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Preference-Based Assessments

Unpaid Caring and Health-Related Quality of Life: Longitudinal Analysis of Understanding Society (the UK Household Longitudinal Survey)

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ABSTRACT

Objectives: Decision models for economic evaluation are increasingly including health-related quality of life (HRQoL) for informal/unpaid carers, but these estimates often come from poor quality data and typically rely on cross-sectional analysis. We aimed to identify within-person effects using longitudinal analysis of 13 waves of Understanding Society (the UK Household Longitudinal Survey).

Methods: We analyzed data for coresident carer and care-recipient dyads, where the carer reported "looking after or giving special help to" the care recipient in any of the 13 waves. We used fixed-effects models to study the effects of caring for the care recipient (the "caregiving" effect) using volume of care (hours per week) and continuous duration of caregiving (years) and caring about the care recipient (the "family" effect) using the care recipient's HRQoL on the carer's HRQoL. HRQoL was measured using the Short Form 6 Dimension, calculated from the Short Form 12.

Results: We found consistent evidence for the family effect: improving care recipient's HRQoL by 0.1 would improve carer's HRQoL by approximately 0.012. We also consistently found evidence of a small but statistically significant decrement to carer's HRQoL for each additional year of caring. These findings were robust to scenario analyses. Evidence for the relationship between volume of care and carer's HRQoL was less clear.

Conclusions: We propose that our estimates can be used to populate economic models to predict changes in carers' HRQoL over time and allow disutilities to be estimated separately for the family and caregiving effect.

Keywords: caregiver, carer, family, longitudinal, spillover.

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Highlights

- Much evidence for the relationship between informal/unpaid caring and health-related quality of life (HRQoL) relies on analysis of cross-sectional data, but we identify within-person effects using longitudinal data.
- Carers' HRQoL declines as the duration of caring increases (the "caregiving" effect) and declines as care recipient's HRQoL declines (the "family" effect").
- Our findings can be used in economic evaluations to estimate carers' HRQoL changes from patient HRQoL changes and caring duration.

Introduction

There is an increasing interest in measuring and valuing the health-related quality of life (HRQoL) of unpaid or informal carers/caregivers, who are typically the close family and friends who look after other people in ill health.[1,2] Capturing carers' HRQoL is important in its own right for understanding whether this group of people experience worse health and well-being than people who are not carers and whether specific interventions and policies can be tailored to address this. It is also of interest when considering the spillover effects of interventions targeted at patients who may have carers, particularly where carers' HRQoL effects may be included in economic evaluation for health technology assessment.

Bobinac et al[3,4] analyzed carers' outcomes (subjective well-being using a happiness scale in 2010 and health status measured by EuroQoL visual analog scale in 2011) as a function of the amount of care provided (termed "the caregiving effect" or "caring for") and the health of the care recipient (termed "the family effect" or "caring about" because people care about other people such as family members and their health). The distinction between these 2 effects is important when considering how to improve carers' outcomes: if the caregiving effect is negative (increasing the amount of care that the carer provides results in worse outcomes for the carer), then this could be relieved by substituting unpaid care with formal care. If the family effect is positive, then, all else being equal, carer's outcomes would be expected to improve when the care recipient's outcomes improved (a spillover effect of interventions for the care recipients). We hypothesize that the same concepts of caring for and caring about would apply in carer's HRQoL. This framework may be useful in distinguishing between (1) the family effect that may apply for all health conditions and (2) the caregiving effect that may apply only to conditions where a household member acts as an unpaid carer.

Data on carers' HRQoL are typically gathered at only one point in time (eg, a survey at one time point) and, therefore, analyzed cross-sectionally. Although such analyses may identify a correlation between caring and HRQoL at a given time point, they have been applied in economic evaluations over multiple time points, where the intention is to represent changes in patients' and carers' HRQoL over time. The longitudinal use of a crosssection estimate may introduce bias. Although there is a body of evidence studying the effects of caring on health using panel data,[5-7] evidence for HRQoL is much more limited: existing studies that have considered longitudinal data for carers' HRQoL have been restricted to only 2 time points,[8,9] whereas longer-term data on the health effects of caring suggest there may be differences between the initial onset and continued caregiving.[10] We aimed to deepen our understanding of the relationship between informal caring and HRQoL and, in doing so, provide HRQoL estimates that can be used to populate economic evaluations/cost-effectiveness models where the effect of caring may change over time.[11] We estimated fixed-effects models to analyze the within-person effects of caregiving using data from up to 13 years of Understanding Society (the UK Household Longitudinal Survey [UKHLS]).

Methods

Data

UKHLS is a longitudinal survey of approximately 40 000 households (when the survey started in 2009-2011) who are surveyed annually to collect information on households and individuals.[12] Thirteen waves of data are now available. Respondents aged 16 years or older complete the adult survey, which contains modules related to health, education, employment, income, and family. The survey also collects demographic information.

