68	1.69	0.000	1.70	2.10	0.000	1.12	1.50	0.000

Coef. coefficient, *MMNL* mixed multinomial logit, *ref.* reference level, *SD* standard deviation

[a] Attribute-specific SD of Cholesky matrix

[b] No/some are merged

[c] Some/a lot are merged

[d] Non-random coefficients in model

other activities. The most important dimension of utility for informal care situations was the physical health of caregivers, while the least important dimensions were problems combining caregiving with other activities and support with caregiving tasks. These findings were in line with those from the Netherlands [22].

However, comparisons between countries remain difficult, given that differences in the data could be explained by genuine issues, such as country-specific attitudes towards informal caregiving or random error [33]. In addition, despite the careful translation process, small differences may have crept into the different language versions of the questionnaire. Moreover, the model specifications between countries differed (e.g., non-random coefficients for the CarerQol-7D dimension of support in Australia and the dimension of fulfilment in Germany).

Some other limitations of this study need to be mentioned. In all five countries, heterogeneity in the preferences for caregiving situations was observed. In contrast to the tariff in the Netherlands, no interaction effects of the seven dimensions of caregiving burden could significantly explain the utility values of caregiving situations in Australia, Germany, Sweden, UK, or US. Other strategies to explain heterogeneity in the choice data, such as subgroup analyses, have not been attempted because the aim of this study was to derive a general tariff for the CarerQol-7D that could be applied among all types of caregivers and study settings. Hence, we attempted to resemble the methodology commonly used and advocated for deriving health state preferences. Moreover, there is discussion in the literature as to which preferences are relevant in the context of economic evaluations: those of the group affected by the intervention or those of the general public [34]. To resemble the methodology of health state values, we collected preferences of the general public to calculate CarerQol tariffs.

Furthermore, it should also be stressed that an Internet panel was used to collect data. Although the use of the Internet has become common for most members of

Table 3 CarerQol tariffs

Country	CarerQol-7D dimensions	No		Some		A lot	
		Tariff	SE	Tariff	SE	Tariff	SE
Australia	Fulfilment	0.0	0.0	13.0	1.5	16.1	1.9
	Relational problems	12.5	1.2	8.7	1.1	0.0	0.0
	Mental health problems	20.1	1.6	13.2	1.2	0.0	0.0
	Problems with daily activities	9.5	1.2	4.8	1.0	0.0	0.0
	Financial problems	16.5	1.6	11.5	1.2	0.0	0.0
	Support	0.0	0.0	5.6	0.9	5.6	0.9
	Physical health problems	19.8	1.7	15.7	1.4	0.0	0.0
Germany	Fulfilment	0.0	0.0	11.9	1.7	15.1	2.1
	Relational problems	17.8	1.7	10.6	1.5	0.0	0.0
	Mental health problems	13.5	1.7	12.7	1.4	0.0	0.0
	Problems with daily activities	9.2	1.5	6.0	1.3	0.0	0.0
	Financial problems	20.3	2.1	13.4	1.6	0.0	0.0
	Support	0.0	0.0	6.6	1.3	9.1	1.4
	Physical health problems	15.1	1.9	13.2	1.7	0.0	0.0
Sweden	Fulfilment	0.0	0.0	12.1	2.0	13.9	2.4
	Relational problems	16.9	2.1	13.0	1.9	0.0	0.0
	Mental health problems	19.0	2.2	15.3	1.8	0.0	0.0
	Problems with daily activities	8.7	1.7	6.0	1.4	0.0	0.0
	Financial problems	16.5	2.1	11.1	1.7	0.0	0.0
	Support	0.0	0.0	4.8	1.2	5.6	1.4
	Physical health problems	19.5	2.2	14.9	1.9	0.0	0.0
UK	Fulfilment	0.0	0.0	10.1	2.1	13.0	2.6
	Relational problems	12.0	1.8	8.8	1.6	0.0	0.0
	Mental health problems	23.9	2.3	16.5	1.7	0.0	0.0
	Problems with daily activities	7.4	1.6	3.1	1.5	0.0	0.0
	Financial problems	17.2	2.1	11.5	1.7	0.0	0.0
	Support	0.0	0.0	6.9	1.4	8.1	1.4
	Physical health problems	18.4	2.3	15.0	1.9	0.0	0.0
US	Fulfilment	0.0	0.0	7.6	1.9	11.7	2.3
	Relational problems	11.6	1.8	7.0	1.7	0.0	0.0
	Mental health problems	23.8	2.2	17.0	1.7	0.0	0.0
	Problems with daily activities	5.8	1.5	5.8	1.5	0.0	0.0
	Financial problems	18.0	2.0	12.5	1.7	0.0	0.0
	Support	0.0	0.0	5.3	1.4	6.2	1.5
	Physical health problems	23.0	2.3	15.8	1.9	0.0	0.0

