The relative value of carer and patient quality of life: A person trade-off (PTO) study

Hareth Al-Janabi [a],[*], Eve Wittenberg [b], Cam Donaldson [c], Werner Brouwer [d]

[a] *Health Economics Unit, Institute of Applied Health Research, University of Birmingham, UK*
[b] *Harvard TH Chan School of Public Health, Harvard University, United States*
[c] *Yunus Centre for Social Business and Health, Glasgow Caledonian University, UK*
[d] *Erasmus School of Health Policy & Management, Erasmus University Rotterdam, the Netherlands*

ABSTRACT

Carer quality of life is increasingly considered alongside patient quality of life in economic evaluation. Important questions remain about how to value carer and patient quality of life effects alongside one another. In this study, we estimated the relative social value of two conceptualisations of carer quality of life (*health-related* and *care-related*) compared to patient quality of life. Relative valuations were estimated using a person trade-off (PTO) study with 990 representative members of the UK public. Participants chose between hypothetical services that improved the quality of life of carers and patients, iterating to a point of indifference. Overall 84% of participants completing the task were willing to trade patient and carer quality of life effects. Relative to a reference point of 1 for patient health-related quality of life, we estimated a social value of 0.74 for carer *health-related* quality of life effects and 0.69 for carer *care-related* quality of life effects. In conclusion, public preferences appear to support the inclusion of carer quality of life effects within economic evaluation. The results provide a means to value different carer quality of life outcomes in economic evaluation, where such values are needed and deemed appropriate.

1. Introduction

Family (unpaid) carers look after, help, or support, family members, friends or neighbours, because of ill health, disability, or old age (Office for National Statistics, 2013). This care can be contrasted with paid care, where individuals, unrelated to the care recipient receive a salary for their caring role. Family carers play an essential role in supporting people with long-term physical health problems (Han and Haley, 1999; Brouwer et al., 2004) and mental health problems (Lefley, 1996; Sörensen et al., 2006), as well as in caring for children (Brouwer et al., 2009; Al-Janabi et al., 2016a; Wittenberg et al., 2013) and people at the end of life (Canaway et al., 2019). Family carers often report impaired quality of life as a result of their caring role (Bobinac et al., 2011; Pinquart and Sorensen, 2003; Wittenberg et al., 2019). Their quality of life can be both positively and negatively affected by individual healthcare interventions and the way that services are organised (Al-Janabi et al., 2019; Bobinac et al., 2010). Economic evaluations of new healthcare interventions are starting to capture these carer quality of life effects (Pennington and Wong, 2019; Goodrich et al., 2012; Lavelle et al., 2019;

Krol et al., 2015). This raises the question of what value to place on carer quality of life effects in economic evaluation when they are incorporated in an economic evaluation alongside patient quality of life effects.

When taking a healthcare perspective, including carer *health-related* quality of life (HRQoL) is logical if the aim is to work out how population health can be maximised from scarce resources (Al-Janabi et al., 2016b; Hoefman et al., 2013). Indeed, guidelines for economic evaluation, including National Institute for Health and Care Excellence (NICE) guidelines in England (National Institute for Health and Care Excellence, 2013), highlight the importance of measuring and valuing carer HRQoL effects. When taking a broader societal perspective, including carer health-related quality of life is equally important (Sanders et al., 2016). However, impacts on *care-related* quality of life (CRQoL), a concept that reflects such attributes such as relationships, fulfilment, control, and support, may also be considered relevant (Hoefman et al., 2013; Al-Janabi et al., 2011a).

Aggregating carer and patient HRQoL gains is, in principle, straightforward, as they are in the same units. The question then is whether we, normatively and empirically, should place the same weight

on both. Aggregating carer and patient quality of life effects when they are in different units, on the other hand, is not straightforward. This issue arises when a CRQoL measure is used with carers and a HRQoL measure with patients. This approach reflects the different 'identity' of the carer and patient within the economic evaluation (Al-Janabi et al., 2011a). However, some form of 'exchange rate' is required to aggregate or compare carer and patient effects.

The typical starting position for cost-utility analysis is the equal valuation of quality of life effects regardless of the context and condition (Drummond et al., 2005). However, this has been challenged by a growing literature showing that the social value of quality adjusted life years (QALYs) can vary by context and individual (Donaldson et al., 2011; Lancsar et al., 2011). This literature shows for example that the value placed on a given quality of life improvement differs depending on the severity of the condition, age, socio-economic status, and the individual's perceived culpability for their condition (Gu et al., 2015). There have also been challenges from decision frameworks used in certain jurisdictions, like that of the Healthcare Institute (ZIN) in the Netherlands which bases the applied threshold on the severity of the illness being treated (Reckers-Droog et al., 2018). In England, in recent years, additional weight has been given to gains at the end-of-life by NICE (McHugh et al., 2018).

At present, there is no empirical basis for weighting carer HRQoL differently from patient HRQoL within economic evaluation. Nevertheless some argue for a low or zero weight for carer health-related quality of life because of a need to focus on patients (Tubeuf et al., 2018) or perceived inequity created by carer effects in terms of prioritising patient groups with bigger social networks (Dixon and Round, 2019; McCabe, 2019). However, others have argued that governments have a special duty of care to family carers given their role in supporting society (Arksey and Moree, 2008) – and this may suggest equal or a higher weighting for carers. The US Panel on cost-effectiveness note this is an area where more conceptual work is needed, stating: *"… [carer] spillover effects [should] be included in the healthcare sector and societal perspectives recognising that the methods for measuring these effects and in particular valuing them need further methodological and ethical investigation"* (p.771) (Neumann et al., 2018).

