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Estimating an exchange-rate between *care-related* and *health-related* quality of life outcomes for economic evaluation: An application of the wellbeing valuation method

ABSTRACT

Quality of life outcomes for family carers and patients may be measured in different ways within the same economic evaluation. We used the wellbeing valuation method to calculate ‘exchange rates’ between care-related outcomes (the Carer Experience Scale and CarerQoL-7D) and health-related (the EQ-5D-5L) outcomes. Data on quality of life outcomes were collected through a postal quality of life survey in the UK. A random effects model was used to estimate carers’ wellbeing as a function of their EQ-5D-5L, Carer Experience Scale (or CarerQoL-7D) and a set of control variables. When life satisfaction was used as the measure of wellbeing, a one-point gain in the Carer Experience Scale (0 – 100 scale) was equivalent (in wellbeing terms) to a 0.014 gain in EQ-5D-5L value; and a one point gain in the CarerQoL-7D (0 – 100 scale) was equivalent to a 0.033 gain in EQ-5D-5L. The exchange rate values were reduced when capability was used as the measure of wellbeing. The exchange rates estimated in this study offer a means to place carer and patient outcomes, measured via different quality of life instruments, on a common scale, although there are important issues to consider in operationalising the technique.

Keywords: C5 Econometric modelling; D6 Welfare economics; I1 Health; I3 Welfare, wellbeing and poverty

1. INTRODUCTION

Family carer outcomes can be included in cost-utility analysis by estimating carer QALYs generated from an intervention, alongside patient QALYs (Goodrich et al, 2012; Lavelle et al, 2019). The QALYs calculated for carers are typically derived from instruments that capture health-related quality of life (HRQoL) (Guets et al, 2020; Wittenberg et al, 2019), with the EQ-5D being the most widely used of these (Wittenberg et al, 2019). However, carers value attributes other than health; especially since caring has important social and relational dimensions that may be missed by common HRQoL instruments (Al-Janabi et al, 2011a). Preference-based measures, such as the Carer Experience Scale (CES) (Al-Janabi et al, 2008) and the CarerQoL-7D (Brouwer et al, 2006) capture care-related quality of life (CRQoL). Their dimensions include, but are not limited to, concepts such as achievement, fulfilment and control (see Table 1 for an overview). Although CRQoL instruments may be desirable for economic evaluation (Al-Janabi et al, 2011a), their use in economic evaluation means carer outcomes are measured in different units and on different scales relative to patient QALYs.

CRQoL outcomes for carers and HRQoL outcomes for patients could be presented alongside each other in a cost-consequence analysis (Coast 2005). However, this leaves the user to implicitly trade off the outcomes in their decision-making. Additional information on the relative value of the two outcomes is therefore likely to be helpful for the user to make an analytical comparison based on the value of the two outcomes. In this study, we aim to generate an ‘exchange rate’ between CRQoL and HRQoL to make explicit their relative value.

To derive relative values, we apply the wellbeing valuation approach (Van Den Berg and Ferrer-i-Carbonell 2007; Van Den Berg et al 2014; Ferrer-i-Carbonell and van Praag 2002). In general terms, this approach estimates the amount of one aspect of an individual's life (traditionally income) they would need, to be compensated for a loss in another aspect of their life (e.g. health) to maintain a constant level of wellbeing. In the past two decades, the wellbeing valuation approach has become popular to value services that do not have an obvious market value. In the field of health economics, researchers have for instance used the wellbeing valuation method to place a monetary value on informal care time (Van Den Berg and Ferrer-i-Carbonell 2007). This work estimated the amount of income required for a carer to maintain the same level of wellbeing after providing an additional hour of care. A similar study has extended this approach using panel data (Van Den Berg et al, 2014). Further applications include to estimate the monetary valuation of illnesses (Ferrer-i-Carbonell and van Praag 2002; Powdthavee and van den Berg 2011), airport noise (van Praag and Baarsma 2005), crime (Powdthavee 2005), air quality (Luechinger, 2009), commuting time (Stutzer and Frey, 2008) and terrorism (Frey et al, 2009). In the present study, we extend the wellbeing valuation method to use the metric of health (specifically HRQoL), rather than income, to value care-related quality of life changes. We use family carers as the basis of the valuation as they experience both care-related and health-related quality of life.

2. METHODS

In this study we model the carer's wellbeing as a function of their CRQoL and HRQoL. This enables us to calculate the marginal rate of substitution between the two variables in 'producing' wellbeing for the carer. We then draw on the concept of compensating variation (see Figure 1) to estimate the 'compensating health variation'. This is the amount of HRQoL

that the carer needs to compensate them for a loss in CRQoL keeping their general wellbeing constant. This concept is based on the premise that wellbeing is a broad concept and both HRQoL and CRQoL are nested within this.