There is a caring module that asks respondents (among other questions):

1. Is there anyone living with you who is sick, disabled, or elderly whom you look after or give special help to (eg, a sick, disabled, or elderly relative; husband; wife; or friend)? (Yes, no, don't know, refuse to answer)
2. Do you provide some regular service or help for any sick, disabled, or elderly person not living with you? (Yes, no, don't know, refuse to answer)
3. Now thinking about everyone who you look after or provide help for, both those living with you and not living with you, in total, how many hours do you spend each week looking after or helping them? (0-4, 5-9, 10-19, 20-34, 35-49, 50-99, 100 more/continuous care, varies less than 20, varies 20 or more, other, don't know, refuse to answer)

We defined carers as people who answered "Yes" to question 1 above at any wave of UKHLS. Respondents who answer "Yes" to question 1 are asked which household member they provide care for, so we were able to link the data files for the carer and person they cared for to create a unique carer and care-recipient dyad (we exclude people who cared for multiple people in scenario analysis). We included data on the care recipient and the carer in each dyad from all waves in which it was available for both respondents, including those waves where the carer answered that they did not look after or provide special help to the care recipient. Therefore, we could consider within-person comparisons for people who would become or have been within-household carers. This was important for addressing selection into caregiving (people who become carers may differ systematically from people who do not) and allowed us to identify the effect of caring on carers, as opposed to comparing the HRQoL of people who are and are not carers, which may be subject to bias. Some carers look after people outside the household, and in these cases, it is not possible to create dyads for these outside-household carers.

Empirical Approach

Our model specification is based on those considered by Bobinac et al,[3,4] but is the first (to our knowledge) to use longitudinal data. We use fixed effects to identify within-person changes in intensity and duration of care and the changes in the HRQoL of the person cared for. This allows us to consider transitions between different care intensities (including starting and stopping caring) and to model carers' HRQoL as a function of care recipient's HRQoL.

We consider fixed-effects transformations, with the original unobserved effects models for individuals $i = 1, \ldots, n$ in wave $= 1, \ldots, 13$:

$$H_{it} = \beta_0 + \beta_1 C_{it} + \beta_2 D_{it} + \beta_3 P_{it} + \beta_4 x_{it} + \mu_i + \epsilon_{it}$$

Where H is the carer's HRQoL, C is the weekly volume of care, D is the duration of caring, P is the care recipient's HRQoL, x is a vector of observable carer (and care recipient) characteristics, $\beta_1 \ldots \beta_4$ are the coefficients, μ_i is the time-invariant individual-specific effect, and ϵ is the error term. β_1 and β_2 represent the caregiving effect and β_3 the family effect. C is a categorical variable with 4 levels (not caring [baseline], low-, medium-, or high-volume care), and D is zero when the carer is not providing care. The carer and cared-for characteristics are included for all observations, including those where the carer is not currently caring.

We hypothesize that β_1 and β_2 will be negative (carers will have lower HRQoL when they care for a longer duration or at a higher intensity) and that β_3 will be positive (carers' HRQoL will worsen when the HRQoL of the person they care for worsens).

We performed scenario analyses using alternative model specifications to check the robustness of the findings, including considering only the volume and/or duration of care, considering only the care recipient's HRQoL, and considering an interaction between these.

Variables

Carer's HRQoL

The UKHLS includes the Short Form 12 (SF-12) version 2 questionnaire in every wave for adults. We converted this into a Short Form 6 Dimension (SF-6D) index score to give a utility anchored between 0 (equivalent to death) and 1 (full health).[13] This is a measure of HRQoL that can be used in economic evaluations. We also considered as outcome variables the domains of SF-12 that are used in calculating the SF-6D (role functioning, physical health, mental health, pain, energy, feeling downhearted/depressed, and social functioning), to understand which aspects of HRQoL are affected by caring.

Volume of care

Using the response to the question "Now thinking about everyone who you look after …in total, how many hours do you spend each week looking after or helping them?", we categorized the weekly amount of care into 3 levels: low volume (less than 10 hours per week), medium volume (10-19 hours per week), and high volume (20 or more hours per week).[14] These categorizations have been used previously,[7] allowed us to use almost all of the available responses (people who reported hours varying more than 20 were included as high volume but the 6% of observations where people reported hours varying less than 20 were excluded because we could not determine whether they provided less or more than 10 hours per week), and avoided issues associated with small sample sizes within some categories (n = 120 for 50-99 hours per week). These volumes also reflected positive and negative trends shown when considering of the reported categories separately.

The threshold of 20 hours per week has been commonly used in analyzing the effect of caring[15,16] and in some cases 50 hours per week has also been used.[17] We considered dichotomous categories using these thresholds in scenario analysis and a model in which carers are classified as pre-, current, or past carers. Although using the reported categories would have increased granularity, there are recognized issues with self-reported care hours at the extreme values: carers tended to under-report the time they spent caring (compared with the care recipient's reporting) at very low volumes and over-report at very high volumes.[18]

This variable reflects the volume of care provided within and outside the household given that we are unable to determine the volume within household only. Therefore, we considered a scenario analysis in which we excluded carers who additionally cared outside of the household.