As noted previously, carer and patient quality of life may be conceptualised in a different way from one another (Wittenberg et al., 2019; Al-Janabi et al., 2011a). Although carer HRQoL may be measured using common health-related measures used with patients (such as EQ-5D) (Al-Janabi et al., 2011a; Bhadhuri et al., 2017), quality of life effects specific to the caring experience may be measured using CRQoL measures, such as the Carer Experience Scale (Al-Janabi et al., 2011b) or CarerQol (Brouwer et al., 2006) which are not suitable for patients as they are carer-specific. Since CRQoL effects are conceptually different from HRQoL effects and on a different scale, this raises the question of how to value carer CRQoL relative to patient (or even carer) HRQoL. Such a quantitative weighting is especially important if benefits to both carers and patients are to be valued alongside each other in an economic evaluation**.**

Given the conceptual debate over the relative value of carer and patient HRQoL effects in economic evaluation, and the need for an exchange rate for carer CRQoL and patient HRQoL effects, our aim in this study was to estimate social weights for carer and patient QoL outcomes relative to one another. Specifically, we sought to:

1. Examine whether the public would trade patient quality of life for carer quality of life. This addressed the question of whether there is public support for including carer effects in the objective function for economic evaluation.
2. Quantify the relative value of carer HRQoL compared to that of patient HRQoL. This provides an empirical estimate of weights attached by the general public to carer and patient QALYs.
3. Quantify the value of carer *CRQoL* relative to patient *HRQoL*. This provides a method for comparing care-related quality of life for

carers and health-related quality of life for patients and yields empirical estimates of weights attached by the general public to these outcomes in the two groups.

2. Methods

2.1. Person trade-off methodology

We used a person trade-off (PTO) task (Nord, 1995; Prades, 1997) to quantify the relative value of quality of life gains to carers and patients. PTOs can be used to estimate the value of quality of life gains experienced by different sub-groups (typically patient populations) in society (Nord, 1995; Green et al., 2000; Petrou et al., 2013; Pinto-Prades et al., 2014). They present participants with a trade-off between treating X number of people in situation B and Y number of people in situation A. X or Y is then varied to determine a point of indifference. Our PTO study investigated how society would balance family carers' and patients' quality of life gains. We investigated this by specifying the patient health or carer health gains from different services and varying the sizes of the patient and carer groups to iterate towards a point of indifference. This provided a quantitative estimate of the relative social value of quality of life improvements for the two groups. A key strength of the PTO task is that by mimicking a resource allocation decision it puts the participant in the position of a societal decision-maker (Damschroder et al., 2004). This provided evidence of whether the public would, in principle, sacrifice resources for patients in order to benefit carers.

2.2. The person trade-off task for carer HRQoL vs. patient HRQoL

A screen shot of the PTO task is shown in Fig. 1. The task required participants to imagine they were making decisions that a Health Authority or Local Council might make, choosing between services that improved the quality of life of carers or patients. 'Stick figures' showed the number and role (carers or patients) of individuals affected by services. An arrow and darker shading was used to show the size of the quality of life gain. Prior to the task, participants were led through explanations of resource allocation and measuring quality of life (described by the EQ-5D-5L (Herdman et al., 2011)) on a 0 to 100 scale. The objective here was not to estimate EQ-5D scores but to familiarise participants with the concept of measuring health states on a numerical scale. We conducted public involvement work as part of the survey design process (Al-Janabi et al., 2020), which informed the size of quality of life gains and number of stick figures. The PTO task differentiated 'carers' and 'patients' in writing and graphically. We explained that carer quality of life was limited by factors related to their caring role and patient quality of life was limited by factors related to their illness.

To directly compare preferences for carers and patients, other factors in the task were held constant: patients and carers were both set to age 50; the starting point for HRQoL for carers and patients was 60%; the size of the annual improvement was 20%, and the duration of benefit for the service was 5 years. All that was varied in the main task was the number of carers or patients in each option.

There are a number of characteristics of the QoL gain that could potentially affect the social value placed on carers relative to patients. Following the main PTO task, three factors were explored:

- **Quality of life starting point**: patient HRQoL will typically be worse than carer HRQoL. There is a large body of evidence showing people value quality of life differently depending on the starting point (Gu et al., 2015; Nord and Johansen, 2014). We tested whether reducing the starting point for patient HRQoL to 40%, while maintaining carer starting point for HRQoL at 60% without changing the size of the change in quality of life, affected the degree to which individuals would trade patient for carer quality of life.
- **Age of patient**: patients may be younger or older than their family carers and there is evidence that age affects the social value of quality
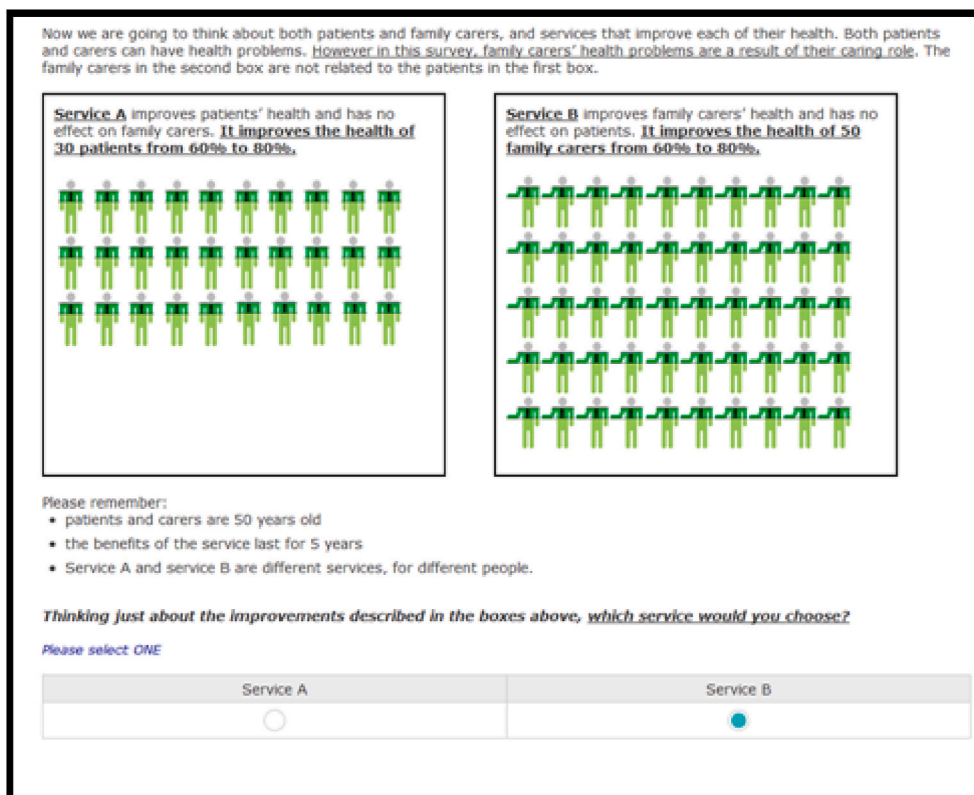
Now we are going to think about both patients and family carers, and services that improve each of their health. Both patients and carers can have health problems. However in this survey, family carers' health problems are a result of their caring role. The family carers in the second box are not related to the patients in the first box.