In Figure 1 indifference curve SWB₂ indicates a higher level of wellbeing than indifference curve SWB₁. Any point on the same indifference curve provides the carer with the same level of wellbeing with different combinations of CRQoL and HRQoL. Consider a carer at point A, they experience a fall in their CRQoL whilst HRQoL remains unchanged (which could be due to a deterioration in health of the care-recipient) bringing them down to point B (which is on the lower indifference curve SWB₁). We can derive the amount of additional HRQoL needed for the carer to bring them back to their original level of wellbeing (SWB₂), i.e. BC.

[Insert Figure 1]

The compensating health variation is calculated based on the marginal impacts of CRQoL and HRQoL on wellbeing. When modelling wellbeing, in addition to the carer's CRQoL and HRQoL, we control for the HRQoL of the care recipient and socio-demographic characteristics of the carer which are known to influence wellbeing. In general terms our model is:

$$WB = f(CRQoL, HRQoL, X) \quad (1)$$

Where WB is a carer's wellbeing, CRQoL is the care-related quality of life, HRQoL is carers' health-related quality of life and X is a vector of control variables. Specifically, for this study, we assume that CRQoL and HRQoL are independently and positively associated with wellbeing. It is based on the premise that we can value CRQoL (relative to HRQoL) by

assessing how the two concepts are implicitly traded off in determining an individual's wellbeing.

Formally the compensating health variation is $-(dWB/dHRQoL)/(dWB/dCRQoL)$

This can also be thought of as the exchange rate between HRQoL and CRQoL

2.1 Empirical analysis

To operationalise the wellbeing model, we used a one-way error component random effects model; this uses both within and between variations in the data to estimate coefficients. The general specification for our model for individual $i=1, \dots, n$ in time $t = 1, \dots, 2$ is:

$$WB = \beta_0 + \beta_1 C_{it} + \beta_2 H_{it} + \beta_3 x'_{it} + \varepsilon_{it} \quad (2)$$

Where WB is wellbeing is measured using either a life satisfaction or capability wellbeing, C is a measure of the CRQoL, H is HRQoL of the carer, the vector X is a set of control variables, and ε_{it} is the error term.

For the random effects model, the one-way error component model with individual specific effects is defined as follows:

$$\varepsilon_{it} = \alpha_i + \mu_{it} \quad (3)$$

α_i is the individual specific effects, assumed to be random across individuals, μ_{it} is the error term for the i_{th} individual at time t . In addition, it is assumed that the individual specific

effects (α_i) are uncorrelated with each explanatory variable. The regression coefficients were estimated with robust standard errors (Cameron and Trivedi, 2010).

The standard econometric approach would be to either use a non-linear ordered probit or logit model. However, Ferrer-i-Carbonell and Frijters (2004) concluded that treating wellbeing as cardinal or ordinal yields similar results when calculating trade-offs. Van den Berg et al. (2007) also tested this notion of assuming cardinality and ordinality in life satisfaction scores using linear and non-linear models. They confirmed that both models yield similar results when calculating trade-offs between variables. Based on this and due to the greater ease of interpretation when calculating the exchange rate, we assume cardinality in the life satisfaction data and apply a linear model. Age-squared was included in the model to control the curvilinear effect of age on SWB, as studies have found a negative relationship between SWB and age but a positive one for age-squared (Blanchflower and Oswald, 2004).

2.2 Data

The data used in the analysis come from a recent UK survey of family carers' quality of life, designed to test the validity of outcome measures (McLoughlin et al, 2020). Participants for the original study were identified from the UK Family Resources Survey across three waves (2013/14, 2014/15 or 2015/16) (Department for Work and Pensions, 2020). Individuals were eligible if they had a recorded caring role, were older than 18, cared for someone over 18, and agreed to be contacted about further research. This resulted in a sample frame of 1004 participants who were approached to take part. The baseline questionnaires were distributed to all eligible participants. Individuals were asked to complete and return the questionnaires within three weeks and given two reminders. The follow up questionnaires were sent to all participants who responded to the baseline questionnaire. The quality of life survey was

designed with this study in mind and included questions about the carer's health and wellbeing, as well as the care recipient's relationship status, living arrangements, gender, age, and clinical conditions; and for the carer: gender, age, education, volunteering, trust, and employment status.