Duration of care

We additionally considered the duration of caring, to reflect either the "adaptation" effect where the impact of caring on HRQoL is greatest in the early stages[19] or the "wear and tear" effect in which the impact accumulates over time.[20,21] We used continuous years of within-household caring in the main analyses and total years of within- or outside-household caring in scenario analyses (total years caring accumulates over time and does not reset to zero when the carer stops caring). We included a squared term for duration, to allow the relationship between duration of care and HRQoL to vary over time (eg, an adaptation effect). We recognize the possibility that some carers may have initially start a caring spell outside of the household before the cared-for person becoming coresident (eg, an elderly parent moving in with an adult child), and so we consider a scenario comprising exclusively spousal carers, where this is likely to be less common. We also considered a scenario excluding people who were carers at the first observation (initial carers).

Care recipient's HRQoL

We used the same measure for care recipients' HRQoL as for carers (SF-6D index score).

Other variables

We included carer demographic variables that have been included in previous analyses and change over time for each person: age (and age squared to permit a nonlinear relationship between age and HRQoL), household monthly Organisation for Economic Co-operation and Development equivalized household income after taxes (on the log scale to allow for a nonlinear effect), and number of people within the household. We included a dummy variable for whether the carer also provided care outside the household and a dummy variable for waves that may potentially be affected by COVID-19 (waves 10 onward). We were unable to include formal care given that the modules that ask about formal care are only provided to a subset of the sample at waves 7, 9, 11, and 13. We instead explored the relationship between formal care and other variables in scenario analyses. We excluded employment from our analysis given the endogeneity between employment and caring. We considered a scenario of exclusively retired carers to exclude potential employment effects.

We considered scenarios excluding carers who cared for multiple people and excluding carers who were also cared for. We considered specific care recipient and carer health conditions and difficulties in scenario analyses.

Weights

We used weights to adjust the UKHLS sample to make it more reflective of the UK population. We used the longitudinal self-completion interview weights, using the latest wave from which data were available for each carer.[22]

Ethics Approval

The University of Sheffield approved the ethics application 039725.

Public Involvement

We organized a workshop with 8 people who were or had been carers (recruited via an advert on People in Research), to better understand their experience and to contextualize our results. We presented our analysis and discussed how people's experience of caring had affected their HRQoL (positively and negatively) and issues around variables relating to the volume and duration of care.

Results

A summary of characteristics for carers (and the person they care for) by whether they are actively caring or not, over all time points, is presented in Table 1. Carers have lower SF-6D index scores than noncarers (not statistically significant) but almost every other characteristic is different too, demonstrating the need to adjust for these in trying to isolate a causal effect of caring.

Respondents were included for a mean of 8.52 waves (SD 3.72).

Results of the fixed-effects models for carers' SF-6D index score, using "caring for" and "caring about", each effect on its own, and an interaction are presented in Table 2. Consistent with our hypothesis, we found that increased duration of care negatively affected HRQoL: duration of care (measured using continuous years of within-household care) is always statistically significant, negative, and a similar size in all models, suggesting that HRQoL decreases annually by a mean of 0.045 as duration of caring increases (the squared term is small and nonsignificant). The relationship between volume of care and HRQoL is less clear: carers providing medium or sometimes high volume care seem to have better HRQoL than those providing less, but this is not always statistically significant and any HRQoL benefit from caring would be cancelled out by the negative effect of care duration within 2 years. Consistent with our hypothesis, we found a positive relationship between carer and care-recipient HRQoL: the coefficient for the family effect is similar across models where the caregiving effect is or is not included and the interaction between the caregiving and family effect is not statistically significant. The coefficient for care-recipient SF-6D index score is approximately 0.12 and significant in all models: improving care-recipient SF-6D index score by 0.1 would improve carer SF-6D index score by approximately 0.012.

Figure 1 presents the margins from the fixed-effects model for caring for and caring about and demonstrates the relationship between carer's SF-6D index score, care recipient's SF-6D index score, caring volume and duration of care.

The results of a fixed effects ordered logit model for the domains of the SF-12 that are used in calculating the SF-6D index score, for the base case model (note that the number of observations here differs to that of the fixed-effects regression model for the SF-6D index score), are presented in Table 3.[23]

An increased duration of caring is statistically significantly associated with worsening physical health, mental health, and social functioning. Worse care-recipient HRQoL is statistically

Table 1. Summary of characteristics.

Variable	Caring			
	Not caring	Caring	Total	Test
n (%)	4465 (80.6)	1072 (19.4)	5537 (100.0)	
Carer's SF-6D	0.763 (0.137)	0.747 (0.134)	0.760 (0.137)	0.009
Carer's age	56.527 (17.551)	52.509 (19.531)	55.749 (18.019)	< 0.001
Proportion of male carers	0.469 (0.499)	0.503 (0.500)	0.476 (0.499)	0.120
Proportion of employed carers	0.425 (0.494)	0.398 (0.490)	0.420 (0.494)	0.210
Proportion of retired carers	0.396 (0.489)	0.330 (0.471)	0.383 (0.486)	< 0.001
Proportion of carers married	0.863 (0.344)	0.823 (0.382)	0.855 (0.352)	0.018
Caring for: duration. Continuous years caring	0.000 (0.000)	1.527 (1.316)	0.295 (0.836)	< 0.001
Household size	2.780 (1.287)	3.253 (1.492)	2.872 (1.342)	< 0.001
Log of household income	7.189 (0.559)	7.151 (0.564)	7.182 (0.560)	0.089
Care recipient's SF6D	0.739 (0.136)	0.669 (0.148)	0.726 (0.141)	< 0.001
Care recipient's age	56.010 (18.231)	52.515 (20.884)	55.333 (18.822)	< 0.001
Proportion of male patients	0.465 (0.499)	0.498 (0.500)	0.472 (0.499)	0.133

