HTA10

A New Approach for Modelling the Complexity of the Impact of Caring Using the Family and Caregiving Effects

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Introduction

Commonly used methods for modelling the health-related quality of life (HRQoL) of unpaid carers/caregivers implicitly assume that the impact of caregiving is either wholly positive (including carer utilities while the patient is alive) or negative (including carer disutilities while the patient is alive).

In reality, caring is complex, and the effect of caring on carers' HRQoL can have positive and negative aspects. Our objectives were to develop a method that allowed a trade-off between the HRQoL benefit of improved patient outcomes and the negative HRQoL impact of increased caregiving burden. We explored the impact of this, compared to the carer utility and disutility approaches, in a series of case studies.

Our method draws on the established concepts of the "family effect" or "caring *about*" someone, and the "caregiving effect" or "caring *for*" someone (Bobinac et al 2010, Bobinac et al, 2011). The family effect is a positive correlation between patient and caregiver utility. The caregiving effect is usually negative and increases in size as caregiving burden increases.

Methods

We chose three case studies where the disease and intervention would impact patients and caregivers: NICE's appraisal of ataluren for Duchenne Muscular Dystrophy (DMD), NICE's appraisal of onasemnogene abeparvovec for Spinal Muscular Atrophy (SMA), and an open-source model for International Pharmaco-Economic Collaboration on Alzheimer's Disease (AD). We extracted input data from publicly available documents, shown in Table 1. We assumed that patients had one carer throughout their lifetime.

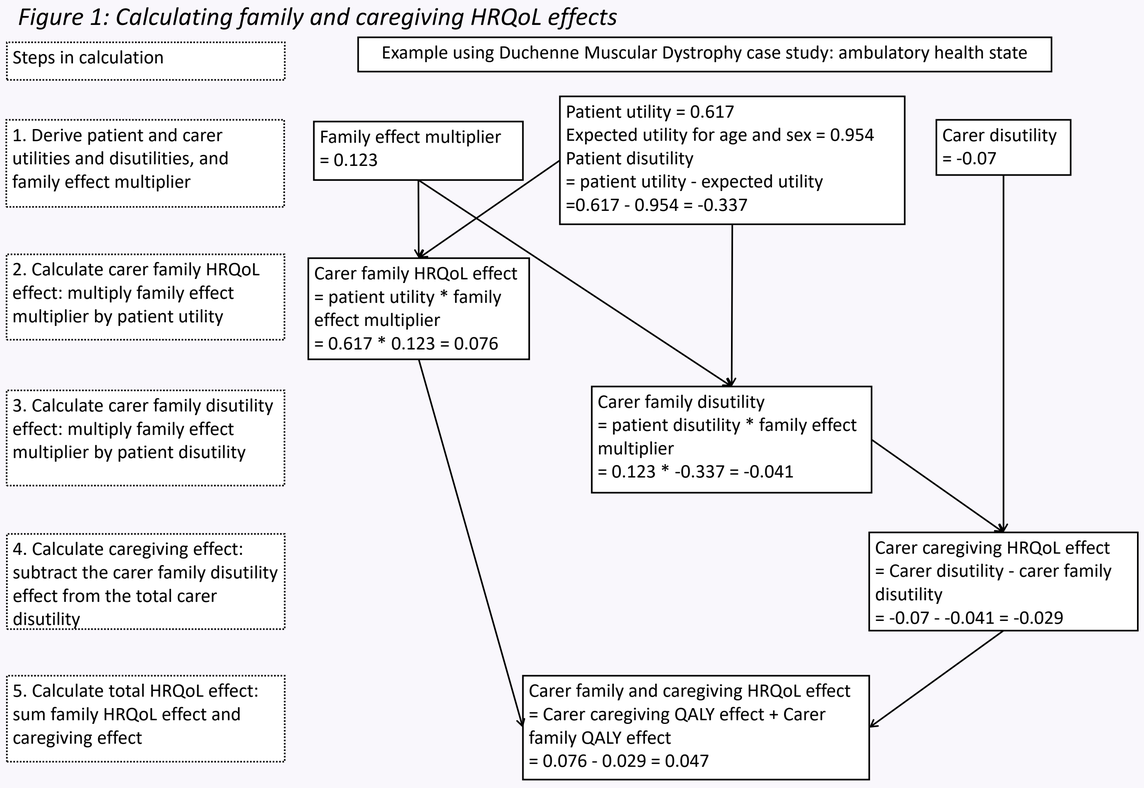
Table 1: Inputs extracted from case studies

Case study	Health state	Patient utility		Carer disutility	Life years: intervention	Life years: comparator
		Intervention	Comparator			
Duchenne Muscular Dystrophy (DMD) (NICE DMD, 2023)	Ambulatory	0.932	0.617	-0.070	17.607	11.572
	FVC >50%	0.318	0.164	-0.080	4.465	5.610
	FVC <50%	0.318	0.164	-0.140	7.170	5.122
	FVC <30%	0.318	0.164	-0.140	2.987	2.988
Spinal Muscular Atrophy (SMA) (NICE SMA, 2023)	Assisted ventilation	0.190		-0.080	0.190	2.180
	Not sitting	0.190		-0.080	1.940	1.260
	Sits unassisted	0.600		-0.030	12.000	0.000
	Walks unassisted	0.954		0.000	0.470	0.000
	Within a broad range of development	0.954		0.000	3.660	0.000
Alzheimer's Disease (AD) (Handels et al, 2024)	MCI community	0.681		-0.016	2.136	1.698
	Mild AD: community	0.631		-0.022	1.779	1.549
	Moderate AD: community	0.491		-0.039	0.790	0.941
	Severe AD: community	0.321		-0.060	0.597	0.730
	MCI institution	0.681		-0.016	0.169	0.132
	Mild AD: institution	0.631		-0.022	0.197	0.164
	Moderate AD: institution	0.491		-0.039	0.234	0.243
	Severe AD: institution	0.321		-0.060	0.593	0.698

Ideally, studies of patient and carer utilities would report the family effect specific to that health condition. However, this was not available for our case studies, so we used a family effect multiplier of 0.123, from a published analysis of patient and carer utilities (Pennington et al, 2025).