2.3 Key survey variables

Wellbeing can be defined in terms of life satisfaction (Kahnemann and Tversky, 2000) or capability (Sen, 1993) – we use both approaches in this study. We use life satisfaction as the primary measure of wellbeing as it commonly used as the valuation metric in the literature. The life satisfaction of the carer was assessed using a simple visual analogue scale ranging from 0 ('completely dissatisfied') to 10 ('completely satisfied'). For capability wellbeing, used in the alternative models, we used the ICECAP-A capability measure (Al-Janabi et al, 2012). This is designed to capture a person's ability to achieve functioning (i.e. what they can do as opposed to what they actually do) in five key areas of life (see Table 1). A single index score is calculated between (0-'no capability'-1'full capability') (Flynn et al, 2015).

[Table 1]

The health-related quality of life of the carer was measured using the EQ-5D-5L (Herdmann et al, 2011) and valued using the crosswalk index (van Hout et al, 2012; NICE, 2017). The care-related quality of life of the carer was measured using the Carer Experience Scale (CES) (Model 1) and the CarerQoL-7D (Model 2) with life satisfaction as the measure of wellbeing. In the alternative analysis, we use ICECAP-A as the measure of wellbeing with CES (Model 3) and CarerQoL-7D (Model 4) as the measures of CRQoL. The CES includes six dimensions with the aim of measuring the experience of caring. The CarerQoL-7D

instrument consists of seven dimensions, with the aim of measuring the carer's quality of life; it contains dimensions focusing on care-related quality of life (which also include mental and physical health). Both instruments provide a single index score (see Table 1 for an overview of the instruments). In this study, the single index score was calculated by aggregating the utility weights for each level of their attributes using their respective UK derived weighting system. The CES provides an overall score between (0 'bottom state' – 100 'top state') (Al-Janabi et al, 2011b) and CarerQoL-7D (0 'worst' – 100 'best') (Hoefman et al, 2017).

We controlled for key determinants of wellbeing based on factors reported in the literature (Dolan et al, 2008) and subsequent data collected in the survey. The factors controlled for were: HRQoL of the care-recipient and the carer's age, gender, marital status (married to care-recipient), education (degree), employment (paid employment), and trust in others.

We hypothesised that there may be some overlap between the health dimensions in the CarerQoL-7D instrument and the health dimensions in the EQ-5D-5L instrument. We ran additional regressions, one excluding the health dimensions from the CarerQoL-7D and the other regressing the EQ-5D instrument on life satisfaction without either the CarerQoL-7D or the CES instrument. In these regressions, we controlled for the same variables as in the main analysis. The variation inflation factor (VIF) was also calculated to analyse the effect that any overlap between measures had on the regression model coefficients. As the VIF cannot be generated with panel data, an ordinary least squares regression model was fitted the baseline data using the same control variables. Scatter plots were generated to visually show the relationship between key variables of interest and augmented component residual-plus-plots were used to check for non-linearity. An alternative model using a second order polynomial

form of the carer's EQ-5D score was used in the model to reflect a non-linear relationship (i.e. curvilinear) between wellbeing and the EQ-5D-5L. 95% confidence intervals were calculated using the delta method in STATA.

3. RESULTS

576 individuals completed the survey at baseline and 55% (n=318) of these responded to the follow up survey; these 318 constituted the analytic sample. The characteristics of respondents are presented in Table 2.

[Table 2]

Most of the non-response at follow up was due to individuals leaving their caring role, either because the care recipient had died or moved into a care home. Descriptive statistics for the variables of interest are provided in Table 3. The mean baseline scores for included participants were: life satisfaction 6.7, ICECAP-A 0.76, EQ-5D-5L 0.75, CES 62.9 and CarerQoL-7D 72.3. Figure 2 shows the distribution of outcome data and correlations between outcomes at baseline.

[Table 3]

[Figure 2]

The regression results are presented in Table 4. In Model 1, the exchange-rate is estimated between the CES and EQ-5D-5L using life satisfaction as the measure of wellbeing. The coefficients on the variables of interest, the CES and carer's EQ-5D-5L scores, were positive

and statistically significant at the 5% level. Few of the control variables were significant at the 5% level. Model 2, which repeated the analysis using the CarerQoL-7D as the measure of CRQoL, had qualitatively similar results in the sense that the CarerQoL-7D and EQ-5D-5L index scores were positively associated (significant at the 5% level) with wellbeing as expected.

[Table 4]

Models 3 and 4 repeated the regression with the ICECAP-A score as measure of wellbeing. In these analyses, the exchange rate variables (CRQoL and HRQoL scores for the carer), were also positively associated with wellbeing and statistically significant. However, a wider range of control variables were also significant.