Note. Table presents mean and standard error for all rows except n (%). Test refers to *t* test for comparison of means.
SF6D indicates short form 6 dimension.

significant associated with worse mental health, pain, energy, feeling depressed/downhearted, and social functioning. (Note that the order of the pain and vitality responses are in the opposite direction to the other domains.) Marginal effects are presented in the Table S1 of Appendix 1 in Supplemental Material found at https://doi.org/10.1016/j.jval.2024.08.004.

Alternative model specifications using a dichotomous 20 or 50 hours per week threshold (as well as duration) and a model in which carers are simply classified as pre-, current, or past carers are presented in Table 4. Using either 20- or 50-hour thresholds, carers providing more care have numerically higher HRQoL, but any HRQoL gain from caring is lost within 2 years of caring given that the coefficient for duration of care remains significant, negative, and similar to the models in Table 2. Current carers have statistically significantly better HRQoL than pre- or past carers when duration of care is considered, but this is cancelled out within 1 year of caring. When care duration is excluded, current and past carers show a trend for worse HRQoL than precarers, but this is not statistically significant.

The results of scenario analyses for different populations are presented in Table 5: findings are robust to scenarios excluding people who care for more than 1 person, excluding carers whose care-recipients also reported providing care for the carer, and excluding people who also care outside the household. In the population of retired carers, the duration of care effect is not statistically significant, likely due to the reduced sample size. The duration of care effect is not statistically significant for only spousal carers. It is possible that spouses identify as carers later than other relationships (married people are more likely to identify as carers using time diaries than self-declaration,[24] and it is recognized that people may take at least a year to identify themselves as carers[25]) and so reported duration of care is shorter than in other populations. In the scenario excluding the 18.24% of respondents who were carers at their first observation, the coefficients for care duration and the family effect decreased but were still statistically significant.

We further explored the effect of care duration by including lagged variables for carer status in the 2 previous years, which did not affect the family effect, and by including initial HRQoL in a regression analysis, which was statistically significant (Tables 2 and 3 in Supplemental Material found at https://doi.org/10.1016/j.jval.2024.08.004). We also considered a scenario in which carers actually began caring the year before they reported caring, because it is recognized that carers often do not immediately identify as carers[25] (Appendix Table 4 in Supplemental Material found at https://doi.org/10.1016/j.jval.2024.08.004). In this analysis, the coefficient for duration of care was statistically significant but slightly smaller (as expected), and the family coefficient was almost unchanged. We also considered models using total years caring within and outside the household rather than continuous years caring within the household, which was statistically significant but slightly smaller than continuous years (Appendix Table 4 in Supplemental Material found at https://doi.org/10.1016/j.jval.2024.08.004).

We further explored the family effect by considering separately the cared-for populations who did and did not report an illness and found the family effect was statistically significant and similar in both (Appendix Table 5 in Supplemental Material found at https://doi.org/10.1016/j.jval.2024.08.004).

We explored the potential role of formal care, using data from waves 7, 9, 11, and 13. We found no statistically significant differences in care recipient's or carer's HRQoL where care recipients received formal care (see Appendix in Supplemental Material found at https://doi.org/10.1016/j.jval.2024.08.004).

Discussion

Main Findings

Our finding of a negative coefficient for caring duration suggests that the effect of caring increases over time. Attendees at our public involvement workshop generally agreed that HRQoL worsened as duration of care increased. This, combined with results of scenario analyses including lagged or initial HRQoL scores, may support the consideration of dynamic models in future analyses.

Table 2. SF6D: caring for, about, and interaction.