Service A improves patients' health and has no effect on family carers. **It improves the health of 30 patients from 60% to 80%.**

Service B improves family carers' health and has no effect on patients. **It improves the health of 50 family carers from 60% to 80%.**

Please remember:
- patients and carers are 50 years old
- the benefits of the service last for 5 years
- Service A and service B are different services, for different people.

Thinking just about the improvements described in the boxes above, which service would you choose?

Please select ONE

Service A	Service B
○	●

Fig. 1. Screenshot of the person trade-off task: carer HRQOL vs. patient HRQOL.

of life gains (Gu et al., 2015; Reckers-Droog et al., 2019). We tested whether raising patients' age to 80 or reducing patients' age to 20 while maintaining carer age at 50 affected relative social values.

- **Distribution of benefit**: a service may affect both patient and carer quality of life simultaneously. Carer quality of life gains may be valued less if they are considered a 'spillover' or indirect effect of the impact on the patient (Lippert-Rasmussen and Lauridsen, 2010). We tested whether this was the case by creating a choice that was logically equivalent to the first scenario in the main task by adding a fixed number of carers (10) and patients (60) to both options and halving the benefits on both sides. As a result, a choice was presented between Service A which benefitted 45 patients and 5 carers, and Service B, which benefitted 30 patients and 30 carers. The scenario was rewritten to explain *both* funding options now benefitted a population of patients and *their* carers.

2.3. The person trade-off task for carer CRQoL vs patient HRQoL

Improvements care-related quality of life (CRQoL) may be valued differently relative to improvements in health-related quality of life (HRQoL). This would for instance be the case if participants felt the role of the state or health care sector was to especially improve health rather than 'broader' aspects of wellbeing. Estimating the relative value of carers' CRQoL and patients' HRQoL allows us to estimate an exchange rate between the two conceptually different outcomes in same economic evaluation. To value carer CRQoL against patient HRQoL, the PTO exercise was repeated, with quality of life for carers described in terms of CRQoL. CRQoL was measured using the Carer Experience Scale (Al-Janabi et al., 2011b) which focuses primarily on non-health issues relevant to caring and participants were informed about the concept as described below.

2.4. The online survey

Two versions of the task were created to control for starting point bias (Stålhammar, 1996) and right-left bias. In version 1, individuals initially chose between a service that improved the HRQoL of 50 carers and a service that improved the HRQoL of 30 patients. In version 2, individuals initially chose between a service that improved the HRQoL of 30 carers and a service that improved the HRQoL of 50 patients. Participants were then presented with three follow-up PTO choices based on their prior answers. The follow-up choices were based on the bisection approach (McHugh et al., 2018) to ensure participants iterated to a point of (near) indifference. The bisection approach presented a follow-up choice (choice 2) with half the number of individuals benefitting from the preferred service, while the less preferred service was unchanged. Follow-up choice 3 and follow-up choice 4 continued this process of bisecting the gap between the upper and lower limits (based on previous choices) to iterate towards a point of near indifference between the two services. This allowed a unique equivalence value to be estimated for participant (see Fig. 2). The participants in both versions then completed a PTO task valuing CRQoL with the start points reversed, so that in version 1, participants initially chose between a service that improved the CRQoL of 30 carers and a service that

Choice 1: 50 carers preferred to 30 patients

Choice 2: 25 carers not preferred to 30 patients

Choice 3: 40 carers not preferred to 30 patients

Choice 4: 45 carers not preferred to 30 patients

Equivalence value = 30 / ((45+50)/2) = 0.63

Fig. 2. Example estimation of an equivalence value from hypothetical set of four consecutive PTO choices using the bisection method.

improved the HRQoL of 50 patients. After the CRQOL task, participants in version 1 then returned to a carer HRQoL vs patient HRQoL task and completed follow-up questions with the parameters of HRQoL gains (quality of life starting point; age of patient; distribution of benefit) altered; version 2 omitted these questions as this was not part of the main PTO experiment.

The PTO task was administered as part of an online survey, given the feasibility of collecting a large representative sample of data in this way. A previous comparison of face-to-face and online methods for PTOs found no differences in data quality (Damschroder et al., 2004). Section 1 of the survey collected information about participants' demographic details, health status, and family caring role. Section 2 introduced the patient and carer icons, the PTO task, and an example task. Section 3 presented the main PTO task where participants traded off HRQoL effects for carers and patients. Section 4 presented the second PTO task where participants traded off CRQoL effects for carers with HRQoL effects for patients. In this case the QoL start point, gain, and duration were identical to the previous PTO exercise. CRQoL effects were shaded in blue to differentiate them from HRQoL effects. Section 5 then repeated the first PTO choice from section 3 (50 carers vs. 30 patients) altering a single parameter of the choice each time to study whether these factors (parameters) influenced the relative trade-off between carer and patient QoL gains. The first of these scenarios reduced the starting point for patient QoL from 0.6 to 0.4; the second altered patient age to 80 (while the QoL starting point was reset to 0.6); the third altered patient age to 20; and the fourth presented a scenario with QoL gains distributed to both patients and carers from both services. Section 6 presented questions about social attitudes towards priority setting and funding services for carers. The full experiment is displayed in Appendix 2.