In the checks where the CRQoL instrument was dropped from the regression, the coefficient on the carer's EQ-5D-5L was more than twice as large compared to the model that included CarerQoL-7D. (3.97 as opposed to 1.67) but only slightly larger when the CES variable was the CRQoL instrument, (3.97 as opposed to 3.16). When removing the health dimensions from the CarerQoL-7D instrument, the coefficient on the CarerQoL-7D variable was 0.08 and the coefficient on the EQ-5D-5L was 2.98. The CarerQoL-7D and EQ-5D coefficients were statistically significant in all models. When the variation inflation factor was estimated for the CES, CarerQoL-7D and EQ-5D-5L, it was found to be less than 2 for all the models. As a rule of thumb, VIF greater than 5 usually would indicate strong multicollinearity. The augmented component residual-plus-plots did not indicate noticeable deviation from linearity for the CES and CarerQoL-7D for majority of the models. However, there does seem to be some deviation from linearity for both the carer's and care-recipient's EQ-5D-5L.

Transforming the carer's EQ-5D-5L using a second order power does reduce deviation from linearity, although the problem of non-linearity is not completely solved.

The CRQoL and HRQoL coefficients from the main analysis were used to estimate the compensating health variation and thus the 'exchange rate' between the CRQoL measure and the EQ-5D-5L (Table 5). For Model 1, we found that a one point decrease in CES requires an increase in the EQ-5D-5L score by 0.014 points for the carer to remain at their original level of wellbeing. For the CarerQoL-7D, we found that a one-point decrease in CarerQoL-7D requires an increase in the EQ-5D score by 0.033 points for the carer to remain at their original level of wellbeing. Replacing ICECAP-A as the measure of wellbeing, we estimate the exchange rates for the CES to be 0.010 (Model 3) and 0.018 with CarerQoL-7D as the measures of CRQoL (Model 4). The results are shown in Table 5. We found no major effects on the exchange rate from removing the care-recipient's HRQoL from the model.

[Table 5]

The potential application of these exchange rates can be demonstrated with a simple comparison of two intervention strategies, that both impact on patient HRQoL and carer CRQoL. For simplicity, we assume an equal number of carers and patients. Intervention A improves patients' HRQoL (measured using the EQ-5D-5L) from a mean of 0.5 to 0.7 for 1 year; it also improves their family carers' CRQoL (measured using the CES) from a mean of 60 to 65 for 1 year. Intervention B improves patients' mean HRQoL from 0.5 to 0.65; it also improves their family carers' mean CRQoL from 60 to 70 for 1 year. Using the exchange rate estimated through Model 1, we find the intervention A increased CRQoL by the equivalent of 0.07 points (0.014×5) on the EQ-5D-5L, while intervention B increased CRQoL by the

equivalent of 0.14 points (0.014×10) on the EQ-5D-5L. While intervention A generates more patient QALYs than B (0.2 vs. 0.15), intervention B generates more net gain to the patient-carer dyad (0.29 vs. 0.27 QALY ‘equivalents’).

4. DISCUSSION

In this study we addressed the question of how ‘care-related’ quality of life effects can be valued relative to ‘health-related’ quality of life effects. As carers are individuals for whom both concepts are relevant, one method is to see how the two concepts are associated with a broader concept such as wellbeing. Previous studies implementing the subjective wellbeing valuation method in relation to informal care have used the approach to place a monetary value on providing informal care (Van den Berg and Ferrer-i-Carbonell, 2007; Van Den Berg et al, 2014). This paper adds a new perspective of using the wellbeing valuation method to estimate the value of CRQoL in terms of HRQoL. We generated an ‘exchange rate’ between CRQoL and HRQoL that could be used to score CRQoL and HRQoL on a common scale for economic evaluations that capture both outcomes.

The exchange rate of 0.014 for the Carer Experience Scale implies a movement from 90 to the best (100) state is valued at 0.14 ‘EQ-5D-5L equivalent’ points – i.e. the same as a movement from 0.86 to 1 (the best state) on the EQ-5D-5L. The exchange rate of 0.033 for the CarerQoL-7D suggests CRQoL gains are valued to an even higher degree using this measure. The comparatively high weighting of changes in CRQoL may be explained by the fact that CRQoL measures reflect issues of central importance in carers’ wellbeing (e.g. relationships, fulfilment, control). The broadly similar valuation for CRQoL changes relative to HRQoL changes is consistent with the findings of other studies that have compared the

relative value of improvements in (social) care-related quality of life and health-related quality of life (Rowen et al, 2012; Stevens et al, 2018).