Variable	For and about	For	For (duration only)	For (volume only)	About	For-about interaction
Caring for: low volume	0.032*	0.016		−0.021*		−0.000
	(0.016)	(0.012)		(0.008)		(0.036)
Caring for: medium volume	0.077*	0.052*		0.014		0.048
	(0.018)	(0.016)		(0.011)		(0.032)
Caring for: high volume	0.058*	0.032*		−0.007		0.027
	(0.019)	(0.015)		(0.007)		(0.033)
Caring for: duration. Continuous years caring	−0.045*	−0.035*	−0.010*			−0.047*
	(0.015)	(0.011)	(0.005)			(0.015)
Caring for: duration. Continuous years caring squared	0.003	0.002	−0.001			0.003
	(0.002)	(0.001)	(0.001)			(0.001)
Carer’s age/10	−0.016	−0.024	−0.028	−0.032	0.003	−0.014
	(0.080)	(0.028)	(0.028)	(0.029)	(0.078)	(0.080)
Carer’s age/10 squared	−0.003	−0.002	−0.002	−0.001	−0.002	−0.003
	(0.004)	(0.002)	(0.002)	(0.002)	(0.004)	(0.004)
Also caring outside household = 1	0.004	0.002	0.005	0.004	0.006	0.004
	(0.006)	(0.006)	(0.006)	(0.007)	(0.007)	(0.006)
Caring about. Care recipient’s SF-6D	0.123*				0.109*	0.114*
	(0.023)				(0.024)	(0.023)
Care recipient’s age/10	0.015				−0.019	0.014
	(0.075)				(0.076)	(0.075)
Care recipient’s age/10 squared	−0.000				−0.000	−0.001
	(0.003)				(0.003)	(0.003)
Covid wave = 1	−0.002	−0.000	0.001	0.001	0.000	−0.002
	(0.007)	(0.007)	(0.007)	(0.007)	(0.007)	(0.007)
Log of household income	0.011	0.009	0.010	0.007	0.010	0.011
	(0.007)	(0.007)	(0.006)	(0.007)	(0.006)	(0.007)
Household size	0.005	0.004	0.005	0.004	0.005	0.005
	(0.005)	(0.004)	(0.004)	(0.004)	(0.004)	(0.005)
Cared for Care recipient’s SF6D						0.049
Constant	0.706*	0.887*	0.887*	0.923*	0.764*	0.710*
	(0.104)	(0.098)	(0.096)	(0.103)	(0.104)	(0.105)
Observations	5124	5698	5878	5698	5283	5124

SF6D indicates short-form 6 dimension.
Standard errors in parentheses.
*$P < .05$.

Comparison With Other Literature

Our results are consistent with previous analyses that found carers have worse HRQoL than noncarers (and our effect sizes for the family effect are within the range identified by Bobinac et al[3,4]). In contrast with Al-Janabi et al, we found it was possible to predict carer’s HRQoL changes from care-recipient data and information on caring time.[8] We also found that the SF-6D index score for carers was significantly associated with changes in care recipient’s HRQoL, in contrast to Bhadhuri et al[9] who found that although EQ-5D index scores detected an effect, SF-6D index scores did not (although we note they used a different version of SF-6D: the SF-6D [SF-36]).

Implications

We propose that our estimates of carers’ HRQoL could be included in economic evaluations to represent spillovers and to separately consider the family effect (if considered relevant, noting that some guidance recommends excluding this[26]) and caregiving effect (composed of both volume and duration of care). For example, considering only the caregiving effect, carers providing 0 to 9 hours of care in the first year of caring would have a mean disutility (utility loss) of 0.013 (0.045-0.032). If the volume of care increased to 20+ hours in the fourth year of caring, the mean disutility would increase to 0.122 ($4 \times 0.045 - 0.058$) in that year. Disutilities for caring in the literature range from

Figure 1. Predictive margins of care volumes by duration of care.