The design of the survey was informed by 'deep piloting' from a lived experience advisory panel (LEAP) of four family carers linked to the wider project (Al-Janabi et al., 2020). The LEAP initially piloted valuation tasks (including variants of the PTO). The lay panel completed a lengthy initial survey with different forms of PTO and discrete choice experiment (DCE) tasks. These were designed to identify the most feasible method for preference elicitation (ultimately an iterative PTO task). This was followed by in-depth focus-group type discussion, a second event with the LEAP completing an online version of the PT, and a third event repeated this task with a lay panel of non-carers. These highlighted the importance of graphical methods, worked examples, and scale and duration of benefit levels that would have face validity. All participants were reimbursed in line with INVOLVE guidelines. The study was reviewed and approved by the University's STEM ethics review committee (ERN_18–0983).

2.5. Survey conduct and analysis

The online survey was completed by participants with and without an unpaid care role in the UK general population. This allowed us to estimate 'societal' preferences for carer quality of life, as well as to examine whether carers and non-carers had distinct preferences. The survey was administered by PureProfile via their UK-wide panel, with a target of 500 current family carers, and 500 individuals not currently providing informal care. Participants were stratified by age and gender to reflect the UK adult population. The survey was administered between March 20th and April 11th, 2019. This included a pilot phase where the full survey was completed by 100 participants. Participants received credits from the survey company for completing the survey which they could exchange for cash.

In total, there were 16 possible pathways in each of the two full PTO tasks (sections 3 and 4 of the survey). Each pathway generated an equivalence value – the number of patients equal to one carer (Appendix 1). Because the choices did not iterate to a point of precise indifference, the equivalence value was set equal to the mean of the range of potential equivalence values for that pathway (Box 1). The range of estimated

equivalence values across versions 1 and 2 of the survey was 0.02–50. For context, an equivalence value of 0.02 implies 50 carers are perceived to equal to 1 patient (i.e. patient quality of life improvements are 50 times as socially valuable as carer quality of life improvements). Conversely, an equivalence value of 50 implies 50 patients are equal to one carer (i.e. carer quality of life improvements are 50 times as socially valuable as patient quality of life improvements). The equivalence value indicates the participant's social value for carer HRQoL (or CRQoL in the second PTO task).

Equivalence values are ratios, so cannot be averaged across a sample to generate 'societal preferences' (McHugh et al., 2018; Pinto-Prades et al., 2014). Instead we used two alternative methods to aggregate individual equivalence values (EVs) to generate societal preferences: ratio of means (the ratio of the sum of numerators across all observed EVs to sum of denominators across all observed EVs) and median of ratios (the median equivalence value observed in the sample) (McHugh et al., 2018). We estimated these values for respondents who were carers and non-carers. We then combined responses across survey versions. To generate a societal weighting, we weighted carer responses by a factor of 0.25 to account for 1 in 8 UK adults having a caring role (as opposed to 1 in 2 in the sample) (Office for National Statistics, 2013). We used chi-squared tests to determine whether the likelihood of selecting the service that benefitted carers was affected by characteristics of the quality of life gain (quality of life starting point; age of patient; distribution of benefit).

3. Results

In total, 1052 participants completed the final PTO experiment, with 495 completing version 1 and 557 completing version 2 of the survey. To ensure balance across versions in the sample, we omitted the final 62 responses from version 2 for the analysis. This left 990 participants split evenly across version 1 and version 2 (Table 1). Individuals completing version 1 of the survey were significantly less likely to prioritise carer quality of life over patient quality of life, compared to those participants who completed version 2 of the survey (12% vs. 34%; p < 0.01). For the remainder of the analysis versions 1 and 2 were combined to counterbalance the starting points for the PTO and minimise systematic bias in relative preferences for carer and patient outcomes.

Across the sample (n = 990), the majority (84%) of participants

Table 1
Characteristics of participants (n = 990) completing the PTO task and included in the analysis (unweighted).

Characteristic	%
Age group	
18 to 30	13%
31 to 50	37%
51 to 65	31%
Over 65	19%
Females	55%
Males	45%
Carers	49%
Non-carers	51%
Care recipient (carer sample only)	
Parent(s)	41%
Spouse/partner	26%
Adult child (ren)	11%
Child (under 18)	6%
Another relative/in law	15%
Other e.g. friend/neighbour	20%
Own health state (measured on VAS):	
0% to 25%	4%
26% to 50%	15%
51% to 75%	26%
76% to 100%	54%

VAS = Visual analogue scale, *where 100% is best health you can imagine and 0% is the worst health you can imagine.*

traded patient and carer quality of life gains. This comprised 42% who preferred patients, 19% who preferred carers, and 22% who made choices consistent with valuing the two equally. For the 16% of participants who did not trade (i.e. never switch from carers to patients, or vice-versa) in the first PTO task, 13% always prioritised patients and 3% always prioritised carers.

3.1. Relative values for carer HRQoL and patient HRQoL

Table 2 shows the distribution of equivalence values for HRQoL (for participant caring status). A larger proportion of carers (25%) compared to non-carers (21%) prioritised carer HRQoL, but this was not significant (p = 0.11).