To our knowledge this is the first study to use a capability measure as the valuation metric for wellbeing valuation. This was possible because the survey was prospectively designed by the research team. When ICECAP-A was used to assess wellbeing, we estimated a slightly lower exchange rate, a one-point CES gain would be equivalent to a 0.010 EQ-5D-5L gain (or 0.018 for the CarerQoL-7D). We opted for life satisfaction to measure wellbeing in the main analysis due to it being the standard approach for assessing wellbeing in wellbeing valuation studies. As noted in the introduction, we assume that the carer's CRQoL and HRQoL are nested within their wellbeing and the results of this study are consistent with this assumption. We found CRQoL and HRQoL had a consistent strong relationship with wellbeing in expected direction, regardless of the way wellbeing was measured. However, our results do highlight that the measure of wellbeing has an important influence of the quantitative values that result. Specifically we found that the exchange rate was almost halved when capability wellbeing (ICECAP-A) was used as the dependent variable rather than life satisfaction. As the ICECAP-A is a more granular measure of wellbeing (1024 response options vs. 10 on the life satisfaction scale) and designed specially to cover wellbeing in a wide sense, reflecting the importance of health and caring influences on wellbeing, it might offer a particularly suitable metric for wellbeing valuation in the future. However, given the exploratory nature of this study and the predominance of life satisfaction in the literature and in surveys, sensitivity analysis with both approaches, where feasible, may be sensible in the short-term.

We also show that the application of the exchange rate, in a simple empirical example, can switch the conclusion as to what intervention strategy may be considered most beneficial. It is important to note that in an economic evaluation it is the net impact of an intervention on both carer and patient we are interested in if we are measuring and valuing the net increment benefits of an intervention to the population. These effects (on carer and patient) need not be independent of one another and indeed are likely to be correlated. For normative analysis the mechanisms by which the effects occur are not obviously important. So an intervention that improved the carer's CRQoL because it improved the patient's HRQoL would result in benefits that would be aggregated in the same way as an intervention that improved the patient's HRQoL and (independently) improved the carer's CRQoL through, for example, a more favourable timing or location of the intervention.

Given the exploratory use of the wellbeing valuation method, there are some issues worth discussing further. The sample of carers had slightly lower care-related quality of life, compared to community-based samples of carers. The mean CES score was 63 at baseline compared to approximately 71 in a UK community-based sample (Goranitis et al 2014). Similarly the mean CarerQoL-7D score at baseline of 73 was somewhat lower than the mean score (76) recorded in a recent community sample in Hungary (Baji et al, 2021). The lower care-related quality of life scores in our sample perhaps reflected the fact that all individuals had been in a caring role for someone with a chronic condition for several years.

We acknowledge that the models may face a multicollinearity problem as there is clearly some conceptual overlap between the HRQoL and CRQoL instruments. A relationship between the instruments could result in high standard errors in the coefficients and prove problematic when disentangling one effect from the other on wellbeing. The CarerQoL-7D

for instance, includes dimensions relating to mental and physical health with questions phrased as “I have problems with my own physical health” and “I have problems with my own mental health”. Similarly, the EQ-5D-5L has dimensions relating to both physical and mental health. The result from excluding the CarerQoL-7D instrument from the regression suggests that when CarerQoL-7D is the measure of CRQoL, the marginal impact of the carer’s HRQoL on wellbeing is decreased quite markedly. One potential solution may therefore be to exclude the health components from the CarerQoL-7D instruments. We tested this by removing both the mental and physical health dimensions from the CarerQoL-7D and calculating revised CarerQoL-7D utilities. Although the coefficients on both variables (CarerQoL-7D and EQ-5D-5L) were lower, when calculating the trade-off the exchange rate values were similar to those generated from Model 2 and Model 4. As the VIF was less than 5, there was not enough evidence to indicate that either the carer’s EQ-5D-5L variable or CarerQoL-7D variables should be dropped from the regression. The augmented component residual-plus-plots indicated in favour of including a higher power on the carer’s EQ-5D-5L. However, including a higher power on the carer’s EQ-5D-5L is not feasible when the objective is to calculate the trade-off between carer’s EQ-5D-5L and their CRQoL. The estimation of a constant exchange rate is also at odds with the classical depiction of convex indifference curves (in Figure 1) for CRQoL and HRQoL. The use of higher powers for the CRQoL and HRQoL variables and estimation of non-constant exchange rates is an avenue for future research in this area.