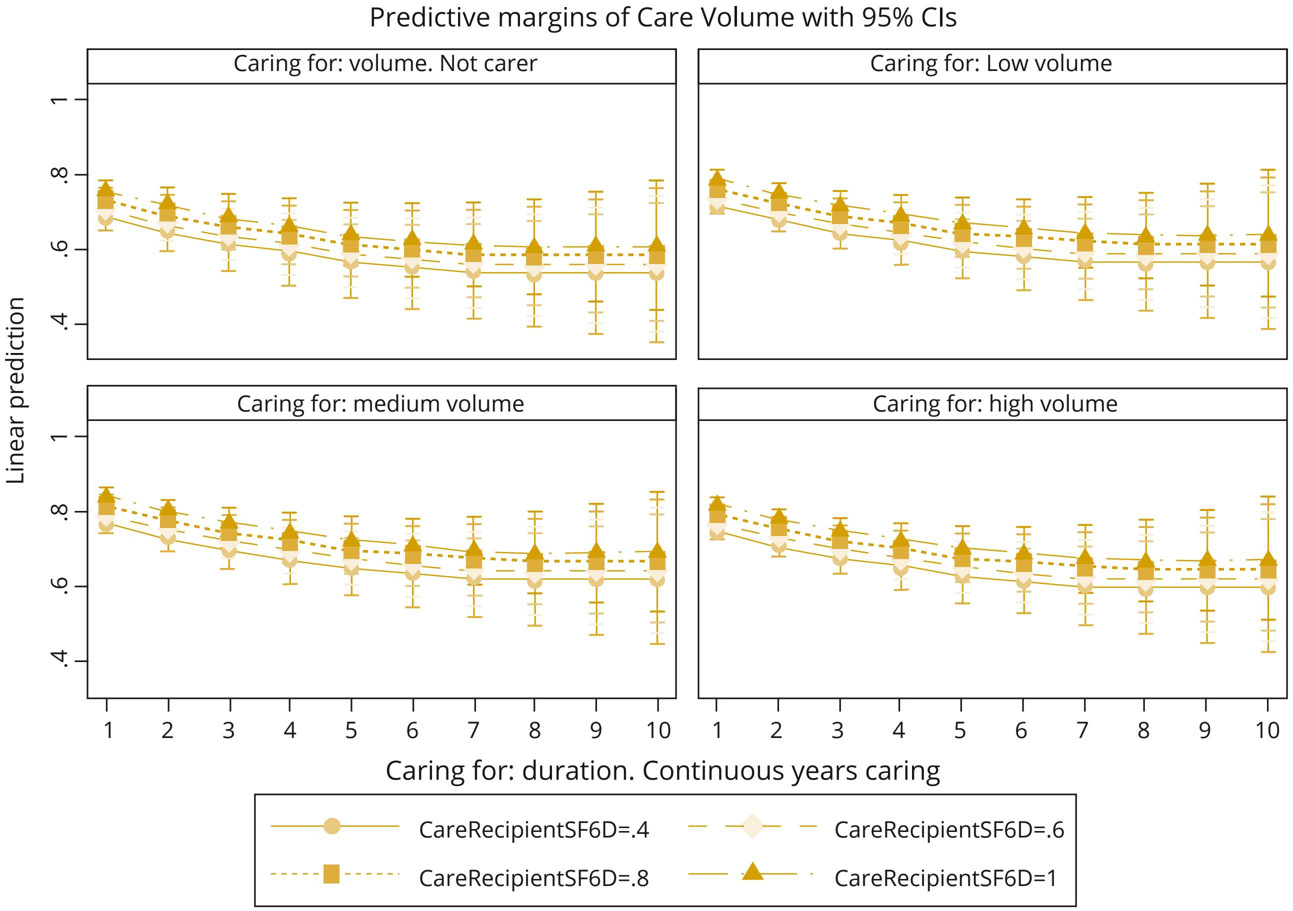

Table 3. SF6D domains fixed effects ordered logit model.

Variable	SF2a RF	SF3b PH	SF4a MH	SF5 P	SF6b E	SF6c D	SF7 SF
Caring for: low volume	0.368	1.026*	1.346*	−0.676	1.000*	0.546	0.701
Caring for: medium volume	1.280*	1.286*	1.319*	−1.746*	0.811	0.548	1.412*
Caring for: high volume	0.560	1.084*	1.520*	−0.980	0.284	0.844	1.115*
Caring for: duration. Continuous years caring	−0.285	−1.040*	−1.102*	1.067	−0.782	−0.427	−0.960*
Caring for: duration. Continuous years caring squared	−0.012	0.081*	0.104*	−0.148	0.117*	−0.000	0.068
Carer’s age/10	0.484	−2.302	−5.159*	−0.624	−1.202	−1.529	−4.166
Carer’s age/10 squared	−0.017	0.048	0.149	0.038	0.101	0.001	−0.001
Also caring outside household = 1	0.085	0.117	−0.056	−0.219	−0.109	−0.059	0.177
Caring about. Care-recipient’s SF-6D	1.037	0.770	2.111*	−0.960*	−1.445*	2.492*	2.316*
Care-recipient’s age/10	−1.417	2.011	4.788*	2.148	2.144	2.018	4.461
Care-recipient’s age/10 squared	−0.061	−0.157	−0.221*	−0.112	−0.088	−0.066	−0.128
Covid wave = 1	0.596*	0.060	0.013	0.137	−0.159	−0.042	0.310
Log of household income	0.248	0.172	0.249	−0.252	−0.172	0.273	0.143
Household size	0.027	−0.118	−0.030	−0.071	0.244	0.131	0.001
Observations	4425	8735	8772	9120	8523	8545	8748

D indicates depression; E, energy; MH, mental health; P, pain; PH, physical health; RF, role functioning; SF, social functioning.
*$P < .05$.

Table 4. SF6D: different care volumes.

Variable	20 hours	50 hours	Pre/ current/ past	Pre/ current/ past without duration
Less than 20 hrs/week	0.041*			
	(0.016)			
20+ hrs/week	0.054*			
	(0.020)			
Caring for: duration. Continuous years caring	−0.042*	−0.042*	−0.041*	
	(0.015)	(0.015)	(0.015)	
Caring for: duration. Continuous years caring squared	0.002	0.002	0.002	
	(0.002)	(0.002)	(0.002)	
Carer's age/10	−0.012	−0.013	0.006	0.036
	(0.080)	(0.082)	(0.081)	(0.081)
Carer's age/10 squared	−0.003	−0.002	−0.003	−0.003
	(0.004)	(0.004)	(0.004)	(0.004)
Also caring outside household = 1	0.003	0.003	0.001	0.003
	(0.006)	(0.006)	(0.007)	(0.008)
Caring about. Care recipient's SF-6D	0.115*	0.119*	0.111*	0.107*
	(0.023)	(0.024)	(0.024)	(0.025)
Care recipient's age/10	0.012	0.012	−0.010	−0.055
	(0.075)	(0.077)	(0.076)	(0.080)
Care recipient's age/10 squared	−0.001	−0.001	0.000	0.002
	(0.003)	(0.003)	(0.003)	(0.003)
Covid wave = 1	−0.001	−0.002	−0.003	−0.001
	(0.007)	(0.007)	(0.007)	(0.008)
Log of household income	0.010	0.010	0.009	0.008
	(0.007)	(0.007)	(0.007)	(0.007)
Household size	0.005	0.006	0.004	0.003
	(0.005)	(0.005)	(0.005)	(0.005)
Less than 50 hrs/week		0.045*		
		(0.017)		
50+ hrs/week		0.049*		
		(0.023)		
Current carer			0.039*	−0.003
			(0.016)	(0.006)
Past carer			−0.007	−0.003
			(0.007)	(0.008)
Constant	0.719*	0.710*	0.728*	0.793*
	(0.102)	(0.106)	(0.113)	(0.119)
Observations	5174	5048	4961	4961