Figure 1 demonstrates how we used the data from the published documents for the case studies, with the family effect multiplier of 0.123, to estimate the family and caregiving effects, for an example using the ambulatory health state from the DMD case study for the comparator.

Figure 1: Calculating family and caregiving HRQoL effects



Results

A comparison of carer QALYs when estimated through the carer utilities, disutilities, and family and caregiving effect approaches for the three case studies are presented in Table 2.
The DMD and SMA case studies are expected to substantially improve patient survival, so lead to substantial patient quality adjusted life year (QALY) gains, large carer QALY gains using carer utilities, and carer QALY losses when using carer disutilities.
Life extension and therefore patient QALY gains in the AD case study are more modest, and the results for carers are less dramatic.

Table 2: A comparison of approaches to estimating carer QALYs across three case studies

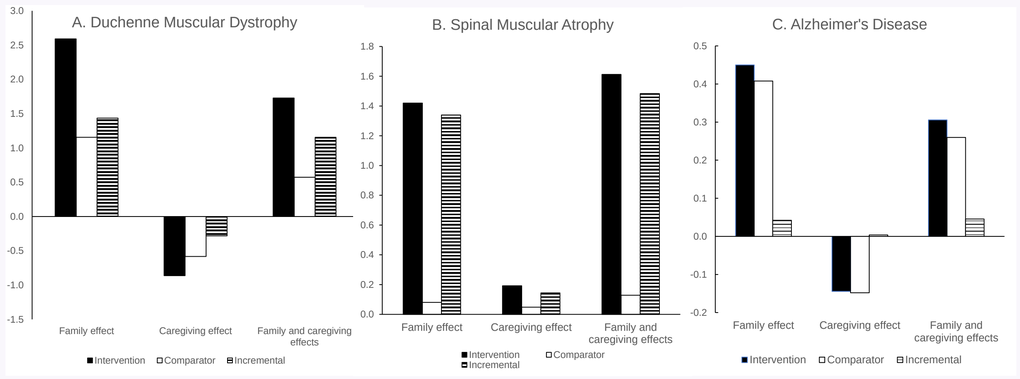
		Patient QALYs	Carer QALYs		
			Carer utilities	Carer disutilities	Family and Caregiving Effect
Duchenne muscular dystrophy (DMD)	Intervention	21.060	26.525	-3.013	1.728
	Comparator	9.390	20.828	-2.391	0.573
	Incremental	11.670	5.696	-0.622	1.154
	Carer QALY gain / patient QALY gain		49%	-5%	10%
Spinal muscular atrophy (SMA)	Intervention	11.545	15.977	-0.723	1.612
	Comparator	0.654	2.836	-0.323	0.128
	Incremental	10.891	13.142	-0.399	1.484
	Carer QALY gain / patient QALY gain		121%	-4%	12%
Alzheimer's Disease (AD)	Intervention	3.658	4.704	-0.369	0.306
	Comparator	3.315	4.429	-0.378	0.260
	Incremental	0.342	0.275	0.09	0.046
	Carer QALY gain / patient QALY gain		80%	3%	13%

The family and caregiving effects are presented separately and combined in Figure 2.
The family effect is always positive since patient utilities are always positive and the family effect multiplier is positive. The family effect is bigger for the intervention than comparator since patients spend more time in better health states.

As expected, the caregiving effect is negative for both the intervention and comparator for DMD and AD. In DMD, the caregiving effect is bigger on the intervention than on the compactor, since carers provide care for longer (because patients live much longer), and so the incremental caregiving effect is negative. But this is much smaller than the positive family effect, so the combined family and caregiving effect is positive.

In SMA, surprisingly, the caregiving effect is positive, suggesting that a higher caregiving burden has a positive effect on HRQoL. This artefact is due to the relative sizes of the patient and carer utilities and indicates it may not appropriate to combine different data sources.

Figure 2: Family and caregiving HRQoL effects from case studies



Conclusion

Our approach modelled a small positive impact on carer QALYs for each intervention, whereas existing approaches had a larger and sometimes negative impact.

Separating carer QALY effects into the family effect and the caregiving effect allows us to trade-off the benefits of improving patient outcomes against the increased caregiver burden. It removes the need for extreme and unrealistic simplification of the effect of caring on HRQoL, and the implications of assuming caring is wholly positive or wholly negative.

We have demonstrated that our approach can currently be used with existing data and borrowing the family effect multiplier from other sources. Our approach, informed by existing literature, offers a consistent and adaptable framework for modelling caregiver QALYs across diseases, balancing the differing impacts of disease and treatment pathways on caregivers. Further research should consider the generalisability of the family effect multiplier and analyse the family and caregiving effects across conditions.

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