Following the reweighting of carer responses, the median of ratios (MOR) was 0.75 and the ratio of means (ROM) was 0.74. The ROM uses information of the relative size of all the equivalence values, which the MOR does not, but in this case is almost identical to the MOR value. Both are estimates of the sample equivalence value (i.e. the number of patients = to 1 carer). These figures can be taken to represent social values for carer, relative to patient, HRQoL effects as based on preferences in the general public. Fig. 3 shows the distribution of equivalence values for the societal valuation work (i.e. once carers' equivalence values were reweighted). Almost half of the distribution is in the range 0.5–1 (inclusive of 1). About one in four observations attached equal weight to carer and patient HRQoL gains, while another quarter of the observations implied that carer HRQoL gains carried between half to the full weight of a patient HRQoL gain.

3.2. Factors affecting relative preferences for carer HRQoL vs. patient HRQoL

Table 3 shows the results of the supplementary PTO questions given to half the sample that completed version 1. The age of the patient beneficiaries had a significant impact on preferences with participants more likely to prioritise carers when patient age was increased to 80, and less likely to prioritise carers when patient age was reduced to 20. Expressing carer HRQoL effects as a 'spillover' increased the relative preference for carers, with 60% of the sample prioritising service A (disproportionally benefitting carers and a larger number of individuals) compared with 54% in the original choice. Reducing the starting point (increasing severity) for patient HRQoL gain to 40% did not significantly change the proportion of respondents prioritising carers.

3.3. Values for carer CRQoL and patient HRQoL

Table 4 shows the distribution of equivalence values for CRQoL when the PTO task was re-run comparing carer CRQoL with patient HRQoL. Overall, the distribution of values for carer CRQoL was similar to values for carer HRQoL, with just over half the sample expressing higher values for patients, and around 20% prioritising carers and patients equally (i. e. always selecting the option with higher number of individuals benefitting) and another 20% prioritising carer CRQoL gains higher than patient HRQoL gains. Participants who were carers (as opposed to non-

Table 2
Preferences for carer HRQoL gains: frequency of equivalence values by caring status (n = 990).

Equivalence value (number of patients equal to one carer)	Carers (n = 489)	Non-carers (n = 501)
<0.2	91 (19%)	84 (17%)
0.2 to 0.5	62 (13%)	96 (19%)
0.5 to 1	115 (24%)	96 (19%)
1	100 (20%)	122 (24%)
1 to 2	69 (14%)	66 (13%)
2 to 5	23 (5%)	18 (4%)
>5	29 (6%)	19 (4%)
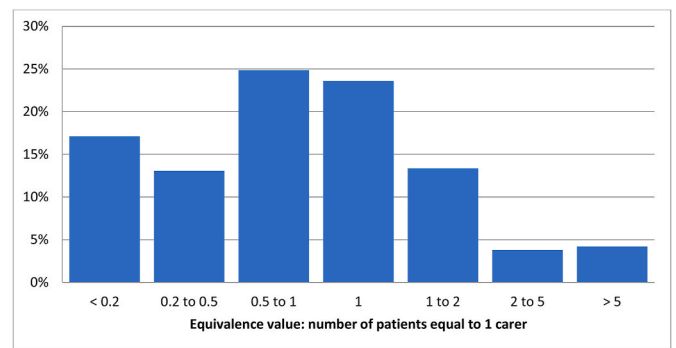
Note: EVs = 0.5 are allocated to the 0.5 to 1 category; EVs = 1 are allocated to the 1 category; EVs = 2 are allocated to the 1 to 2 category.

Fig. 3. Distribution of equivalence values for societal weighting of HRQoL values (n = 990).

Table 3
Influence of *characteristics of quality of life gain* on relative preferences for carer HRQoL vs. patient HRQoL (n = 495).

Parameter changed	Proportion prioritising 50 carers over 30 patients
Basecase (main PTO task)	**267 (54%)**
Patient severity increased (HRQOL reduced to 0.4)	280 (57%) [p = 0.40]
Patient age increased (from 50 to 80)	299 (60%) [p = 0.04]
Patient age decreased (50–20)	229 (46%) [p = 0.02]
Carer effect as spillover (both services benefit patients and their carers)	298 (60%) [p = 0.05]

p-values for difference in proportion prioritising carers from the basecase.

Table 4
Preferences for carer CRQoL and patient HRQoL: frequency of equivalence values by caring status.

Equivalence number (number of patients equal to one carer)	Carers (n = 489)	Non-carers (n = 501)
<0.2	89 (18%)	102 (20%)
0.2 to 0.5	55 (11%)	78 (16%)
0.5 to 1	122 (25%)	131 (26%)
1	95 (19%)	100 (20%)
1 to 2	66 (14%)	48 (10%)
2 to 5	25 (5%)	18 (4%)
>5	33 (7%)	24 (5%)

carers) were more likely to prioritise carer CRQoL gains than patient HRQoL gains (25% vs. 18%; p < 0.01).

Following the reweighting of carer responses, the distribution of equivalence values is shown in Fig. 4. Based on these values, the median of ratios was 0.70 and the ratio of means was 0.69. These figures can be taken to represent societal weights for *carer CRQoL* effects, relative to *patient HRQoL* effects, according to the general public.

4. Discussion

The study provides the first evidence of the relative social value of carer and patient quality of life effects to the general public. Using a person trade off experiment in the UK, we found a sizeable majority of participants (around 84%) traded patient and carer quality of life effects with a larger sub-group who placed more value on patient quality of life and a smaller sub group who placed more value on carer quality of life. Based on the ratio of means, we estimated a central 'social value' of 0.74 for carer *health-related* quality of life effects and 0.69 for carer *care-related* quality of life effects. These are relative to a value of 1 for a unit of patient health-related quality of life. This suggests that a health-related
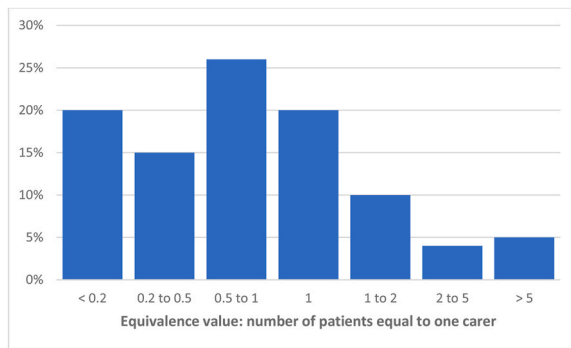
Note: EVs = 0.5 are allocated to the 0.5 to 1 category; EVs = 1 are allocated to the 1 category; EVs = 2 are allocated to the 1 to 2 category.