SF6D indicates short form 6 dimension.
Standard errors in parentheses.
*$P < .05$.

approximately 0.02 to 0.27.[27] These are expected to be larger than our estimates mentioned earlier given that they measure both the caregiver and the family effect. In contrast, our analysis disentangles both effects; including the family effect would increase our disutility. Our estimates are consistent with the literature on carers' HRQoL but allow modelers to predict how carer's HRQoL changes over time based on information either already included in economic models (patient characteristics and HRQoL) or relatively

Table 5. SF6D for alternative populations.

Variable	Retired carers	No multi-carers	No cared-for carers	Spousal carers	Within-household only	Excluding initial carers
Caring for: low volume	−0.053	0.030	0.032*	0.014	0.029	0.007
	(0.043)	(0.016)	(0.016)	(0.017)	(0.016)	(0.015)
Caring for: medium volume	−0.020	0.077*	0.077*	0.045	0.072*	0.039*
	(0.058)	(0.018)	(0.018)	(0.024)	(0.018)	(0.019)
Caring for: high volume	−0.036	0.057*	0.057*	0.033	0.060*	0.022
	(0.044)	(0.019)	(0.020)	(0.022)	(0.020)	(0.015)
Caring for: duration. Continuous years caring	0.051	−0.045*	−0.044*	−0.029	−0.044*	−0.026*
	(0.045)	(0.015)	(0.015)	(0.016)	(0.015)	(0.012)
Caring for: duration. Continuous years caring squared	−0.006	0.003	0.002	0.001	0.002	0.003*
	(0.004)	(0.002)	(0.002)	(0.002)	(0.002)	(0.001)
Carer's age/10	0.079	−0.017	−0.009	−0.045	0.034	0.007
	(0.175)	(0.080)	(0.081)	(0.108)	(0.086)	(0.094)
Carer's age/10 squared	−0.007	−0.003	−0.003	0.003	−0.005	−0.003
	(0.009)	(0.004)	(0.004)	(0.007)	(0.004)	(0.004)
Also caring outside household = 1	−0.005	0.003	0.006	0.005		0.001
	(0.010)	(0.006)	(0.006)	(0.006)		(0.006)
Caring about. Care recipient's SF-6D	0.135*	0.122*	0.125*	0.136*	0.138*	0.102*
	(0.031)	(0.023)	(0.023)	(0.023)	(0.024)	(0.023)
Care recipient's age/10	−0.201	0.016	0.010	0.039	−0.030	0.016
	(0.148)	(0.075)	(0.076)	(0.102)	(0.083)	(0.087)
Care recipient's age/10 squared	0.012	−0.001	−0.000	−0.005	0.002	−0.003
	(0.006)	(0.003)	(0.003)	(0.006)	(0.003)	(0.003)
Covid wave = 1	0.004	−0.002	−0.001	−0.007	−0.003	−0.001
	(0.009)	(0.007)	(0.007)	(0.007)	(0.008)	(0.007)
Log of household income	−0.001	0.011	0.011	0.007	0.011	0.007
	(0.009)	(0.007)	(0.007)	(0.009)	(0.008)	(0.008)
Household size	0.006	0.005	0.004	0.001	0.005	0.005
	(0.020)	(0.005)	(0.005)	(0.005)	(0.005)	(0.005)
Also caring outside household = 0					0.000	
					(.)	
Constant	1.278*	0.706*	0.705*	0.730*	0.676*	0.683*
	(0.462)	(0.104)	(0.105)	(0.133)	(0.112)	(0.114)
Observations	2391	5117	5076	4349	4265	4417

SF6D indicates short form 6 dimension.
Standard errors in parentheses.
*$P < .05$.

easy to estimate for carers (volume and duration of caring). They allow modelers to differentiate between interventions that may affect carers through improving (or delaying the decline of) patient's HRQoL and changing the volume of care required, as well as those that delay the need for informal care (and therefore only affect the duration of caring).

We would advise against extrapolating beyond 5 continuous years of care, given that fewer than 40 carers in our sample provide care for more than 5 years so there is little evidence to support the decline in HRQoL beyond this point.

If an intervention improved the patient's HRQoL by 0.1, then the carer's HRQoL would improve by 0.0123 due to the family effect. We note that the lowest care recipients' SF-6D index scores in our sample were approximately 0.4 (partly due to the range of scores available for this version of SF-6D), so it may not be appropriate to apply our family effect calculations to patients with very low HRQoL scores from different HRQoL measures and particularly not to negative scores or situations where the patients' HRQoL is zero because they have died (all care recipients in our sample were alive).