Another potential limitation of the analysis is that the exchange rate is based solely on carers’ valuation of health and care-related quality of life (in terms of how these concepts are associated with their wellbeing). This is necessary for practical reasons, as carers are logically the only individuals who experience CRQoL and can thus provide evidence on

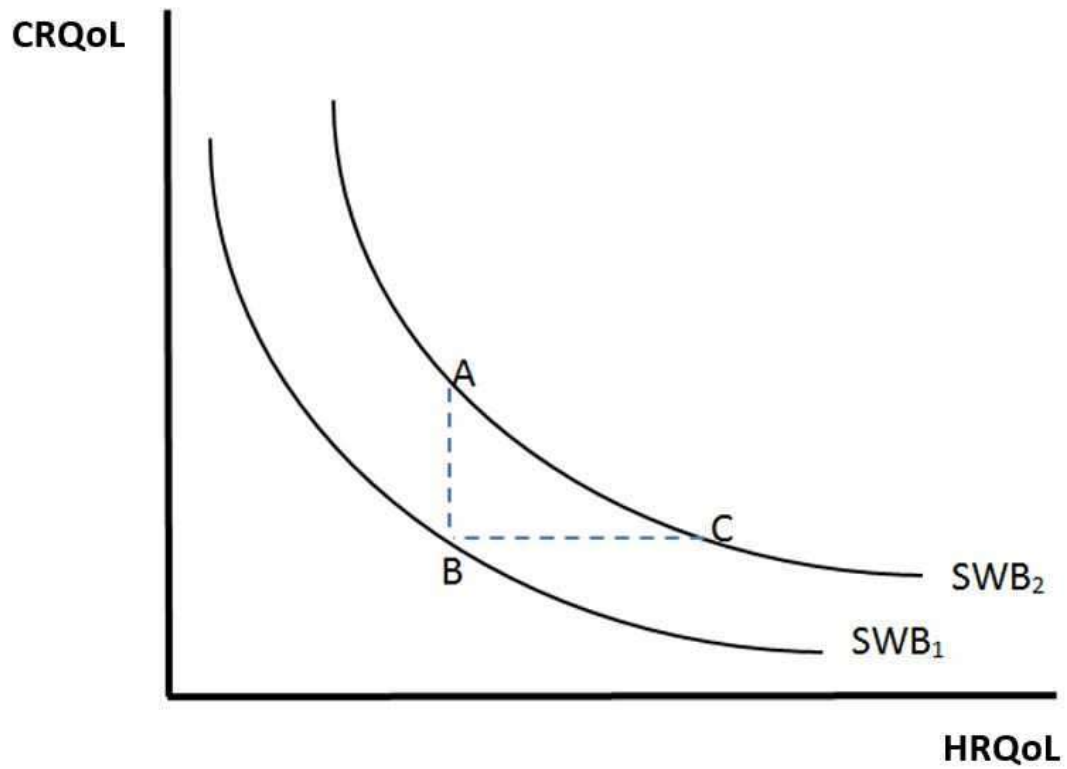
association between CRQoL and wellbeing. However, it does mean the exchange rate is estimated in quite a different context to the context in which it would then be applied. The application of the exchange rate would be to estimate the relative value of CRQoL effects for carers and HRQoL effects for *patients*. Preference based approaches can also be used to estimate exchange rates between different outcomes for economic evaluation (Rowen et al, 2012; Stevens et al 2018). Furthermore, an alternative approach, undertaken as part of the broad research programme (Al-Janabi et al 2020) is to use person trade-off tasks to see how the *general public* weigh CRQoL for carers and HRQoL for patients from a societal perspective.

Despite the exploratory nature of the study, the estimates from this study provide a first estimate of the relative weight of CRQoL and HRQoL outcomes. An advantage of using panel data is that the follow-up data allows us to control for unobservable factors such as personality that may affect wellbeing which are not normally captured in cross-sectional data. In this study we fitted a random effects model to the data. Alternatively a fixed effects model could also have been fitted. However, this approach was not deemed feasible as some of the control variables are time-invariant so would be omitted when carrying out a fixed effects regression.

In conclusion, the exchange rates estimated in this study offer a means for providers and users of economic evaluation to quantitatively compare and aggregate CES or CarerQoL-7D outcomes with EQ-5D-5L outcomes in economic evaluations that include both effects. The wellbeing valuation method offers promise for estimating the relative value of different outcomes for economic evaluation. However more research is needed to address multi-