Fig. 4. Distribution of equivalence values for societal weighting of CRQoL values.

quality of life improvement from 0.6 to 0.8 for 15 patients, would be approximately equal (in social value) to the same (0.6–0.8) quality of life improvement for 20 family carers.

The difference in social value for carers and patients was modest when compared to other studies that have studied social values for different 'types' of quality of life effect. For example, in reviewing the literature on severity, Nord and Johansen (2014) find HRQoL improvements at the top of the scale (i.e. mild health problems) are valued at just one-fifth (0.2) of the same sized improvements at the bottom end of the scale (i.e., more severe end). Comparing values across studies is difficult because of differences in the methods used. However, PTO experiments that value quality of life effects for age groups (Petrou et al., 2013; Reckers-Droog et al., 2019; Baker et al., 2010) and perceived levels of culpability (Singh et al., 2012) also find larger variability in social values relating to characteristics of quality of life gain compared to our study. The most obvious explanation for this is that the individuals overall perceive a relatively similar level of priority for services that benefit patient quality of life and carer quality of life. Furthermore it reflects the finding that a sizeable group in society would prioritise patient quality of life and a slightly smaller group prioritise carer quality of life. Factors such as severity may split samples less in terms of their preferences. Clearly the different study methods employed in preference elicitation studies also has a role, although evidence generally points towards the PTO generating larger differences in social value of characteristics of QoL compared to other methods (Baker et al., 2010).

We also examined the effect of other characteristics of HRQoL on relative preferences, finding that HRQoL for carers was prioritised more when carers were caring for older patients and less when they were caring for younger patients. Our finding that age was negatively associated with social value, even when controlling for the length of the QoL gain, is line with previous research (Gu et al., 2015; Petrou et al., 2013). This seems to reflect the lower priority (on average) the public put on benefits to older people and may reflect, for example, participants' notions about 20 years olds being far short of their 'fair innings' (Williams, 1997; Tsuchiya, 2000) relative to 80 year olds.

The finding that carer QoL appears to be valued more highly when their benefits are expressed as a 'spillover' is surprising because the effects are more distal from the intervention. Hence, one might expect these to attract a lower social value. The PTO where carer effects were expressed as 'spillovers' was arguably more complex than the base-case because participants weighed two services, both benefitting carers *and* patients. As a result, it is possible more participants used a heuristic where they selected the option with the biggest number of beneficiaries. Future research could investigate this. However, on the face of it, this finding strengthens the case for including carers QALYs in economic evaluations, when they are not the direct target of the intervention.

An important finding is that the public were also willing to sacrifice patient HRQoL for carer *CRQoL*. This suggests inclusion of carer CRQOL, as an alternative evaluative space for carers, would also have some empirical legitimacy. Indeed the overall social value for CRQoL effects (0.69) and the distribution of CRQoL equivalence values was quite similar to carer HRQoL effects. The estimate of social value also provides a quantitative weighting for CRQoL effects, estimated using the Carer Experience Scale, in economic evaluation. Based on these results, a movement of 60–80 on the Carer Experience Scale, sustained over a year, would be 'worth' 0.14 (0.69 x (0.8–0.6)) QALYs.[1] It may be interesting to investigate this 'exchange rate' using other methods, especially since the concept of care-related quality of life may be considered to be broader than health-related quality of life (Brouwer et al., 2006) and therefore might have expected to carry more weight. Recently, for instance, a higher monetary value for wellbeing gains (as defined by ICECAP-A) was found compared to health-related QALY scale (Himmler et al., 2020).

This study provides evidence of the social value of carer quality of life effects. There are important implications of this work for the conduct of economic evaluation. First, this study provides empirical support for including carer quality of life effects in economic evaluation. Most participants traded patient and carer quality of life. This adds empirical support to theoretical work (Al-Janabi et al., 2016b) and methods guidance (Hoefman et al., 2013; National Institute for Health and Care Excellence, 2013; Sanders et al., 2016) highlighting the need to include carer effects in economic evaluation in order to properly maximise health or wellbeing from scarce resources. Second, this study provides a potential social value weight for carer HRQoL gains, if a normative position is taken that QALYs are to be weighted by social value. However, we note that the case for societal weighting for carer quality of life, other than equal to patient quality of life, is potentially less strong than for other factors such as severity or age (Petrou et al., 2013; Nord and Johansen, 2014; Reckers-Droog et al., 2019; Baker et al., 2010). Third, this study provides a first estimate of an exchange rate between carer CRQoL effects and carer HRQoL effects. Such an exchange rate offers a starting point for quantitatively comparing outcomes in economic evaluations that include patient HRQoL effects and carer CRQoL effects. Fourth, the study demonstrates the application of PTO methodology to weigh quality of life outcomes for individuals with different roles in the health system (carers and patients), as well as different quality of life concepts (HRQoL and CRQoL).