We also note that all dyads in our sample were coresident, and so our estimates of both the family and caregiving effect will not necessarily apply where the carer does not live with the patient (eg, where the patient has moved into a nursing home and the carer visits them). Our analysis only considers within-household carers, because information on the HRQoL of nonresident cared-for people is not available within UKHLS. Our analyses suggested that the effects of additionally caring outside the household are not significant and that excluding people who also care outside the household does not affect the results. When considering the total duration of care including care outside the house, the effect of duration decreased—this may be because people were caring for someone who then moved in with them and so the duration of care is longer in this analysis or the effects of caring outside the house on HRQoL is smaller. It is difficult to disentangle the effects of within- and outside-household care given the current setup of questions within UKHLS.

Strengths and Weaknesses

A strength of our analysis is that we report changes in the domains of SF-6D and not solely the index score. Our public involvement workshop attendees agreed that unpaid caring had affected all of their HRQoL domains, with social functioning particularly affected. Although many studies have reported utilities/disutilities from spillovers,[27] relatively few have reported the domains. A 2021 analysis of EQ-5D-5L in Ireland found that people who have experienced a serious illness in the family were statistically significantly more likely to report slight or moderate (or worse) problems in the anxiety/depression domain only.[28] Analyzing the domains of HRQoL that are affected by caring is important in understanding why caring affects HRQoL and potentially in targeting interventions to improve carers' HRQoL. Our analysis indicates that the effects of caring are not limited to mental health.

A further advantage of the fixed-effects specification is that it accounts for reporting style of individuals (some people will tend to report better health than another person with comparable health)—removing the individual effect also removes that effect.

Fixed-effects analysis is not the only potential method for analyzing changes in carer's HRQoL, and other methods such as event studies or difference-in-differences analysis may offer additional insight and have been used in a caregiving context.[29] However, this would require the assumption that caring is irreversible and may not be appropriate where people provide care for acute conditions.

A limitation of the family effect and the way it was included in both previous and our analyses is the one-directional effect specification: care recipient's HRQoL affects carer's HRQoL. It is feasible that spillovers could be bidirectional: carer's HRQoL may also affect care recipient's HRQoL (eg, parent health conditions may affect children's medication adherence[30]). If this is true, then a unidirectional analysis will be subject to simultaneity bias. This would need to be addressed through methods such as instrumental variables or simultaneous equations. The existence of family effect in the absence of care-recipient health conditions may support the theory of bidirectional spillovers and may support the idea of excluding the family effect from economic evaluation. Because of this, we believe our estimates for the family effect are likely to be an upper bound.

Furthermore, our estimates of the caregiving effect may also be an upper bound given that our analysis considers the first year of care reported in this sample to be the first year of care, whereas respondents may have been caring for any number of years before this—this is supported by the smaller caring for effect in the scenario excluding initial carers.

A limitation of our analysis is the exclusion of variables related to formal care, but given that this did not correlate with either carer or cared-for HRQoL, we consider that the absence of a formal care variable from our preferred model is unlikely to have led to bias in the results.

Our analysis assumes the effect of caring on HRQoL is homogeneous across carer groups, which may not be true—for example, men and women may be affected differently.[10] Al-Janabi et al[31] demonstrate that spillovers may not be constant across interventions and that explicitly considering this is necessary to maximize health benefits. We recognize the limitation of assuming a constant family effect but propose that additionally including caregiving time and duration (as well as patient and carer characteristics) will help to differentiate between health spillovers of different interventions.

Our analysis is limited to carers who care for other adults, because respondents must be 16 years or older to complete the questionnaire containing SF-12. This means that we do not have data on parent carers (excepting those who care for adult children) and so our results may not be applicable to the scenario in which children with health conditions require care from their parents.

Our analysis including specific care recipient's health conditions did not suggest any diseases were predictive of worse carer HRQoL but was limited by the reporting of health conditions in UKHLS.

A further limitation is the lack of information on the type of care provided in UKHLS. Our public involvement group suggested that the type of care provided is important and may differ across volumes of care (and so the positive effect we found for medium volume care may actually be due to a different type of care). Latent class analyses of carers' HRQoL suggest that both caregiving volume and strain are important in determining the trajectory.[32] We included care-recipient difficulties as a proxy for the informal care they may require but none were statistically significant. Alternative data sets would be required to explore this further.

Conclusion

Our analysis demonstrates that changes in carers' HRQoL are related to both the duration of providing informal care and the HRQoL of the care recipient. An increased duration of caring and worse patient HRQoL are associated with worse carer HRQoL. Our estimates can be used to predict the effect of changes in informal care provision and patient's HRQoL in economic evaluation, allowing disutilities to be estimated separately for the family and caregiving effect. Interventions for patients that reduce the duration of informal caregiving may be most likely to improve HRQoL for carers.

Author Disclosures

Author disclosure forms can be accessed below in the Supplemental Material section.

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