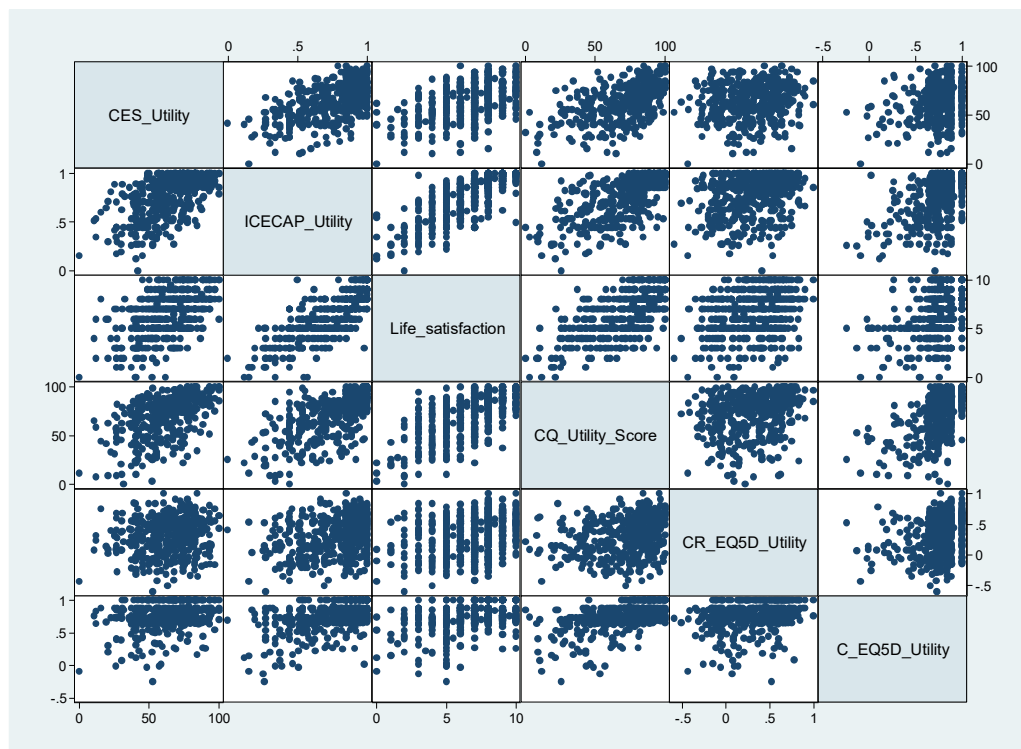
collinearity issues, as well as analysing the normative implications of using wellbeing valuations for outcomes in cost-utility analysis.

Figure 1: Indifference curves for a hypothetical carer, illustrating the compensating health variation (BC) for a loss in CRQoL (AB)



Note: The diagram depicts classical convex indifference curves, which in turn imply a changing marginal rate of substitution between CRQoL and HRQoL

Figure 2: Scatter plots for baseline data on the instrument



Note:

CES_Utility is Carer Experience Scale index score (0 worst caring state through to 100 best caring state)
 ICECAP_Utility is the carer ICECAP-A index score (0 no capability through to 1 full capability across all 5 items)
 Life_satisfaction is self rated life satisfaction on a 0 to 10 scale
 CQ_utility_score is the CarerQoL-7D index score (0 worst caring state through to 100 best caring state)
 CR_EQ-5D-5L_utility is the carer recipient's EQ-5D-5L index score (0 death to 1 full health)
 C_EQ-5D-5L_utility is the carer's EQ-5D-5L index score (0 death to 1 full health)

Table 1. Overview of the instruments used in this study				
Instrument	Number of items	Items	Response levels	Source
EQ-5D-5L	5	Mobility, self-care, usual activities, pain/discomfort, anxiety/depression	5	Herdman et al. (2012)
CES	6	Getting on, organisational assistance, social support, activities, control, and fulfilment.	3	Al-Janabi et al. (2008)
CarerQoL-7D-7D	7	Fulfilment, Relational problems with the care receiver ,Problems with my own mental health, Problems combining my care tasks, Financial problems, Support with carrying out my care tasks, Problems with my own physical health	3	Brouwer et al. (2006)
ICECAP-A	5	Attachment, stability, achievement, enjoyment, autonomy	4	Al-Janabi et al. (2012)
SWB	1	Scale from completely dissatisfied to completely satisfied	10	NA*

*The life satisfaction question was designed specifically for the survey used in this study.

SWB-subjective well-being

CES – Carer Experience Scale

Table 2. Summary descriptive statistics for control variables			
	Baseline (n=576)	Responsive sample at baseline *(n=318)	Follow up (n=318)
Age, years, mean(SD)	62.1 (11.10)	63.7 (10.01)	-
Gender, freq (%)			
Male	202 (36)	116 (36)	-
Female	376 (65)	199 (63)	-
Education, freq (%)			
No degree	356 (62)	192 (60)	-
Degree	201 (35)	117 (37)	-
Employment, freq (%)			
Paid	172 (30)	86 (27)	-
Other	395 (69)	229 (72)	-
Relationship to carer, freq (%)			
Partner/Spouse	199 (35)	120 (38)	-
Other	377 (66)	198 (62)	-
Trust, freq (%)			
Yes	-	-	196 (62)
No	-	-	116 (36)
Volunteer, freq (%)			
Yes	-	-	78 (25)
No	-	-	234 (74)

*Baseline summary statistics of individuals who responded at follow up.