SE standard error

Table 4 CarerQol-7D states of radar plot (Fig. 3)

| CarerQol-7D dimension	State 1	State 2	State 3	State 4	State 5	State 6
Fulfilment	A lot	No	Some	Some	Some	A lot
Relational problems	A lot	Some	No	Some	Some	No
Mental health problems	A lot	A lot	Some	Some	No	No
Problems with daily activities	A lot	Some	Some	Some	No	No
Financial problems	A lot	No	Some	Some	No	No
Support	A lot	Some	No	Some	Some	Some
Physical health problems	A lot	A lot	A lot	Some	No	No
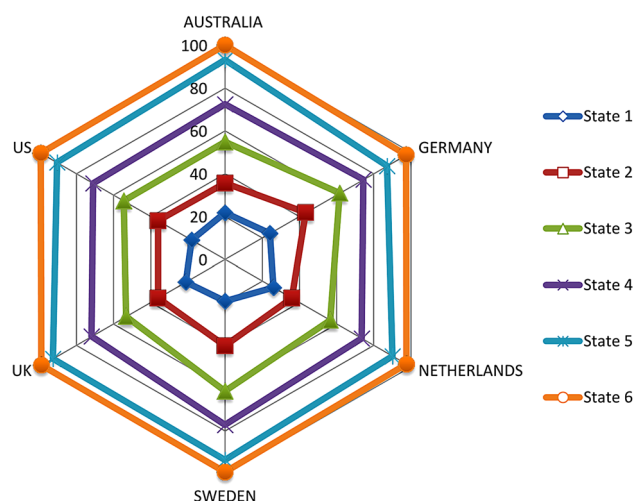
Fig. 3 Radar plot CarerQol-7D scores per country (states 1–6)

society, including the elderly [35], the study sample might be somewhat selective because of the use of an Internet panel. Moreover, persons with a low educational level are somewhat underrepresented in four out of five countries in the study (UK, US, Australia, and Sweden). Here, a note should also be made on the country-specific classifications of educational level in the Internet panels per country. For example, the classification applied in the Internet panel in Australia is relatively strict in defining a low educational level including only persons with primary education, while the categorization in other countries is somewhat broader. In US, for example, persons that were in high school but did not graduate are classified in the lowest educational level. As a result, the number of persons with a low educational level in Australia is relatively low compared with the other countries in the study.

A limitation for the use of the CarerQol in studies with international comparisons of informal care is the selection of relatively comparable Western countries in this article. It would be interesting to study preferences for caregiving in a broader range of countries with different healthcare systems and/or cultural values towards family care, such as countries in southern Europe where, in general, the role of the family is more central in caregiving [12].

Informal care can be included in economic evaluations in different ways. If informal care is considered, it usually is included at the cost side of economic evaluations. In this way, little attention is being paid to the impact that caregiving can have on caregivers. Hence, it is recommended to measure and value the impact of caregiving on caregivers in terms of quality of life [7, 36]. Care-related quality-of-life values can be used as an outcome in different types of economic evaluations of

healthcare programs. In the often-used CEA/CUA, the CarerQol can only be applied when interventions targeted at caregivers are evaluated. Care-related quality of life could then serve as the main outcome of interest. When evaluating patient interventions, the CarerQol cannot be used in the CEA/CUA, where health (-related quality of life) is the outcome of interest. In these types of economic evaluations, the effect of caregiving on caregivers can be measured in terms of health-related quality of life with the same health utility instruments as applied to measure health-related quality of life in patients. The health utilities of informal caregivers can then be added to those of patients at the effect side of the CEA/CUA. The risk of double counting the effects of caregivers seems to be low. Evidence suggests that respondents include the effects of a health state on loved ones in different ways in health state valuations. Hence, on average, the effect on loved ones seems not significantly to influence health state valuations [37]. Although the CarerQol measures both physical and mental health of caregivers, care-related quality of life also encompasses other important dimensions of caregiving and therefore CarerQol-7D utility scores cannot be summated with common health-related utilities measured in patients.

It should also be noted here that, in contrast to common health state valuations, the duration component of the valued good is not included. In further research, investigating how the time component could be added to valuation exercises and its influence on outcomes would be interesting and relevant. Alternatively, the CarerQol can be used as an outcome measure in a multi-criteria analysis of patient interventions. Care-related quality of life of caregivers can then be used as a measure of the effect of a patient intervention next to other effect measures, such as health-related quality of life in patients. In this way, policymakers are explicitly informed about the consequences of a patient intervention on caregivers. A more detailed discussion on how informal care can be included in economic evaluations can be found in Koopmanschap et al. [21] and in Hoefman et al. [20, 38].

5 Conclusions

This article presents utility values for the CarerQol instrument for Australia, Germany, Sweden, UK, and US. These population-specific tariffs enhance the practical application of the instrument in evaluation studies, and ultimately facilitate informed public decision making in healthcare, aiming to increase the welfare of all, including informal carers.

Appendix

See Table 5.

Table 5 Conditional logistic model of CarerQol-7D states in The Netherlands [22]

		Coef.	SE	*p* value
Fulfilment (ref. no)	Some	0.89	0.05	0.000
	A lot	1.28	0.05	0.000
Relational problems (ref. a lot)	No	0.86	0.05	0.000
	Some	0.62	0.04	0.000
Mental health problems (ref. a lot)	No	0.88	0.06	0.000
	Some	0.67	0.05	0.000
Problems with daily activities (ref. a lot)	No	0.64	0.04	0.000
	Some	0.34	0.04	0.000
Financial problems (ref. a lot)	No	0.85	0.05	0.000
	Some	0.62	0.04	0.000
Support (ref. no)	Some	0.33	0.04	0.000
	A lot	0.51	0.04	0.000
Physical health problems (ref. a lot)	No/some	0.94	0.04	0.000
Mental no × physical no		0.21	0.09	0.022

Coef. coefficient, *SE* standard error, *ref.* reference level

[a] Minimum number of independent choice probabilities: $S \times (J - 1) \geq K$, where S is the number of choice sets, J is the number of alternatives, and K is the degrees of freedom of parameters

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