This is the first study to compare the relative value of carer and patient quality of life—inevitably there are limitations and areas for further development. First, it is notable that the PTO starting point had a large influence on relative preferences for carers and patients. Notably when individuals faced a scenario comparing a larger number of carers to a smaller number of patients, they ended up with lower EVs (and less priority for carers). This is consistent with an interpretation that the (version 1) design primed respondents to think of patient gains as more important than carer gains (i.e. a larger number of carers is equal to a smaller number of patients). However, this creates a design challenge for preference elicitation tasks because we seek a true underlying preference, yet require some initial start point. We sought to minimise bias in the end result by ensuring half the sample were primed equally in the opposite direction, and societal values were based on a combination of the two versions. Second, the experiment is based on a single quality of life gain of 20%, sustained for 5 years. Relative preferences for carers and patients may change if a different magnitude, duration, or direction of quality of life gain was used. Third, the influence of age, starting point and distribution of quality of life effect was only examined through a single PTO question, in each case, given space constraints in the survey.

---

[1] Assuming that 0 on QALY scale equals the 0 'worst health' on our VAS scale. If the worst health state is, for example, −0.5 on a 0 (death) to 1 (full health) scale, then the CES gain is worth 0.69 x (0.8−0.6) x 1.5 = 0.21 QALYs.

Furthermore carer as opposed to patient age could have been varied. Finally, questions about the application of social value weights remain. If we weight carer QALYs for an intervention targeted at patients but 'spilling over' to affect carers, should we also weight carer QALYs when they are the direct recipient of the service? These are important social value judgements that different public bodies may take different views on – the empirical research here can simply inform such judgements.

There are a number of avenues for further work. It would be interesting to see if the findings here are broadly replicated in different contexts, for example in different countries, in different intervention contexts (e.g. when considering social care, public health, or health technologies for example), in specific disease contexts (paediatrics, older people, mental health), and when using different methods, with different quality of life changes (scale, direction). Furthermore, there are a wide array of 'significant others' (Al-Janabi et al., 2016a; Canaway et al., 2019; Brouwer, 2006) affected by healthcare interventions, in the family, household, or social network, and the social value of these outcomes vis-à-vis patient quality of life could also be explored.

In conclusion, public preferences support the inclusion of carer quality of life alongside patient quality of life in the objective function for health and social care decision-making. The results from this study may provide a starting point to include and 'weight' different carer quality of life outcomes in economic evaluation, where such weights are needed and deemed appropriate.

Acknowledgements

Appendix A. Supplementary data

Supplementary data to this article can be found online at https://doi.org/10.1016/j.socscimed.2021.114556.

Credit author statement

Hareth Al-Janabi; Conceptualisation; Methodology; Formal analysis; Writing – original draft; Writing – review & editing; Funding acquisition; Eve Wittenberg; Methodology; Writing – review & editing; Cam Donaldson; Methodology; Writing – review & editing; Werner Brouwer; Methodology; Writing – review & editing.

References

Al-Janabi, H., Flynn, T., Coast, J., 2011a. QALYs and carers. Pharmacoeconomics 29 (12), 1015–1023.

Al-Janabi, H., Flynn, T., Coast, J., 2011b. Estimation of a preference based carer experience scale. Med. Decis. Making 31 (3), 458–468.

Al-Janabi, H., et al., 2016a. Measuring health spillovers for economic evaluation: a case study in meningitis. Health Econ. 25 (12), 1529–1544.

Al-Janabi, H., et al., 2016b. A framework to include family health spillovers in economic evaluation. Med. Decis. Making 36 (2), 176–186.

Al-Janabi, H., et al., 2019. Six mechanisms behind carer wellbeing effects: a qualitative study of healthcare delivery. Soc. Sci. Med. 235, 112382.

Al-Janabi, H., et al., 2020. Patient and Public Involvement (PPI) in Health Economics Methodology Research: Reflections and Recommendations. The Patient, pp. 1–7.

Arksey, H., Moree, M., 2008. Supporting working carers: do policies in England and The Netherlands reflect 'doulia rights'? Health Soc. Care Community 16 (6), 649–657.

Baker, R., et al., 2010. Weighting and valuing quality-adjusted life-years using stated preference methods: preliminary results from the Social Value of a QALY Project. Health Technol. Assess. 14 (27), 1–162.

Bhadhuri, A., et al., 2017. A comparison of the validity and responsiveness of the EQ-5D-5L and SF-6D for measuring health spillovers: a study of the family impact of meningitis. Med. Decis. Making 37 (8), 882–893.

Bobinac, A., et al., 2010. Caring for and caring about: disentangling the caregiving effect and the family effect. J. Health Econ. 29 (4), 549–556.

Bobinac, A., et al., 2011. Health effects in significant others: separating family and caregiving effects. Med. Decis. Making 31 (2), 292–298.

Brouwer, W., 2006. Too important to ignore: informal caregivers and other significant others. Pharmacoeconomics 24 (1), 39–41.

Brouwer, W., et al., 2004. Burden of caregiving: evidence of objective burden, subjective burden, and quality of life impacts on informal caregivers of patients with rheumatoid arthritis. Arthritis Rheum. 51 (4), 570–577.

Brouwer, W., et al., 2006. The CarerQol instrument: a new instrument to measure care-related quality of life of informal caregivers for use in economic evaluations. Qual. Life Res. 15, 1005–1021.

Brouwer, W., Van Exel, J., Tilford, J., 2009. Incorporating caregiver and family effects in economic evaluations of child health. In: Ungar, W. (Ed.), Economic Evaluation in Child Health. Oxford University Press, Oxford, UK, pp. 55–76.

Canaway, A., et al., 2019. Close-person spill-overs in end-of-life care: using hierarchical mapping to identify whose outcomes to include in economic evaluations. Pharmacoeconomics 37 (4), 573–583.

Damschroder, L., et al., 2004. The validity of person tradeoff measurements: randomized trial of computer elicitation versus face-to-face interview. Med. Decis. Making 24 (2), 170–180.

Dixon, P., Round, J., 2019. Caring for carers: positive and normative challenges for future research on carer spillover effects in economic evaluation. Value Health 22 (5), 549–554.

Donaldson, C., et al., 2011. The social value of a QALY: raising the bar or barring the raise? BMC Health Serv. Res. 11 (8).