Table 3. Summary descriptive statistics for SWB, EQ-5D-5L, CES, CarerQoL-7D and ICECAP-A			
	Baseline (n=576)	Responsive sample at baseline* (n=318)	Follow up (n=318)
Life satisfaction, mean (SD)	6.74 (2.23)	6.69 (2.31)	6.96 (2.24)
Carer EQ-5D, mean (SD)	0.76 (0.21)	0.75 (0.21)	0.73 (0.23)
CES, mean (SD)	64.7 (18.12)	62.9 (18.8)	65.1 (19.3)
CarerQoL-7D, mean (SD)	73.0(21. 1)	72.4(21.34)	73.9 (20.41)
ICECAP-A	0.77 (0.21)	0.76 (0.22)	0.81 (0.18)
Care recipient EQ-5D	0.32 (0.31)	0.33 (0.31)	0.34 (0.31)

*Baseline summary statistics of individuals who responded at follow up.

Table 4. Regression estimation results for Life satisfaction (Model 1 and Model 2) and ICECAP-A (Model 3 and 4)

Dependent variable: Life satisfaction					
Independent variables :					
	CES (Model 1)			CarerQoL-7D (Model 2)	
	Coefficient	Z-value		Coefficient	Z-value
CES	0.043*	8.62		-	-
CarerQoL-7D	-	-		0.055*	12.63
Carer EQ-5D	3.155*	7.04		1.672*	3.71
Care recipient EQ-5D	0.650*	2.32		0.564*	2.13
Male¹	0.342	1.61		0.163	0.83
Age	0.052	0.74		0.041	0.60
Age Squared	0.000	-0.51		0.000	-0.51
Married to care recipient ²	-0.154	-0.68		-0.151	-0.69
Degree ³:	-0.211	-1.14		-0.046	-0.27
Paid employment ⁴	0.239	1.03		0.081	0.38
Do not Trust ⁵	-0.386	-1.92		-0.381*	-2.14
Intercept	-0.562	-0.25		-0.028	-0.01
Dependent variable: ICECAP-A					
Independent variables:					
	CES (Model 3)			CarerQoL-7D (Model 4)	
CES	0.004*	9.5		-	-
CarerQoL-7D	-	-		0.004*	10.29
Carer EQ-5D	0.367*	10.37		0.244*	6.29
Care recipient EQ-5D	0.038*	1.7		0.035	1.58
Male¹	0	-0.03		-0.003	-0.22
Age	0.004	0.84		0.003	0.6
Age Squared	0	-0.44		0	-0.36
Married to care recipient ²	-0.046*	-2.78		-0.054*	-3.06
Degree ³:	0.022	1.58		0.039*	2.79
Paid employment ⁴	0.012	0.67		0.000	-0.03
Do not Trust ⁵	-0.049*	-3.06		-0.050*	-3.39
Intercept	0.076	0.46		0.17	1.09

*P<0.05

¹ Base case: Female

² Base case: Not a spouse or partner

³ Base case: No Degree

⁴ Base case: All other activities

⁵ Base case: Trust most people

*Removing the care-recipients HRQoL in the regression model.

Table 5. Compensating health variation and the (reciprocal) “exchange rate” calculated for the different scenarios	
	Exchange Rate: CRQoL for HRQoL (per 1 point) [95% CI]
Model 1: Exchange rate between CES and EQ-5D-5L, with LS as wellbeing metric	1 point = 0.014 [0.008,0.018]
Model 2: Exchange rate between CarerQoL 7D and EQ-5D-5L, with LS as wellbeing metric	1 point = 0.033 [0.123,0.053]
Model 3: Exchange rate between CES and EQ-5D-5L, with ICECAP-A as wellbeing metric	1 point = 0.010 [0.007,0.014]
Model 4: Exchange rate between CarerQoL-7D and EQ-5D-5L, with ICECAP-A as wellbeing metric	1 point = 0.018 [0.009,0.026]

Note: Both CRQoL measures (CES and CarerQoL) are on a 0 (worst state) to 100 (best caring state) scale. The HRQoL measure is on a 0 (death) to 1 (full health scale).

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