Drummond, M., et al., 2005. Methods for the Economic Evaluation of Health Care Programmes, third ed. Oxford University Press, Oxford.

Goodrich, K., Kaambwa, B., Al-Janabi, H., 2012. The inclusion of informal care in applied economic evaluation: a review. Value Health 15 (6), 975–981.

Green, C., Brazier, J., Deverill, M., 2000. Valuing health-related quality of life: a review of health state valuation techniques. Pharmacoeconomics 17 (2), 151–165.

Gu, Y., et al., 2015. Attributes and weights in health care priority setting: a systematic review of what counts and to what extent. Soc. Sci. Med. 146, 41–52.

Han, B., Haley, W., 1999. Family caregiving for patients with stroke: review and analysis. Stroke 30, 1478–1485.

Herdman, M., et al., 2011. Development and preliminary testing of the new five-level version of the EQ-5D (EQ-5D-5L). Qual. Life Res. 20, 1727–1736.

Himmler, S., van Exel, J., Brouwer, W., 2020. Estimating the monetary value of health and capability well-being applying the well-being valuation approach. Eur. J. Health Econ. 21 (8), 1235–1244.

Hoefman, R., van Exel, J., Brouwer, W., 2013. How to include informal care in economic evaluations. Pharmacoeconomics 31 (12), 1105–1119.

Krol, M., Papenburg, J., van Exel, J., 2015. Does including informal care in economic evaluations matter? A systematic review of inclusion and impact of informal care in cost-effectiveness studies. Pharmacoeconomics 33 (2), 123–135.

Lancsar, E., et al., 2011. Deriving distributional weights for QALYs through discrete choice experiments. J. Health Econ. 30, 466–478.

Lavelle, T., et al., 2019. Family spillover effects in pediatric cost-utility analyses. Appl. Health Econ. Health Pol. 17 (2), 163–174.

Lefley, H., 1996. Family Caregiving in Mental Illness. Sage, California, US.

Lippert-Rasmussen, K., Lauridsen, S., 2010. Justice and the allocation of healthcare resources: should indirect, non-health effects count? Med. Healthc. Philos. 13 (3), 237–246.

McCabe, C., 2019. Expanding the scope of costs and benefits for economic evaluations in health: some words of caution. Pharmacoeconomics 37 (4), 457–460.

McHugh, N., et al., 2018. Are life-extending treatments for terminal illnesses a special case? Exploring choices and societal viewpoints. Soc. Sci. Med. 198, 61–69.

National Institute for Health and Care Excellence, 2013. Guide to the Methods of Technology Appraisal.

Neumann, P., et al., 2018. Future directions for cost-effectiveness analyses in health and medicine. Med. Decis. Making 38 (7), 767–777.

Nord, E., 1995. The person-trade-off approach to valuing health care programs. Med. Decis. Making 15, 201–208.

Nord, E., Johansen, R., 2014. Concerns for severity in priority setting in health care: a review of trade-off data in preference studies and implications for societal willingness to pay for a QALY. Health Pol. 116 (2), 281–288.

Office for National Statistics, 2013. Census Analysis: Unpaid Care in England and Wales, 2011 comparison with 2001.

Pennington, B., Wong, R., 2019. Modelling Carer Health-Related Quality of Life in NICE Technology Appraisals and Highly Specialised Technologies.

Petrou, S., et al., 2013. A person trade-off study to estimate age-related weights for health gains in economic evaluation. Pharmacoeconomics 31 (10), 893–907.

Pinquart, M., Sorensen, S., 2003. Differences between caregivers and noncaregivers in psychological health and physical health: a meta-analysis. Psychol. Aging 18 (2), 250–267.

Pinto-Prades, J., et al., 2014. Valuing QALYs at the end of life. Soc. Sci. Med. 113, 5–14.

Prades, J.P., 1997. Is the person trade-off a valid method for allocating health care resources? Health Econ. 6, 71–81.

Reckers-Droog, V., Van Exel, N., Brouwer, W., 2018. Looking back and moving forward: on the application of proportional shortfall in healthcare priority setting in The Netherlands. Health Pol. 122 (6), 621–629.

Reckers-Droog, V., van Exel, J., Brouwer, W., 2019. Equity weights for priority setting in healthcare: severity, age, or both? Value Health 22 (12), 1441–1449.

Sanders, G., et al., 2016. Recommendations for conduct, methodological practices, and reporting of cost-effectiveness analyses: second panel on cost-effectiveness in health and medicine. Jama 316 (10), 1093–1103.

Singh, J., et al., 2012. Does responsibility affect the public's valuation of health care interventions? A relative valuation approach to health care safety. Value Health 15 (5), 690–698.

Sörensen, S., et al., 2006. Dementia care: mental health effects, intervention strategies, and clinical implications. Lancet Neurol. 5 (11), 961–973.

Stålhammar, N., 1996. An empirical note on willingness to pay and starting-point bias. Med. Decis. Making 16 (3), 242–247.

Tsuchiya, A., 2000. QALYs and ageism: philosophical theories and age weighting. Health Econ. 9, 57–68.

Tubeuf, S., Saloniki, E., Cottrell, D., 2018. Parental Health Spillover in Cost-Effectiveness Analysis: Evidence from Self-Harming Adolescents in England. PharmacoEconomics, pp. 1–18.

Williams, A., 1997. Intergenerational equity: an exploration of the 'fair-innings' argument. Health Econ. 6, 117–132.

Wittenberg, E., Saada, A., Prosser, L., 2013. How illness affects family members: a qualitative interview survey. The Patient-Patient-Centered Outcomes Research 6 (4), 257–268.

Wittenberg, E., James, L., Prosser, L., 2019. Spillover effects on caregivers' and family members' utility: a systematic review of the literature. Pharmacoeconomics 37 (4), 475–499.